Fibromyalgia FOR DUMMIES®

2ND EDITION

by Roland Staud, MD, with Christine Adamec

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About the Authors

Roland Staud, MD, is a rheumatologist and a professor of medicine at the University of Florida in Gainesville, Florida, as well as a noted and internationally renowned medical researcher. Dr. Staud's continuing and cutting-edge research on fibromyalgia is supported by the National Institutes of Health and other funding organizations. His research has clearly demonstrated that patients with fibromyalgia syndrome (FMS) have detectable central nervous system abnormalities of pain processing resulting in increased pain sensitivity and prolonged pain experiences.

Dedicated to helping FMS patients by sharing his knowledge as much as possible, Dr. Staud is greatly appreciated by attendees at major national and international fibromyalgia and arthritis conferences, where he is a frequent speaker. He is also on the editorial boards of *Pain* and *European Journal of Pain*. In addition, he is a reviewer for the *Clinical Journal of Pain, Journal of Pain, European Journal of Pain,* and *Pain.* He has authored many medical journal articles on fibromyalgia and other topics.

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Dedication

Dr. Staud: I would like to dedicate this book to all the fibromyalgia volunteers who participated in my studies at the University of Florida, helping me to characterize the abnormal pain mechanisms of fibromyalgia syndrome.

Christine Adamec: I would like to dedicate this book to my ever-patient husband, John Adamec.

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Contents at a Glance

Introduction 1

Part I: The What, When, and Why of Fibromyalgia 7

Chapter 1: Yes, Fibromyalgia Is Real 9
Chapter 2: Recognizing Key Symptoms of Fibromyalgia 21
Chapter 3: Understanding Possible Causes of Fibromyalgia 37
Chapter 4: Understanding Fibromyalgia Pain 57

Part II: Finding Out Whether You Have Fibromyalgia 67

Chapter 5: Who Gets Picked to Have Fibromyalgia? 69
Chapter 6: Identifying Diseases Often Confused with Fibromyalgia 75
Chapter 7: Working with a Good Fibromyalgia Doc: You Need a True Believer 93
Chapter 8: Getting Physical: Your Initial Exam and Diagnosis 105

Part III: Looking At All Your Treatment Options 119

Chapter 9: Medicating the Problem: Over-the-Counter Drugs May Help 121
Chapter 10: Prescribing Health with Medications 131
Chapter 11: Using Hands-On Therapies 147
Chapter 12: Considering Alternative Remedies and Treatments 161

Part IV: Modifying Your Lifestyle: Small Changes, Big Results 175

Chapter 13: Depressurizing Yourself: Controlling the Stress-Eyed Monster 177
Chapter 14: Sweet Dreams! Combating Sleep Disorders 189
Chapter 15: Exercising, Losing Weight, and Avoiding Trigger Foods and Drinks ..203
Chapter 16: Coping with Emotions: Your Own 217

Part V: Managing Fibromyalgia at Work and at Home 227

Chapter 17: Working with Fibromyalgia — Or Going on Disability 229
Chapter 18: Helping Loved Ones Deal with Your Fibromyalgia 243
Chapter 19: Helping Someone You Care About Who's Hurting 257
Chapter 20: Parenting a Child or Adolescent with Fibromyalgia 267

Part VI: The Part of Tens 279
Chapter 21: Ten Alternative Remedies That Help People with Fibromyalgia.........281
Chapter 22: Ten Mistakes to Avoid When You Have Fibromyalgia 287
Chapter 23: Ten Ways to Beat the Effects of Brain Fog...293
Chapter 24: Ten Myths about Fibromyalgia..297
Part VII: Appendixes 301
Appendix A: Glossary 303
Appendix B: Fibromyalgia Medications...307
Appendix C: Resources and Support 315
Index 321

Table of Contents

Introduction *1*

Part I: The What, When, and Why of Fibromyalgia *7*

Chapter 1: Yes, Fibromyalgia Is Real **9**

Dumping Your Doubts about Whether FMS Is Real 9
Examining the Symptoms, Causes, and Pain Problems Associated with Fibromyalgia..10
  Sizing up the symptoms 10
  Considering causes 11
  Pondering pain..11
Considering Who Gets Fibromyalgia 12
Looking at Related Medical Problems 12
Do You Have Fibromyalgia? A Self-Test 13
Finding a Doctor Who's a "True Believer" in Fibromyalgia 16
Treating the Problem 17
Making Lifestyle Changes: Pulling Yourself into a Non-Fibro World........17
Coping with Fibromyalgia at Home and on the Job..................................18
  Working with fibromyalgia at work 19
  Handling fibromyalgia with family and friends.................................19
  Sorting it out when you don't have fibromyalgia.............................20

Chapter 2: Recognizing Key Symptoms of Fibromyalgia **21**

Describing Where It Hurts: Almost Everywhere! 22
  Feeling the aches and body pains of your fibromyalgia — but being unable to show proof...22
  Suffering from muscle stiffness — especially in the morning 23
  Singling out a source of your pain: You can't 23
  Chronically feeling your pain..24
  Migrating pain: The worst pain may move from place to place.....24
Being Terribly Fatigued 25
  Feeling exhausted...25
  Considering whether you have chronic fatigue syndrome.............26
Facing Fibro Fog: Mental Malaise 26
  Feeling "out of it" 26
  Being frequently inattentive...27
  Wondering about attention deficit/hyperactivity disorder 27
  Coping with temporary confusion 28
Weathering Your Reactions to Weather 28
Dealing with Common Sleep Disorders 29

Experiencing Related Medical Problems 29
  Dealing with irritable bowel syndrome 30
  Coping with interstitial cystitis 31
  Aching with arthritis 32
  Suffering from frequent headaches 33
  Hurting with heartburn 34
  Dealing with depression 35

Chapter 3: Understanding Possible Causes of Fibromyalgia 37

Down But Not Out: Physical Trauma 38
  Looking at types of trauma that may cause fibromyalgia 38
  Investigating how physical trauma can trigger fibromyalgia 42
Catching Fibromyalgia 42
  From a viral infection 43
  From an autoimmune reaction 43
  From hepatitis B or hepatitis C 44
  From other infections 45
Regarding Gulf War Syndrome 45
  Homing in on hormonal changes in fibromyalgia 47
  Helping Gulf War veterans 47
Studying Chemical Imbalances 47
  Substance P = Pain 48
  Neurochemically affecting your pain or symptomatic levels 50
Examining Environmental Causes 50
  Considering an allergic reaction 50
  Experiencing a hypersensitivity to chemicals 51
  Feeling the effects of phosphates 51
  Suffering from hyper-arousability 51
Exploring Other Theories 52
  Linking genetics and fibromyalgia 52
  Exercising too little or too much 53
  Considering muscular or structural abnormalities 54
  Suffering from a combo platter of illnesses 54
Looking to the Future 55

Chapter 4: Understanding Fibromyalgia Pain 57

Grasping Pain and Why People Have to Have It 58
  Pain defined 58
  Its advantages and disadvantages 58
Regarding the Different Kind of Pain That's Fibromyalgia 60
Working with Your Doctor to Manage Fibromyalgia Pain 61
  Define your terms 61
  Plan a course of treatment 62
  Chart any changes 62
  Move on to Plan B 64

Part II: Finding Out Whether You Have Fibromyalgia.....67

Chapter 5: Who Gets Picked to Have Fibromyalgia? 69

Looking at the Numbers: Who Has Fibromyalgia?....................................70
Wondering Why Women Suffer More than Men from Fibromyalgia 70
Considering How Fibromyalgia Relates to Women's Ages........................71
    Young and middle-aged women and menstruation..........................71
    Older women and menopause...72
Fibromyalgia and Men: It Isn't Just a Woman Thing.................................73

Chapter 6: Identifying Diseases Often Confused with Fibromyalgia . . .75

Understanding the Uncertainty...76
Chronic Fatigue Syndrome...77
    About chronic fatigue syndrome..77
    How chronic fatigue syndrome differs from fibromyalgia 78
    Treating chronic fatigue syndrome..79
Myofascial Pain Syndrome...80
    About myofascial pain syndrome...80
    How myofascial pain syndrome differs from fibromyalgia 81
    Treating myofascial pain syndrome...82
Arthritis..82
    About arthritis 83
    How arthritis differs from fibromyalgia...85
    Treating arthritis 85
Thyroid Disease...87
    About hypothyroidism (low thyroid) 87
    Treating thyroid disease..88
The Other Suspects 88
    Being ticked off by Lyme disease 89
    Reflecting on Raynaud's phenomenon 90
    Evaluating other possibilities 91

Chapter 7: Working with a Good Fibromyalgia Doc: You Need a True Believer 93

Working with Your Primary-Care Doctor 94
Looking Elsewhere for a Doctor: How to Know if It's Time 96
Considering Types of Specialists 97
    Regarding rheumatologists 98
    Nerving up about neurologists 98
    Considering pain-management experts...98
    Pondering other physician specialists 98
Finding a Good Specialist or a New Primary-Care Doctor 99
    Looking at doctors within your insurance network 99
    Asking your own doctors whom they'd see or send a family member to 100

- Contacting friends and relatives 101
- Checking with major medical centers and universities 101

Interviewing Your Physician Candidate: What's Up, Doc? 102

Chapter 8: Getting Physical: Your Initial Exam and Diagnosis 105

Diving into Your Medical History: What the Doctor Should Ask You....106

Volunteering Info if the Doc Doesn't Ask You about It 107
- Telling your doctor about your pain....................108
- Mentioning the other doctors you see 109
- Bringing your medications, vitamins, and supplements with you 109

Getting All Your Questions Out in the Open....................110

Identifying the Tender Points of Fibromyalgia 110
- Touching is part of the process....................111
- Locating your tender points 111
- Assigning a tender number to FMS 113

Test-ifying about FMS 113
- Ordering up a round of lab tests 114
- Testing the function of your autonomic nervous system 115
- Considering CT scans or MRIs....................116
- Using ultrasound for diagnosis....................117

Part III: Looking At All Your Treatment Options..........119

Chapter 9: Medicating the Problem: Over-the-Counter Drugs May Help 121

Considering Guaifenesin 122
- Looking at some background info....................122
- Ordering guaifenesin....................124
- Weighing the pros and cons of guaifenesin....................124

Relieving Pain with Painkillers 125
- Acetaminophen....................125
- Aspirin....................126
- Ibuprofen 126
- Naproxen 127

Warming Up to Cold Remedies for Fibromyalgia 127
- Dealing with dextromethorphan 127
- Trying antihistamines 128

Talking About Topical Remedies....................129
- Considering your options....................129
- Deciding which topical remedy is best 130

Chapter 10: Prescribing Health with Medications 131

Relaxing Your Fibromyalgia: Muscle Relaxants....................132
- Naming names 132
- Weighing the risks and benefits of muscle relaxants....................133

Easing Pain with Painkillers 133

Considering key pros and cons of prescribed painkilling medications 134
Investigating controlled/scheduled drugs 134
Prescribing painkillers: The dilemma 136
Lessening Pain with Lidoderm 138
Reducing Inflammation with Non-Steroidal Anti-Inflammatory Drugs 138
Fighting Fibromyalgia with Antidepressants 139
I'm not depressed! Why do I need an antidepressant? 140
Balancing the pluses and minuses of antidepressants 141
Other Medicines Prescribed for Fibromyalgia 142
Analyzing anticonvulsive drugs 143
Pondering anti-anxiety medicines 143
Analyzing antihistamines 144
Considering pramipexole and ropinirole: Parkinson's drugs may offer pain relief 144
Opening Your Eyes to Sleep Remedies 145
Assessing whether sleep medication is needed 145
Gazing at the ups and downs of sleep remedies 146
Pondering Future Remedies 146

Chapter 11: Using Hands-On Therapies 147

Heating Up the Problem: Heat Therapy 147
Delivering the heat 148
Avoiding overheating 148
Chilling Out! Icing the Pain 149
Wetting Down Your Fibromyalgia Symptoms 150
Rubbing Out the Problem: Massage Therapy 151
Realizing that it's not a cure, but it can be helpful 151
Finding a massage therapist 152
Forming a non-aggression pact with your massage therapist 154
Magnetically Decreasing Your Pain: Transcranial Magnetic Stimulation 155
What it is and how it works 155
Who should avoid TMS 156
An Electrifying Solution: Transcutaneous Electrical Nerve Stimulation 157
The working theory behind TENS 157
What happens during therapy 157
Doing TENS to yourself 158
Considering Chiropractors 159

Chapter 12: Considering Alternative Remedies and Treatments 161

Thinking Through Alternative Remedies 162
Fighting Fibromyalgia Naturally with Herbs and Supplements 163
Notifying your doctor about your natural choices 163
Looking at magnesium 164
Evaluating valerian 165

Watching out for dangerous remedies....165
Pinning Down a Solution: Acupuncture....166
Understanding acupuncture....167
Finding an acupuncturist....167
Homing In on Homeopathy....169
Beating Fibromyalgia with Botox Injections....169
Botox and fibromyalgia....170
How much Botox costs and whether insurance pays....172
Taking On Tai Chi....172
Repelling Magnet Therapy....174

Part IV: Modifying Your Lifestyle: Small Changes, Big Results....175

Chapter 13: Depressurizing Yourself: Controlling the Stress-Eyed Monster....177

Knowing When You're Too Stressed....178
Chilling Out with Relaxation Therapy....180
Stress-Busting with Biofeedback Therapy....181
Understanding what happens....182
Weighing the pros and cons of biofeedback therapy....183
Finding biofeedback providers....184
Mesmerizing the Pain: Hypnotherapy....184
Considering what hypnosis is and isn't....185
Knowing exactly what goes on during hypnotherapy....185
Locating a hypnotherapist....186
Mastering self-hypnosis....186
Meditating, Doing Yoga, and Praying....187
Meditation....187
Yoga....187
Prayer....188

Chapter 14: Sweet Dreams! Combating Sleep Disorders....189

What Is Sleep?....190
Understanding the Importance of Sleep Stages....190
Light sleep....191
Deep sleep....192
REM sleep....192
Identifying Key Sleep Problems....192
It's 2 a.m. and I'm still awake: Difficulty falling asleep....193
Too many wake-up calls: You're constantly waking....193
Not enough downtime in deep sleep....194
Analyzing Your Sleep: A Self-Test....194
Adjusting Your Lifestyle to Cope with the Problem....197
Consuming soporific suppers....197
Relaxing....197

Using your bed for sleeping (and sex)..198
Quieting a snoring partner..198
Slipping into Slumber Using Medications and Other Remedies 198
Buying nonprescription medicines...199
Using helpful alternative remedies 199
Taking prescriptions for sleepyland 200

Chapter 15: Exercising, Losing Weight, and Avoiding Trigger Foods and Drinks 203

Exercising to Relieve Fibromyalgia Pain 203
Exploring Pain-Relieving Exercises...205
Walking off the pain and strain of fibromyalgia.............................205
Swimming, cycling, and other choices 207
Losing Weight to Decrease Pain and Fatigue...211
Figuring your ideal weight...212
Improving your diet and exercising to shed pounds.....................214
Considering some weight-loss meds...214
Discovering Dietary Effects: Good Foods/Bad Foods.............................216

Chapter 16: Coping with Emotions: Your Own 217

Dealing with Depression...217
Defining depression and its symptoms 218
Connecting fibromyalgia and clinical depression..........................218
Treating depression 218
Cognitive-behavioral therapy and fibromyalgia.............................219
Determining If It’s an Anxiety Disorder 219
Defining anxiety disorders 219
Treating anxiety disorders 220
Sorting out anxiety versus depression...221
Taking Your Emotional Temperature..221
Finding a Therapist...223
Identifying different types of mental-health professionals 223
Finding and screening therapists 224
Meeting with a therapist...224
Treating Emotional Problems with Medication.......................................225

Part V: Managing Fibromyalgia at Work and at Home 227

Chapter 17: Working with Fibromyalgia — Or Going on Disability 229

Explaining Fibromyalgia to Your Boss and Co-Workers: Should You?...230
Deciding whether to tell 231
Forming an explanation...231
Deciding Whether You Should Stay at Your Job 232

Getting Your Insurance Company to Pay for Treatment 234
    Providing more info 234
    Understanding why your claim may be denied 234
    Appealing insurance denials: Do it! 235
Taking the Next Step if FMS Is Disabling 237
    Questioning yourself 238
    Getting disability from work 238
    Going on Social Security 239
    The burden of proof 241
Finding an Attorney to Help You 241

Chapter 18: Helping Loved Ones Deal with Your Fibromyalgia 243

Understanding How Fibromyalgia Can Affect Your Relationships 244
Moving Yourself to a Better Frame of Mind 245
Opening Up for Some Honest Dialogue 246
Anticipating Difficulties 248
Knowing How to Respond to “Helpful” Comments 248
Helping Your Significant Other Cope 249
Explaining Fibromyalgia to Your Kids 251
    Keep it simple 251
    Stress that it’s chronic 252
    Clarify that they didn’t make you sick 252
    Anticipate questions 252
Joining a Support Group 253
    Looking at the pros and cons of support groups 254
    Deciding whether to take others with you to meetings 254

Chapter 19: Helping Someone You Care About Who’s Hurting 257

Understanding without Feeling Their Pain 258
    Empathizing without saying that you know how FMS feels (because you don’t) 258
    Knowing what not to say 259
    Leaving them alone: Sometimes, solitude helps 259
    When hugging hurts 260
    Paying attention to body language 261
Coping with Your Own Emotions 262
    Dealing with anger 262
    Fighting frustration 263
    Getting rid of your guilt 264
Going to Support Meetings 264

Chapter 20: Parenting a Child or Adolescent with Fibromyalgia . . .267

Looking at Fibromyalgia Symptoms in Children and Teens 268
    Showing fewer tender points than adults 268
    Suffering from more stomachaches 268
    Having poor sleep (like adults) 269
    Discovering other key FMS symptoms 269

Accurately Diagnosing the Problem 270
Finding Help for Your Child with FMS 270
Treating a Child with Fibromyalgia 271
    Using medication 271
    Trying therapy 272
Including Your Children Who Don't Have Fibromyalgia 274
Working with Your Child's Teacher 274
    Sharing information with teachers 275
    Holding off on informing teachers 276
    Handling difficult teachers 276
Dealing with Jeers from Peers 277
    If your child is bullied 277
    If your child is physically attacked 278

Part VI: The Part of Tens 279

Chapter 21: Ten Alternative Remedies That Help People with Fibromyalgia 281
Herbs 282
Magnesium 283
Echinacea 283
Green Tea 283
Massage Therapy 283
Aromatherapy 284
Mud Baths 284
Acupuncture 285
Homeopathy 285
Transcutaneous Electrical Nerve Stimulators 285

Chapter 22: Ten Mistakes to Avoid When You Have Fibromyalgia 287
Ignoring Your Pain and Hoping It Goes Away 288
Believing a Doctor Who Says Fibromyalgia Is "All in Your Head" 288
Trying One Medication or Therapy, and If It Doesn't Work, Giving Up 288
Assuming That the Problem Is All Your Fault 289
Assuming That the Problem Is Everyone Else's Fault 290
Turning to Alcohol or Other Substances 290
Believing That All Your Problems Are Caused by Fibromyalgia 291
Overeating to Make Yourself Feel Better 291
Feeling That You're a Defective Person Because of Your Fibromyalgia 292
Trying to Hide Your Symptoms from Family, Friends, and Others 292

Chapter 23: Ten Ways to Beat the Effects of Brain Fog 293
Avoiding Brain and Energy Drains When You're Hurting or Tired 293
Asking Others to Help You Stay On Task 294

Making Lists and Checking Them Twice 294
Banning Self-Blame 295
Avoiding Blaming Others 295
Getting Enough Sleep 295
Keeping a Calendar of Activities 295
Watching What You Eat 296
Putting Things in Their Places 296
Catching Yourself Slipping Away 296

Chapter 24: Ten Myths about Fibromyalgia 297

People with Fibromyalgia Are Lazy or Crazy 297
Fibromyalgia Symptoms Are a Way to Get Attention 298
People with FMS Just Want Drugs 298
Looking Well Means You Are Well 298
Pain Is Pain: It's All the Same 299
Feeling Good Today Means You're Well 299
Relaxing Will Cure What Ails You 299
Taking Some Pills Should Fix You Right Up 300
Ignoring the Problem Will Make It Go Away 300
Therapy Always Works 300

Part VII: Appendixes....................301

Appendix A: Glossary 303

Appendix B: Fibromyalgia Medications 307

Appendix C: Resources and Support 315

Index....................321

Introduction

Fibromyalgia is a chronic medical problem that can be terribly aggravating and sometimes even maddening for people who have it, especially if they aren't receiving the latest medications or treatments, such as those discussed in this new edition of *Fibromyalgia For Dummies.* But if you have fibromyalgia, you may find comfort in the fact that you're not alone. Fibromyalgia affects 6 million or more people in the United States and millions more in other countries. You can also find comfort in the fact that many effective options may help you significantly decrease the problems that you're experiencing, problems that stem from fibromyalgia.

Also known as fibromyalgia syndrome (FMS), fibromyalgia's major symptom is pain in the muscles, tendons, and bones throughout the body. (And for some people, the pain and its location vary from day to day.) FMS pain often occurs without a specific cause or injury. In other cases, it may be linked to an injury (such as from a car crash), may be tied to a traumatic event (such as past physical or sexual abuse), or may be connected to combat experiences (such as in the Iraq War or past service in Vietnam).

Yet some people, including some doctors, persist in thinking that *fibromyalgia* is just another word for *hypochondria* — or maybe even *slacker* or *goof-off.* They think that people who say they have fibromyalgia symptoms are really lazy or crazy — or both. They dismiss FMS as just another "disease of the month."

They're wrong. The pain isn't imaginary, and the problem is no fad. At the University of Florida, I've conducted studies that have proven that subjects diagnosed with fibromyalgia suffer heightened pain sensitivity and low pain threshold, and that they retain their pain longer than those individuals without the syndrome.

It's true that if fibromyalgia sufferers can be depressed, anxious, or stressed, they'll feel worse. But depression, anxiety, and stress don't actually *cause* fibromyalgia. People with FMS will have pain whether they're upset or not. But their pain often increases when they're distressed.

What does fibromyalgia feel like? Many people say that to truly understand how FMS can be experienced, you need to imagine how you feel when you have the flu. Recall the aching and pain in parts of your body or in your entire body. Then multiply those achy feelings by about ten times. Now imagine feeling that way nearly *every day.* That is what fibromyalgia feels like for a lot of people. Pretty nasty.

The good news is that you can feel much better with both the traditional and alternative medications and treatments, as well as with the lifestyle choices, that I describe in this book. They work for other people, and they can help you (or someone you know who suffers from FMS), too.

About This Book

Although this is a new edition, my two primary goals in writing this book remain the same:

- I want to show that fibromyalgia pain is real — and now there's more evidence than ever to help me prove that. This goal is important because some doubters are still out there.
- I want to discuss the pain of FMS and provide the most current information on medications, alternative remedies, lifestyle changes, and other treatments that work.

You don't have to read this book from the first page straight on through to the end — although you certainly can if you want to. You may instead want to read Chapter 1 to get a feel and flavor for the rest of the book. Then you can use the table of contents at the front of the book or the index in the back to help you move on to the chapters that interest you the most.

Also, keep an eye out for the many personal stories that I've sprinkled throughout the book. These anecdotes come from real people who suffer from fibromyalgia.

Conventions Used in This Book

The following conventions are used throughout the text to make things consistent and easy to understand:

- All Web addresses and e-mail addresses appear in `monofont`.
- New terms appear in *italics* and are closely followed by an easy-to-understand definition.
- I use **bold** to highlight the action parts of numbered steps or keywords in bulleted lists.
- Sidebars, which are enclosed in a shaded gray box, include information that may fascinate you but that isn't critical to your understanding of FMS.

Also, you may have noticed that two names appear on the front cover, but I use the singular pronoun *I* in the text. I do so because this book reflects only my views as a medical professional, while Christine Adamec, an experienced medical writer, assisted with the preparation and production of the book. Thus, she's also credited on the cover.

What You're Not to Read

You can read this book in any order you want, dipping into it to find the information you need and then moving on. You can safely skip the sidebars (text in gray boxes); they contain interesting information, but they're not critical to the subject at hand. Finally, you can skip any text marked by the Technical Stuff icon (for more on this icon, see "Icons Used in This Book," later in this Introduction).

Foolish Assumptions

In writing this book, I'm making some basic assumptions about you. I'm assuming that:

- You have fibromyalgia, think that you have it, or you have a friend, child, teenager, or other family member with FMS, and you want information in order to be able to help.
- You want information on pain relief and remedies.
- You're curious about alternative remedies and treatments, and want to know what works and what to avoid — and you need some basic guidelines on how to know the difference.

How This Book Is Organized

Fibromyalgia For Dummies, 2nd Edition, is divided into seven convenient parts, starting with what fibromyalgia is, moving to who's most likely to have it, and zeroing in on the many ways to deal with the pain, fatigue, and other common symptoms that fibromyalgia sufferers share. Here's how it breaks down.

Part I: The What, When, and Why of Fibromyalgia

In the first four chapters, I cover the realities of fibromyalgia. I offer a self-test, in case you need help in determining whether you may have FMS. The various symptoms of fibromyalgia are important to understand, and I cover them in detail in Chapter 2. I also talk about possible causes of fibromyalgia in Chapter 3. Nobody knows exactly what causes FMS, but there are some intriguing theories about the perpetrators of this medical problem (such as, it may be in your genes). Chapter 4 covers pain and its purpose, including good pain and bad pain. Most fibromyalgia pain is bad pain, so don't imagine that I think otherwise, because I don't! However, you need to *manage* FMS pain, instead of having that pain manage you.

Part II: Finding Out Whether You Have Fibromyalgia

To know whether you may have FMS, it helps to consider patterns found among people already diagnosed. You can still have FMS even if you don't fit neatly into one or more of these categories, but it's less likely. I cover this information in Chapter 5. Then, moving to Chapter 6, I describe medical problems often confused with fibromyalgia, such as chronic fatigue syndrome, myofascial pain syndrome, arthritis, lupus, Raynaud's phenomenon, and thyroid disease. Some people have more than one of these medical problems — I hope you won't have "all of the above." Next, Chapters 7 and 8 walk you through working with your primary-care doctor, and, if needed, finding a new physician.

Part III: Looking At All Your Treatment Options

Here's where I talk about what to *do* about your fibromyalgia. In Chapter 9, I cover over-the-counter medications, such as aspirin, guaifenesin, and dextromethorphan, as well as different categories of medications, such as antihistamines and topical remedies applied to the skin. And I describe the full gamut of prescribed remedies for FMS in Chapter 10, including some new medications that you need to know about. I then talk about some hands-on therapy that can help you, such as icing or heating the painful spots or applying direct massage to your hurting areas, in Chapter 11.

In Chapter 12, I cover alternative remedies and treatments that may help you feel better, such as herbs, supplements, Botox treatments (not just for facial wrinkles anymore!), acupuncture, tai chi, and other complementary medicine choices, as well as some treatments that you really should steer clear of and some advice on how to tell the good guys from the scammers out there.

Part IV: Modifying Your Lifestyle: Small Changes, Big Results

You can make some nonmedical lifestyle changes to ease your pain. In Chapters 13 and 14, I tell you how you can control stress using relaxation therapy, hypnotherapy, meditation, and yoga, and provide details on how to get a good night's sleep. In Chapter 15, I include important information on exercising, losing weight, and making key dietary changes that may help considerably. In Chapter 16, I cover dealing with the emotional fallout of FMS, and, if you need a therapist, I offer advice on finding a good one.

Part V: Managing Fibromyalgia at Work and at Home

You can't switch FMS off and on (if you could, it'd always be in the off position!), so the illness affects you both at work and at home. In Chapters 17 and 18, I discuss how you can help your family, friends, co-workers, and even your boss to help you. Sometimes, work may become impossible, and you may need to apply for a disability — an important subject I also cover. I offer Chapter 19 for those who don't have FMS themselves, but who have a friend or family member who's hurting — and whom they want to help. I also include a chapter on children and adolescents with fibromyalgia, in case your child, or the child of someone you know, suffers from FMS.

Part VI: The Part of Tens

This part presents helpful information in lists of ten items each. You can read about ten pieces of advice on remedies related to fibromyalgia. Another list offers ten mistakes to avoid when you have FMS. I also have ten ways to beat brain malaise *(fibro fog).* Last, I debunk ten myths about FMS.

Part VII: Appendixes

In this part, I provide a glossary of commonly used terms related to fibromyalgia. I also offer an up-to-date appendix of over-the-counter (OTC) drugs and prescribed medications that are useful to many patients with FMS. I include the brand and chemical names of the drug, common starting dosage, symptoms it combats, and side effects.

Another appendix is an Internet resource guide of interesting Web pages where you'll find resources and articles to read as well as support groups to contact online. And, in case you're not a Nethead, I offer an appendix of helpful organizations to contact through the mail. I also provide a list of publications devoted to fibromyalgia.

Icons Used in This Book

To help you remember the important points of each chapter, this book marks certain paragraphs with the following helpful icons:

REMEMBER

This icon denotes critical information that you really need to take away with you. Be sure to read it.

TIP

When you see this icon, you find a helpful hint for coping with fibromyalgia that may save you time or money. Or maybe both!

WARNING!

The Warning icon cautions you against something that's potentially harmful. Be sure to read and heed these icons.

TECHNICAL STUFF

When I get a bit technical on you, I use this icon. You can safely skip any paragraphs marked by the Technical Stuff icon — of course, if you read them, you're sure to discover something interesting.

Where to Go from Here

After you've read this book and started using my suggestions to begin your journey to less pain and better health, I hope that you'll experience the considerable improvement that many others have felt. In particular, I hope you maintain your personal commitment to managing your own health. I also hope that you'll be well armored against attacks from people out there who somehow still (and wrongly!) think that fibromyalgia is fake. Fibromyalgia is a real medical problem; it's not something that's in your head. But it's also a real medical problem that you can successfully control.

Part I

The What, When, and Why of Fibromyalgia

The 5th Wave By Rich Tennant

"The doctors call it fibromyalgia, but I call it 'Military Arthritis' because it comes with a lot of fatigue."

In this part . . .

Fibromyalgia is a real medical problem — no matter what you may have heard from other people (including some doctors!) who act as though they know what they're talking about. Fibromyalgia isn't "just in your head" — actually fibromyalgia pain and tenderness are usually spread throughout the entire body!

In Part I, I describe the key aspects of fibromyalgia that you need to know, such as exactly what fibromyalgia is and what the major symptoms are. I include a fibromyalgia self-test that you can take. I also discuss intriguing theories on why you and others may have developed fibromyalgia. I cover car crashes, infections, autoimmune systems run amuck, traumatic experiences, genetic predispositions, and other theories. Pain is the main problem with fibromyalgia, and I devote an entire chapter to this topic (quite painless to read), which I hope will provide good insight into what's actually going on with your poor aching body.

Chapter 1

Yes, Fibromyalgia Is Real

In This Chapter

- Considering symptoms, causes, and the pain aspect
- Knowing who gets fibromyalgia
- Looking at medical problems confused with fibromyalgia
- Finding a good doctor
- Exploring over-the-counter and prescribed medications and alternative remedies
- Considering how fibromyalgia affects work and family
- Improving sleep, decreasing stress, and dealing with emotional effects

Knowing that fibromyalgia syndrome (FMS) is a real medical problem that needs to be dealt with is an important first step toward mastering your fibromyalgia — and moving toward that place where you can start to feel like you're making progress. Sure, you can try to ignore the problem. But mostly, it won't let you.

Fibromyalgia has many aspects to consider. In this chapter, I line up the major issues for you and refer you to chapters later in this book where I discuss how fibromyalgia affects you individually and what treatments and medications may work best for you.

Dumping Your Doubts about Whether FMS Is Real

Many people spend months or years questioning their fibromyalgia symptoms, sometimes wondering if they're imagining how bad the symptoms are. After all, if you feel terrible one day and then significantly better or almost normal the next day, you may start to think that maybe you were exaggerating the pain and fatigue of the previous day.

The thing is, most people can't remember pain well. They can remember that they *had* pain, but they can't remember what it actually felt like. (This is generally a good thing!) As a result, people experiencing the ups and downs of pain and other symptoms that accompany fibromyalgia worry sometimes that perhaps the problem isn't that big of a deal and could even be all in their heads. Consequently, they may try to ignore the problem and hope that it'll go far, far away — preferably today.

But if you have fibromyalgia (and I recommend that you take my self-test later in this chapter to see whether you could be a possible candidate), simply ignoring the problem doesn't work. The sooner you acknowledge that fibromyalgia is a real and long-term problem, the sooner you can work toward reclaiming your life.

You can gain enormous control over the symptoms that stem from your fibromyalgia, but only rarely can you eradicate them altogether. Most people have plenty of room for improvement, however.

Examining the Symptoms, Causes, and Pain Problems Associated with Fibromyalgia

Fibromyalgia isn't a one-size-fits-all kind of medical problem, but I can make some descriptive generalizations about it regarding symptoms, causes, and pain.

Sizing up the symptoms

Many people with fibromyalgia report that the following statements are true about their fibromyalgia symptoms. In fact, most people with fibromyalgia say that they have at least several, if not all, of these symptoms (which I cover in much more detail in Chapter 2):

- ✓ Flu-like pain that can be severe
- ✓ A constant feeling of extreme fatigue
- ✓ Several tender body areas that hurt
- ✓ Overall body aches
- ✓ Depression and/or anger
- ✓ Feeling very anxious
- ✓ Muscle stiffness and pain
- ✓ Chronic back pain

- Insomnia
- Worsening of pain after physical activity
- Mental malaise and confusion, often referred to as *fibro fog*

Many people with FMS have other pain-based medical problems as well, which I also cover in more depth in Chapter 2. Some examples of the array of medical conditions that people with fibromyalgia may experience, on top of the fibromyalgia that they already have (as if FMS isn't enough), include

- Restless legs
- Irritable bowel syndrome
- Interstitial cystitis (a chronic, painful bladder condition that may feel like a constant bladder infection)
- Tension headaches or migraine headaches
- Benign joint hypermobility syndrome (BJHS; an often painful form of hereditary joint hyperextension)
- Attention deficit hyperactivity disorder (ADHD)
- Chronic fatigue syndrome

Considering causes

No one knows for sure what causes fibromyalgia, but physicians and other experts have many fascinating theories to explain what may induce the onset of FMS. The cause could be hormones or an autoimmune problem or biochemicals gone awry, chronic stress, or it may be related to a previous trauma, such as an injury that you incurred in a car crash or in another serious accident. Individuals who have been abused as children or adults are more likely to develop fibromyalgia than others.

The cause could also be a combination of different factors coming together at just the right time (or the wrong time when you think about it) for you to develop FMS. For example, maybe you got the flu, and then were involved in a serious accident. Or some other awful combination may have occurred.

As researchers (like me) continue to study this medical problem, they move closer to the truth. Speculating about causes can be fascinating, and Chapter 3 offers some common theories for what causes fibromyalgia.

Pondering pain

Thinking about pain is certainly no fun, and yet pain is part of what makes us alive and human. But when pain runs rampant in our bodies, extracting particular pain in certain parts of it, it becomes a major problem, and fibromyalgia pain can be very intense. I talk about the purpose of pain and how and why it needs to be managed in Chapter 4. It may sound like a chapter to avoid, but hold on! You need to read it because it includes some important and useful ideas.

And by the way, I'm not just *saying* that I believe that the pain and symptoms of fibromyalgia are real because I'm a nice guy who doesn't want to hurt your delicate feelings. I think that I *am* here to help you, but even more important, I'm a physician who's a clinical researcher, and I've proven in my studies on the pain of people with fibromyalgia that their pain (and yours) is real.

My studies, as well as the studies that have been done by other researchers, have shown that the pain sensations experienced by people with fibromyalgia (especially women) are actually more intense, and the pain lasts longer than does the pain of people who don't have fibromyalgia. Read Chapter 4 for further information on the ins and outs of fibromyalgia pain.

Considering Who Gets Fibromyalgia

Just about anyone of any age can develop fibromyalgia, but most research so far indicates that the majority of people with FMS are of the female persuasion, partly because women are more sensitive to pain than men. This is a time where a little equal opportunity of pain would be preferable (if you're a woman). But who gets fibromyalgia isn't about fairness.

Although women are the primary sufferers of fibromyalgia, many men have been diagnosed with FMS, too, and some men with fibromyalgia go undiagnosed for years. For more information about some of the major patterns that have been identified so far among people who develop fibromyalgia, which you may share with these fellow sufferers, be sure to read Chapter 5.

What about children and adolescents? Do they have fibromyalgia? Sadly, yes. If your child or teenager has FMS, he may have a difficult time because most physicians, as well as the general public, still don't realize that kids can experience chronic pain from FMS. Instead, they think kids are faking it when they say that they're too sick to go to school. Maybe they *are,* but then again, maybe they're not. Skip ahead to Chapter 20 for some advice on how to tell the difference.

Looking at Related Medical Problems

Sometimes, people strongly suspect (or are *sure*) that they have fibromyalgia. Instead, however, they may have arthritis, Lyme disease, lupus, thyroid dysfunction, Raynaud's phenomenon, or a variety of other common and not-so-common medical problems. And sometimes people have both fibromyalgia *and* other serious medical problems. Having fibromyalgia doesn't exempt you from getting sick with other illnesses (even though it seems like it would be only fair that it should).

With the existing array of possible medical problems and their often-overlapping symptoms, even doctors can become confused sometimes about which is which when they're working on a diagnosis. A good doctor is up to this task, of course, as long as you don't expect instant results on your first visit.

For example, suppose that one of your primary symptoms is extreme fatigue, possibly to the point of total exhaustion — even though you haven't been doing anything more strenuous than using the remote control to change channels. This action may use up one calorie or less, but you feel like you've climbed Mount Everest. Maybe your problem is fibromyalgia, but maybe not.

Extreme tiredness is one of the possible symptoms of many medical problems, including hypothyroidism, anemia, chronic fatigue syndrome, Lyme disease, arthritis, and — oh, yes — fibromyalgia, too. No wonder sorting it all out can be so hard sometimes! To find out more about illnesses often confused with FMS, and how doctors sort them out, read Chapter 6.

Do You Have Fibromyalgia? A Self-Test

Only your physician can diagnose you with fibromyalgia and then treat you. Reading this book is a very good idea, but it still doesn't really cut it when it comes to making an actual diagnosis in your own individual case. What I can give you is a simple self-test to use to help you determine if you *may* have fibromyalgia syndrome.

Grab a scratch piece of paper and jot down your answers to the following "yes" or "no" questions. Then, read my analysis at the end of the list. If you think that you may be a possible candidate for fibromyalgia, make an appointment with your physician and find out for sure.

1. **Do you have a lot of pain in certain specific areas of your body? If so, do these areas lack any obvious damage (such as bruising or swelling)?**
2. **Is your overall body pain sometimes severe?**
3. **Do you have trouble sleeping on three or more nights per week?**
4. **Do you feel exhausted about half the time or more?**
5. **Do people often say that you look sick?**

6. **Do you turn down social invitations rather than risk having to go out feeling achy and tired?**
7. **Do you find yourself wondering whether your aches and pains will *ever* go away or if you'll feel like this forever?**
8. **Are you always losing things and forgetting things? Do you have so much mental confusion that you sometimes wonder if it could be an early onset of Alzheimer's disease?**
9. **Are you having trouble finding any real pattern to your pain — because some days it's bad and some days it's not?**
10. **Have you started to feel "down" about your pain and fatigue? Are you wondering whether depression could be the underlying problem?**

If you answered "yes" to as many as three or more of these questions, you may have fibromyalgia, although every person's case is different. That's why even if you only answered "yes" to one or two of the questions, but you think that you may have fibromyalgia, a consultation with your physician is a good idea.

Now, here's some explanation of what may be happening to you, depending on your answers to Questions 1 through 10. Keep in mind, though, that only your doctor can actually diagnose you with fibromyalgia.

- **Question 1:** If you're experiencing pain in specific parts of your body, but you're not seeing bruises or any apparent evidence of tissue damage (and neither is your doctor), these painful areas may be the muscle pains characteristic of fibromyalgia. Read Chapter 8 for more information on tender points.
- **Question 2:** If you said that your pain is sometimes very severe, this is another indicator that you may have fibromyalgia. Be sure to consult a physician to find out.
- **Question 3:** If you have trouble sleeping three or more nights per week, this is serious. The problem may or may not be connected with fibromyalgia (although nearly everyone with FMS has sleep problems), but it's important to resolve your serious sleep deficit. If you're a walking zombie because you're not getting enough sleep, you can't perform well at work or home, nor will you be a happy person.

  Also, if you're prone to developing fibromyalgia, this continuing bad pattern of a lack of sleep every night will make your other symptoms, such as your pain and fatigue, much worse.
- **Question 4:** Severe fatigue is a chronic problem among nearly everyone who has fibromyalgia. Often, it's linked to a lack of sleep. But it may also be an element of FMS as a medical problem. You may also have chronic fatigue syndrome or thyroid disease, and your doctor will need to help you sort it out.

- **Question 5:** If you agreed that those you care about, or maybe even strangers around you, are commenting that you look sick, something about you probably doesn't look right. You may be displaying your chronic pain and associated depression on your face without even knowing it.

  On the other hand, other people tell individuals with fibromyalgia that they look "fine" and "great," and the pain and symptoms are *not* reflected in the face or body language of the fibro sufferer. If this has happened to you, you're definitely not alone.

- **Question 6:** If you're turning down invitations that you would have accepted in the past, have a serious talk with yourself to find out why. Is it because of pain and fatigue? Or could you be having a problem with depression or anxiety — both very common problems for people with and without fibromyalgia?

- **Question 7:** When your pain is constant and chronic, asking yourself if it's ever going to end is only natural. But what you need to do is consult with a physician. You may have fibromyalgia, or you may have another problem altogether. Don't wait for the pain to magically disappear. Take action.

- **Question 8:** If you constantly lose things or forget things, you may have the "fibro fog" that often stems from fibromyalgia. You may also have attention deficit hyperactivity disorder (ADHD). Another possibility is that you may have neither of these but you're simply trying to do too many things at once, and you need to take some things off your plate.

  How do you know which it is? You make a stab at analyzing what you're forgetting and when. If you can't even begin to do that, and you're also experiencing chronic pain, fatigue, and sleep problems, you may have fibromyalgia. But see your doctor to find out for sure.

- **Question 9:** If your pain is severe on some days and then far less of a problem on other days, and you think there doesn't seem to be any pattern to it at all, you may be experiencing the chronic ups and downs of fibromyalgia.

  Pain that can appear in one part of your body one day and migrate elsewhere on another day is a common symptom of FMS, as are days when you feel really bad and other days when you feel only mildly bad.

- **Question 10:** If you don't seem to enjoy anything anymore and maybe are sort of overwhelmed by your many aches and pains, you may have depression. Many people with fibromyalgia have both depression and FMS. You could also have a problem with an anxiety disorder, such as generalized anxiety disorder (GAD), where you are overwhelmed with extreme worry.

> But before rushing off to the nearest psychiatrist to ask for the latest antidepressant or anti-anxiety medication approved by the Food and Drug Administration (FDA), as a first step, consider talking to your regular doctor or to a pain specialist. Why? Your primary problem may actually be fibromyalgia, and if your medical problem is treated and then your symptoms subsequently improve, so may your sad mood. Many doctors prescribe antidepressant medications to treat pain *and* FMS. Get more details on this in Chapter 10.

This test is just a starting point. If you're really concerned that you may have FMS and/or another chronic illness, make an appointment with your doctor.

Finding a Doctor Who's a "True Believer" in Fibromyalgia

Although I believe that most well-educated physicians are at least *aware* of the existence of fibromyalgia and its basic symptoms, and also know that it's a valid problem that needs to be treated, I also know that a few doctors out there still haven't gotten the word yet. If your doctor isn't helping you with your FMS symptoms, you need to help him understand it. Taking this book to your appointment and showing him what you're reading is a good start.

A good doctor will consider your symptoms as valid, take a complete medical history, and perform a physical examination. Read Chapters 7 and 8 for more details.

Sometimes, no matter what you do, a particular physician isn't working out for you. Maybe the two of you have a personality conflict, or maybe he thinks that you should just tough out your fibromyalgia. Or maybe the problem stems from something else altogether. Whatever it is, sometimes, you just need to find a new doctor. (I've devoted a significant part of Chapter 7 to help you find a new doc, if that's what you need to do.)

After you find a good doctor who's interested in working with you, she can formulate a plan for you to follow — one that's doable in your life. Usually, such a plan involves medications to take (over-the-counter and/or prescribed drugs and, sometimes, supplements or alternative remedies, too), as well as advice on basic lifestyle changes that you can make to improve your health. Some of these lifestyle changes may involve foods to eat or avoid (for example, foods high in caffeine may make you feel worse), exercises to perform, and other therapies that may improve your symptoms.

Treating the Problem

When you have fibromyalgia, at least some of the time you may want to take some medications, whether they're over-the-counter drugs; prescribed medications, such as muscle relaxants or painkillers; or other medications such as prescribed or over-the-counter topical ointments that can help to ease your pain and symptoms. I cover these topics thoroughly in Chapters 9 and 10. You can also often gain benefit from hands-on therapy, including heat, ice, and massage therapy, all covered in Chapter 11.

And don't forget about the promise of alternative remedies! People with fibromyalgia have some very intriguing choices to consider, including acupuncture, acupressure, biofeedback, herbal or homeopathic remedies, and neurofeedback. Read more details about all these different choices in Chapter 12.

Making Lifestyle Changes: Pulling Yourself into a Non-Fibro World

As you work to pull yourself farther back into the non-fibromyalgia world, you may sometimes feel like a person loaded down with 50 pounds of extra weight, trying to slog your way through the swamp. During your struggle you watch others on dry land with no heavy packs dart by you, maybe waving at you and telling you that they'll see you later.

If you want to improve your quality of life and be able to reduce your backpack of troublesome symptoms, consider the following basic ideas:

- **De-stress yourself.** Stress is a normal part of life, but if you have fibromyalgia on top of the usual daily stresses, or maybe with some extra stress thrown in once in a while, you're in a bad situation. Stress can greatly worsen the chronic pain, fatigue, and other symptoms of the person with fibromyalgia. Be sure to read Chapter 13 for my suggestions on relaxation therapy, hypnosis, meditation, and other methods to "de-stress" yourself. They work!
- **Improve your sleep to decrease your pain.** Don't kid yourself. Five or even six hours of sleep each night aren't enough. So, if insufficient sleep is a problem for you, as it is for many people with fibromyalgia, face up to it. You may need medication (such as a sleep aid or an antidepressant or anti-anxiety medicine), an alternative remedy (such as valerian or melatonin), or another form of treatment to solve this no- or low-sleep problem that you're going through. Read Chapter 14 for some ideas on how to resolve sleep problems and help yourself feel better.

- **Exercise.** Unless you're an exercise-aholic, you probably don't much like the idea of exercising (most people don't), and the mere thought of it may be nearly migraine inducing for some readers. But the fact is, aerobic exercise will usually help you to limber up and lose weight, making you more mobile and also helping you to feel better. So consider "getting physical." Read Chapter 15 to find out more about the benefits of exercises and for some specific, FMS-friendly exercises you can try.

  Exercise shouldn't hurt a lot, nor should it be really unpleasant and something to dread. If you hate swimming or bicycling, don't use those activities as your exercises. Maybe walking would suit you better, or maybe dancing or some other form of aerobic exercise with your partner or a friend. You can exercise in many different ways: Be creative and find the best ways for you.

- **Pay attention to your emotions.** Stress isn't the only problem that people with fibromyalgia often face. Depression and anxiety are also very common, and they may be problems that you face. These problems are treatable and, in Chapter 16, I talk about how to know if you may have a problem, and how to identify a good therapist to help you, if you need one.

Coping with Fibromyalgia at Home and on the Job

Unfortunately, fibromyalgia doesn't end at 6 p.m. or whenever you arrive home from work, nor does it go away when you wake up in the morning, struggling to get ready for another day at work or at home. When you have FMS, it's always there on the sidelines, waiting to jump on you yet again with its aggravating symptoms.

You also need to keep in mind that other people you interact with on a daily basis (your partner, children, friends, co-workers, and other family members) are directly affected by your fibromyalgia, even if they don't have FMS themselves.

Virtually anyone you interact with on a regular basis needs some understanding of what you need from them, whether you tell them that you have fibromyalgia or not. (Some people with fibromyalgia tell everyone that they have "arthritis" because they think that it sounds better.)

TIP

Even as you become more aware of your symptoms and how best to resolve them, you still have to deal with the "non-fibro" world, comprised of your family members who don't have fibromyalgia, your fellow workers, and many others you interact with. You need to develop workable strategies to cope with these varying situations and come up with a winning game plan for your life. I cover these topics in Chapters 17 and 18.

Working with fibromyalgia at work

Many people with fibromyalgia continue to work full-time or part-time, despite their pain and fatigue. They struggle with what to do when their symptoms make it hard to continue to work.

Many people worry about whether they should tell others at work about their FMS, whom they should tell, what they should say, and so much more. In Chapter 17, I provide a thorough overview of these issues and how they've affected real people. I also include advice from an attorney expert in getting people with FMS approved for Social Security disability.

Handling fibromyalgia with family and friends

Even the most loving family members and friends usually don't really understand fibromyalgia if they don't have it themselves. And even if they do have FMS, too, their symptoms may be very different from what you experience, and the intensity of their symptoms may be better or worse than the way your symptoms grab hold of you.

As nice as it would be if this were true, the reality is that fibromyalgia isn't a quickie one-time explanation. For people to understand what your problem is, especially the people with whom you share your home and your life, helping them get a clue about what you're going through and what you need takes a lot of work.

You have to be candid, and you also need to know how to respond to the dumb things that people often say to people who have fibromyalgia. Read Chapter 18 for more information on how (and also how not) to explain fibromyalgia to your children of all ages, your partner, and other family members and friends, so that they can better understand what's really going on here.

Don't miss the information that I provide on sex and fibromyalgia for readers who are sensing that their partners are maybe feeling a teensy bit deprived in this area of life. (Thinking about sex when you hurt is a hard thing to do, but it's not hard for your non-FMS partner to think about it. Finding common ground is a good idea.)

Sorting it out when you don't have fibromyalgia

Maybe you don't have fibromyalgia, but you live with someone who does, and you really want to understand the problem and to help as much as possible. But where do you begin? Not to worry, I've provided a chapter just for you — Chapter 19.

This chapter describes techniques to assist you in helping your friend or loved one deal with FMS, and it also tells you some things you should *not* do or say because they drive most people with fibromyalgia wild. (People who do have fibromyalgia may enjoy reading Chapter 19, too, and sharing it with their friends and family members who don't have FMS.)

Chapter 2

Recognizing Key Symptoms of Fibromyalgia

In This Chapter

- Regarding the pain and stiffness
- Analyzing the fatigue
- Sorting out fibro fog
- Coping with your body’s reaction to weather changes
- Suffering from sleep problems
- Identifying related medical problems that you may have

For Sandy, the horrible pain is what bothers her most about her fibromyalgia. Sure, she has some other symptoms that bother her as well, such as fatigue and chronic muscle stiffness, especially in the morning. But only the severe pain counts, in her mind.

For Lisa, the pain is also terrible, but she thinks that if she weren’t so horribly tired *all* the time, maybe the pain drugs that she takes would allow her to actually accomplish something — anything. As it is, it’s like she’s trapped in quicksand.

Andy, another person with fibromyalgia, says that he feels overwhelmed by *everything.* The pain. The constant tiredness. The confusion. The frequent headaches. Andy wants it all to go away — preferably right now.

In this chapter, I cover key symptoms of fibromyalgia, including — first and foremost — the pain and stiffness that nearly everyone complains about. I also cover the extreme fatigue that causes constant problems for most people with fibromyalgia syndrome (FMS). In addition, I include information on what some people with fibromyalgia call *fibro fog,* which is really a sort of temporary mental confusion resulting in difficulty concentrating.

I also cover syndromes and diseases commonly associated with fibromyalgia, such as irritable bowel syndrome, interstitial cystitis, chronic headaches, chronic heartburn, depression, and arthritic conditions. You may be interested to discover that some treatments for these individual ailments are similar to (or the same as) treatments recommended for fibromyalgia.

Describing Where It Hurts: Almost Everywhere!

Most people with fibromyalgia say that the widespread pain drives them the most crazy. Sure, they don't like fatigue or muscle aches, nor do they enjoy fibro fog. These symptoms are common for many people with FMS. But they may seem minor league compared to the hurting-all-over pain, which can sometimes escalate from mild or moderate to severe pain.

Eva has had FMS for years, and says that if you want to understand how FMS feels, imagine a giant truck ran over you — and backed up and ran over you again.

Feeling the aches and body pains of your fibromyalgia — but being unable to show proof

You probably find it hard to explain to people *where* you hurt. You can get pretty strange looks when you say that you hurt almost *everywhere.* Not just in your back, legs, neck, or other sites of your body. All those places may hurt, and maybe other places, too. Nor do you have visible damage to point to. No broken bones, no gushing wounds, not one bruise to show someone, "*Here* is where it hurts me the most. Look at this."

Laboratory tests can't diagnose fibromyalgia — at least, not yet. Tests can only tell you that you don't have other medical problems known to cause pain. You shouldn't, therefore, be surprised if doctors can't find anything except some *tender points,* where you wince when pressure is applied there. (Read more about the tender points of fibromyalgia in Chapter 8.)

So you have no hard evidence that you can present for your pain. And yet you continue to hurt and hurt and hurt and hurt.

As an FMS sufferer, you're not alone in regard to a lack of specific laboratory findings. People with chronic migraine headaches, tension headaches, and back pain have recurrent pain, and often doctors find no specific abnormalities. In fact, many chronic-pain conditions lack overt physical findings. But remember, you don't have to *prove* to anyone — including your doctor — that you hurt. You know that you have pain, and that should be good enough for your physician.

Focus on finding a knowledgeable doctor who can diagnose your illness. If you have FMS, you'll also have classic symptoms, such as chronic widespread pain and tenderness as well as fatigue, insomnia, and distress. A doctor who takes a thorough medical history, performs screening tests for other possible diseases, and does a careful physical examination can diagnose most FMS sufferers. (See Chapter 7 for advice on finding a good fibromyalgia doctor.)

Suffering from muscle stiffness — especially in the morning

Many people with fibromyalgia say that the severe muscle stiffness and achiness is the worst in the morning. You may wake up and feel as though you've already participated in a major marathon — or maybe as though gremlins beat you all night long. The stiffness may diminish as you move about, but usually it doesn't go away completely. People with arthritis also often experience muscle stiffness, so maybe in the past, doctors told you that your problem was arthritis.

You may have both arthritis *and* fibromyalgia. Unfortunately, having fibromyalgia doesn't exempt you from other medical problems. If you suffer from chronic stiffness, turn to Chapter 15, which includes some good, easy stretching exercises to help you with this problem.

Tammy, whose fibromyalgia was diagnosed several years ago, feels that one of the hardest parts is the severe morning stiffness. In fact, when she gets up in the morning or rises after sitting for a long period, her husband calls her contortions her "rigor-mortis walk" because her movements look so stiff. (Tammy says that she doesn't mind his teasing because he's supportive and understanding of the problems that she faces with fibromyalgia.)

Singling out a source of your pain: You can't

When you try to analyze where all this pain is coming from — the master generator of your agony — you most likely can't figure it out. Nor can you deduce *why* you're experiencing it. However, you may have found out that stress makes almost all your symptoms worse. Your doctor may often be puzzled by these questions, too. (Read about possible causes of fibromyalgia in Chapter 3.)

Some experts believe that extreme exercise or injuries from a car accident or a fall may induce FMS. But you probably *haven't* been exercising like crazy because you've felt too bad to exercise a lot (or at all). You probably haven't just fallen or had an accident or injury, either.

Chronically feeling your pain

Another key aspect of fibromyalgia is that the pain is *chronic,* which means it's sticking around. Sometimes, it's better; sometimes, it's worse. But it's almost always *there* in the background, seemingly waiting to ambush you. Time for the big annual dinner at work! All of a sudden, your pain escalates to excruciatingly high levels. As with many chronic illnesses, stress often aggravates fibromyalgia. As a result, pain can flare up at the worst times.

TECHNICAL STUFF

Are you suffering from *oligoanalgesia?* This word refers to the undertreatment, ineffectual treatment, or total nontreatment of pain — a problem that many people with fibromyalgia relate to. Yet both nontreatment and inadequate treatment of pain can seriously weaken your immune system and impair your quality of life. Turn to Chapter 4 for more information on pain and its role in your life.

Migrating pain: The worst pain may move from place to place

Another truly maddening aspect of FMS is that the worst pain can be in your lower back today, your neck tomorrow, and maybe in your upper back the next day. Or maybe your whole spinal column is okay now, but you're having a serious problem with pain from irritable bowel syndrome or chronic headaches — both common conditions for people with fibromyalgia.

Pam says that her fibromyalgia feels like a kind of radiating pain that pops up like a poltergeist in new places all the time. She never knows when or where it'll hit her next. It's the kind of surprise she'd prefer to live without, so Pam is actively seeking treatment.

REMEMBER

Fibromyalgia isn't the only chronic medical syndrome. Many medical problems are chronic. High blood pressure is a chronic problem for many people; diabetes is another. Many people suffer from chronic back pain. You're not alone in experiencing a chronic disease.

As if the other symptoms weren't enough . . .

Some people with FMS suffer from an array of other symptoms beyond pain, fatigue, sleep difficulties, brain fog, and so forth. Here are some annoying, but more unusual, symptoms:

- **Restless legs:** People with this symptom feel an achiness and irritability in their legs (sometimes at night when lying in bed) that makes them move about or shake their legs.
- **Paresthesia:** Also known as "pins and needles," this symptom primarily affects the legs, hands, or feet of fibromyalgia sufferers.
- **Tinnitus:** A high-pitched ringing in the ears is a problem that some people with fibromyalgia experience.

Of course, these symptoms may be caused by other medical problems, so if you have them, be sure to let your doctor know.

Being Terribly Fatigued

Darla says that sometimes she orders her feet to move, but they just don't go, which is especially true when she gets up in the morning. This extreme fatigue is common among people with fibromyalgia. Yet, despite such profound fatigue, few patients with FMS get a satisfactory night's sleep. Although the pain is still the worst part for most people with fibromyalgia, the bone-numbing exhaustion is also terribly distressing for many people, who say that this kind of fatigue goes far beyond simple tiredness.

Feeling exhausted

If you actually *were* exercising vigorously, you could understand this extreme pain and exhaustion. But if you've been in couch-potato mode, sitting or lying down all day (because it hurts to move), you can feel really frustrated when doing *nothing* seems to take all the energy you've got.

Your frustration may increase when you hear that you should be sure to exercise. What? When you can barely drag your body out of bed or from the chair? Is your doctor totally nuts? Well, no, actually exercise *is* good advice. I tell you why in Chapter 15, and I recommend some basic exercises to try, too. (Be sure to read it!)

Considering whether you have chronic fatigue syndrome

Some people who haven't been diagnosed with FMS yet are so extremely tired that they wonder if they really may have *chronic fatigue syndrome* (CFS), a medical problem characterized by extreme exhaustion. (Read Chapter 6 for more information on CFS.) In general, if pain is the prevailing symptom and other symptoms of fibromyalgia are also present, it's likely to be fibromyalgia rather than chronic fatigue syndrome.

But, of course, a physician must make this determination. Don't try to diagnose yourself. And by the way, it's also possible to have *both* CFS and fibromyalgia. Hopefully, though, that's not the case with you.

Facing Fibro Fog: Mental Malaise

Many people say that the mental confusion and forgetfulness, particularly the attention and concentration difficulties, are what really bothers them. People with fibromyalgia are bookkeepers, attorneys, doctors, and so on. All these careers require mental alertness. But you can have the easiest job in the world, and it still requires more mental acuity than you can muster up in the middle of a fibro-fog attack — even if you're a certified genius.

TIP

If you have a sense of humor, it can help you relax — at least a little. In fact, you *need* a sense of humor with fibromyalgia. Linda was diagnosed with fibromyalgia several years ago and says that a sense of humor is very important for her. She recalls pouring cereal on a dinner plate, followed by the milk, and then realizing: Oops! That wasn't a bowl she was filling up. She finds that laughing at the results of her fibro fog helps a lot.

Feeling "out of it"

You may feel like you're one of those walking zombies that you see in late-night movies. Feeling as though you're a sleepwalker through life, rather than an active participant in it, can be hard.

Avoid labeling yourself as stupid, crazy, or worthless. Do the best you can. That's all that anyone should expect. Still, dealing with it can be hard.

Judy says that her fibromyalgia developed about a year after she was treated for Graves' disease, a form of *hyperthyroidism* (overactive thyroid gland). She says that she wants her brain back the way it was before. She's tired of forgetting words, names, and faces. Treatment may help Judy considerably. But it's best for most people with fibromyalgia to deal with things the way they are now, instead of fixating on the way things were in the past.

Being frequently inattentive

You probably have a hard time paying attention to what's going on around you when you're saddled with the mental malaise characteristic of fibromyalgia. Sure, you'd love to be actively involved, but it's just not possible now. It's not that you don't care about your friends or that you don't love your family members. You do. You just can't help being so inattentive on so many occasions.

Normally, you stride along, accomplishing your daily tasks at a regular pace. But when you're hit with fibro fog, it's like slogging through knee-deep mental mire. (Be sure to read Chapter 18 on how to help your friends, family members, and others you care about understand fibromyalgia and what's going on with you.)

Wondering about attention deficit/hyperactivity disorder

You may wonder whether your real problem could actually be *attention deficit/hyperactivity disorder* (ADHD), a syndrome characterized by chronic disorganization, distractibility, inattentiveness, and impulsivity. Sometimes people with ADHD are also hyperactive, but adults with ADHD are far less likely to be hyperactive than are children with the disorder. Of course, everyone is disorganized, distractible, and so on — on some occasions — but for the person with ADHD, these are constant problems.

If your primary problem is chronic pain all over, pain that doctors can't attribute to anything other than fibromyalgia, FMS is most likely the cause of your problems with disorganization, distractibility, and the rest. (Of course, as with other conditions, you could have *both* fibromyalgia and ADHD.)

Some researchers have found that adults with the primary problem of untreated ADHD are more likely to have fibromyalgia and chronic fatigue than others, and when their ADHD is treated, the muscle pain and severe exhaustion improve dramatically. Also, what these patients often thought was fibro fog was actually the distractibility of ADHD. It often improves with treatment for ADHD. If you think you may have ADHD, see a psychiatrist or psychologist experienced with treating this disorder in adults.

Coping with temporary confusion

Coping with your temporary mental confusion can be very difficult. After all, how can you solve a problem when you're unable to pay attention to the task at hand or concentrate on it? Plus, stress can trigger or worsen your distractibility. The trick is to find remedies when you're *not* confused that will work (or at least, help) when you *are* confused.

You may want to try some tricks that help people with ADHD cope with confusion, such as creating simple lists, always keeping your car keys in the same place, and quickly checking yourself in the mirror before you leave home. (Yes, your clothes are right side out and your hair is combed. Or they aren't, so you fix them.)

Weathering Your Reactions to Weather

Many people with fibromyalgia feel that they're very *weather-sensitive.* When a cold or warm front is coming on, before they hear it on the radio or see a TV report about the impending storm, they feel pain intensifying in their bodies. Major temperature changes may also cause flare-ups of fibromyalgia symptoms. Cold and wet weather seems to bother weather-sensitive fibromyalgia sufferers the most.

Some people study the phenomenon of weather changes and their impact: It's called *biometeorology,* or the study of how weather (changes in air pressure, precipitation, temperature, wind, and so forth) can affect people's bodies.

People who have increased fibromyalgia pain with weather changes have reported that the worst months for them are November and December, and the best month is July. However, you shouldn't count on July as being a no-pain month, nor should you basically go into hibernation at the end of October. In fact, you may notice no differences in those months at all, because individual reactions to weather vary.

Some anecdotal reports indicate that women may be more weather-sensitive than men are. Of course, how you feel really depends on your individual circumstances, the type of climate that you live in, and other factors. In general, most people with fibromyalgia do better in milder climates. However, experts say that if you're a weather-sensitive person with fibromyalgia, relocating to a warm, dry climate won't automatically make you feel completely well. You may feel *better,* but don't assume that moving to Arizona will mean a cure for you — it usually won't.

Dealing with Common Sleep Disorders

Difficulty with sleeping is extremely common for people with fibromyalgia. In fact, if you *don't* have this problem and you've been diagnosed with FMS, you're unusual — and you may not have fibromyalgia at all. (On the other hand, maybe whatever you're doing to combat your sleep disorder is working, and that's good.)

Fibromyalgia pain often causes insomnia and other sleep disorders. In a vicious cycle, the lack of sleep usually makes you feel worse, which in turn, makes it even harder for you to sleep the next night. You can build up a serious sleep deficit. Solutions, however, are available. If you suffer from sleep problems, read Chapter 14 to find out more about how to improve your sleep cycles.

Experiencing Related Medical Problems

Many people with fibromyalgia also suffer from a variety of other pain-based medical problems that affect the digestive system, the joints, the nerves, and the mind, such as

- Irritable bowel syndrome (IBS)
- Interstitial cystitis (IC)
- Osteoarthritis
- Rheumatoid arthritis
- Lupus
- Benign joint hypermobility syndrome (BJHS)
- Chronic headaches
- Heartburn

Experts don't know why these types of painful problems seem to go together, but they have plenty of theories to explain it. One theory is that the system that controls pain — whether it's a *neurochemical* (brain chemical), hormone, or something else — has gone awry. As a result, the afflicted person can suffer from a variety of painful conditions. (Read more about possible causes of fibromyalgia in Chapter 3.)

If you have more than one illness, you may receive medications for each medical problem. The situation can be further complicated when you see more than one doctor, particularly if you make the bad mistake of not telling each doctor about every medication you take, including all vitamins and supplements, as well as all prescribed drugs. Each drug has the potential to change the effect of every other drug. It may boost or weaken the effects of other medications or change their effects in some other way. Some drug interactions can be dangerous.

Dealing with irritable bowel syndrome

Having the pain, achiness, and mental confusion that can accompany fibromyalgia is bad enough. But many people with FMS also suffer from *irritable bowel syndrome* (IBS), a colonic condition that, very simply put, causes the person to feel bloated and alternate between having constipation and diarrhea. (Another name for IBS is *spastic colon.*)

Many people with IBS either can't go at all or are constantly running for the bathroom. Some people with IBS have *only* chronic constipation or *only* chronic diarrhea. Studies indicate that about 15 percent of adults in the United States have symptoms of IBS, and the disease is about three times more prominent among women.

As with fibromyalgia, experts disagree on what actually causes IBS, although most concur that stress makes it worse. Most experts also agree that certain types of foods can aggravate IBS. Interestingly, some of the same foods that can cause a flare-up of fibromyalgia can also worsen IBS, such as citrus fruits, chocolate, and alcohol, to name the leading culprits.

Diagnosing irritable bowel syndrome

Your primary-care doctor can usually diagnose and treat IBS, although she may want to refer you to a *gastroenterologist,* a specialist in digestive diseases. Based on your physical examination and a review of your medical history, the gastroenterologist may perform a *colonoscopy,* which is an internal exam of your colon done while you're under mild sedation. This procedure is especially likely to be done if you're over age 50 or at risk for developing colorectal cancer. When the doctor examines your colon from the inside with a special scope, he'll see any indications of disease.

Treating irritable bowel syndrome

How is IBS treated? The doctor will usually urge you to increase your intake of vegetables and cut back on (or eliminate) alcohol and chocolate. Medication can help, and sometimes the same drugs that help a person with fibromyalgia can also alleviate some IBS symptoms. For example, a low dose of an antidepressant such as Elavil (generic name: amitriptyline) may ease IBS symptoms as well as FMS symptoms. Some medications used specifically to treat IBS symptoms have been withdrawn from the market because of side effects, for example, Zelnorm (generic name: tegaserod maleate) for constipation and Lotronex (generic name: alosetron hydrochloride) for diarrhea.

For more on irritable bowel syndrome, turn to *IBS For Dummies,* by Carolyn Dean, MD, ND, and L. Christine Wheeler, MA (Wiley).

Coping with interstitial cystitis

Some people with fibromyalgia suffer from a painful bladder condition called *interstitial cystitis* (IC). This chronic and sometimes severe condition makes people with it feel like they must urinate constantly. The person feels this way even after she just went to the bathroom. The condition may feel like a bladder infection, but no bacteria are found when the urine is cultured.

Often, the bladder aches painfully. Many people with IC have been treated with repeated courses of antibiotics because doctors assumed that they must have had bladder infections, despite a negative culture, because they were in such pain. Yet unnecessary antibiotics can aggravate the painful bladder even further.

Experts don't know what causes IC, but it may be a reaction to a previous infection, or could have an autoimmune basis — meaning that the immune system attacks its own tissue. Most IC sufferers are women, but men can have IC, too.

Diagnosing interstitial cystitis

Because IC is rare, most primary-care physicians find it difficult to diagnose. Generally, *urologists* (physicians specializing in diseases of the urinary tract) diagnose IC.

In the case of most people who think they may have (or do have) a bladder infection, many doctors recommend drinking copious quantities of cranberry juice to help stave it off. Don't do this if you have IC! Your bladder is unusually sensitive, and the high acidity of cranberry juice will accelerate spasms and pain. Instead, ask your doctor for another remedy. And be sure to drink plenty of water.

Treating interstitial cystitis

Chronic cases of IC can be treated with medications instilled directly into the bladder through a catheter. Patients can also take certain oral medicines to calm bladder spasms.

As with IBS, some of the same medications that help other symptoms of fibromyalgia may help the person with IC. For example, Elavil (generic name: amitriptyline) may help with pain from IC.

Doctors also often recommend dietary changes. As with IBS and other conditions commonly experienced by patients with FMS, doctors often advise IC patients to avoid citrus fruits, chocolate, and alcohol.

Aching with arthritis

Joint inflammations can be very painful, worsening the already-existing problem of fibromyalgia. Sometimes people who have fibromyalgia are diagnosed with arthritis instead. They may be treated with anti-inflammatory drugs and other medications that often work well for people with arthritis but may do little or nothing for people who have FMS.

Diagnosing arthritis

Arthritis isn't a tough call for most doctors to diagnose, although some rarer forms, such as lupus, can be tricky. *Rheumatologists,* or doctors who specialize in treating arthritis and other diseases of the joints, bones, and muscles, are the best experts to diagnose all forms of arthritis.

In general, the diagnosis of arthritis is based on the doctor's findings during the physical examination combined with the results from X-ray and laboratory tests that the doctor ordered. (Read Chapter 8 for more information on the physical examination and diagnosis of fibromyalgia.) However, many different types of arthritis exist, and the necessary tests may vary depending on what type your doctor believes that you may have.

Osteoarthritis

The most common form of arthritis is *osteoarthritis,* which causes the progressive deterioration of the cartilage and joints of your body. It often comes with aging, although you can be in your 30s or younger when osteoarthritis first becomes a problem. Very simply, osteoarthritis causes pain and deterioration of your joints. It can often be detected by simple X-rays. The doctor will usually order an X-ray of the joints that bother you the most — whether your knees, back, or another part of your skeletal system.

Rheumatoid arthritis

Rheumatoid arthritis, much less common than osteoarthritis, is another form of arthritis. It is triggered when the body's immune system turns on you. This disease may be detected with several special blood tests that can identify factors found in rheumatoid arthritis. If these factors are not found, you may not have this illness.

Patients with rheumatoid arthritis risk developing joint erosions, joint destruction, and severe physical deformities and disability, in addition to the inflammation of other organs. They may be treated with anti-inflammatory medications and ice. They are often also treated with one or more disease-modifying drugs specific to the treatment of rheumatoid arthritis, such as Rheumtrex (generic name: Methotexate), Enbrel (generic name: etanercept), Humira (generic name: adalinumab), or Remicade (generic name: inflixamab).

Lupus

Lupus is a rare autoimmune arthritis disorder that also attacks the joints and other tissues including the kidneys. It is often characterized by a facial rash in the shape of a butterfly, as well as by pain that migrates from one area to another.

Benign joint hypermobility syndrome

Benign joint hypermobility syndrome (BJHS) is a condition that enables a person to hyperextend joints, as with people who are double-jointed. This may sound like an advantage, but it often causes joint pain, as well as widespread pain. BJHS may be treated with anti-inflammatory medications, as well as physical therapy. Strength training may be used as well.

People with BJHS may have some joints that are hypermobile while others are below-normal. Interestingly, BJHS is often associated with poor balance and autonomic nervous system abnormalities, similar to people with fibromyalgia.

Treating arthritis

How your arthritis is treated depends on what type of arthritis you have, how severe it is, how long you've had it, and many other factors. Many forms of arthritis are treated with over-the-counter or prescribed medications, such as anti-inflammatory drugs, as well as with heating or icing the painful area or sometimes massage. (Flip to Chapter 11 for more information on hands-on therapies, such as icing and heating your pain problems.)

The doctor may also prescribe a muscle relaxant, if your muscles appear to be spasming around the damaged joint. Painkillers are frequently prescribed, ranging from over-the-counter ibuprofen to strong narcotics. What the doctor recommends depends on the patient and the situation.

Suffering from frequent headaches

Do you suffer from FMS as well as regular bouts with severe headaches? If so, you're certainly not alone. No one knows how many people with fibromyalgia suffer from periodic migraines or tension headaches, but doctors know that they happen a lot. The underlying problem could be that whatever in the body that controls pain has gone wrong. Or it could be that the body is overly sensitive to pain. It may even be both.

Diagnosing headaches

A *migraine* is a special kind of headache that can be extremely severe and is often accompanied by nausea and vomiting. The pain is usually excruciating;

people often describe it as “blinding.” People with migraines often complain that light and sounds bother them, and they generally want to lie down in a dark place alone and in the same position as long as possible (or until their medication kicks in). (For more on migraines, check out *Migraines For Dummies,* by Diane Stafford and Jennifer Shoquist, MD [Wiley].)

A *tension headache* is another type of headache. It isn’t necessarily caused by stress or tension, although it can be. Tension headaches stem from tightened muscles, often in the neck. Virtually everyone has had a tension headache at some point. When tension headaches (or any type of headaches) become chronic, though, you need to see your doctor to get a handle on the *why* of this frequency and to rule out any serious underlying problems.

If your headaches constantly occur and are severe, your doctor may order a magnetic resonance imaging (MRI) scan of your brain, a special test to rule out a brain tumor or other dangerous condition.

Treating your headache problem

If you have headaches that happen for no apparent reason (much like your fibromyalgia), your doctor will probably treat you with painkilling medications. Drugs such as Elavil (generic name: amitriptyline) — as used with IBS, interstitial cystitis, and fibromyalgia — are often prescribed to keep chronic headaches under control or (even better) to prevent them from happening in the first place.

Generally, doctors also recommend that you avoid acidic fruits, chocolate, and alcohol. (I’m not making this up. Are you starting to see a pattern here?) In addition, although caffeine may be used in some drugs to treat severe headaches, you’ll generally be discouraged from heavy consumption of caffeinated beverages, such as coffee, tea, and sodas.

Some research indicates that migraine headaches may be caused by a minor deficiency of magnesium, and in such cases, supplemental magnesium may help. Of course, before you consider adding magnesium to your diet, check with your doctor. Also realize that magnesium may stimulate your colon, so if you already have IBS and suffer from chronic diarrhea, magnesium may not be the right answer for you.

Hurting with heartburn

Many people who have fibromyalgia also suffer from chronic heartburn. They may have *gastroesophageal reflux disease* (GERD), a condition in which food comes partly *up* the esophagus, which connects to your stomach, instead of going down where it’s supposed to go. The condition can be extremely irritating to the esophagus. Although the stomach has a protective layer of mucous, the esophagus has no such protection. Chronic heartburn can wear down the esophagus and may create a precancerous condition.

Diagnosing gastroesophageal reflux disease

Most primary-care doctors can easily diagnose GERD. If a person appears to have symptoms of chronic heartburn — belching, upset stomach, food that she tastes repeatedly a long time after she ate it, because it backs up (otherwise known as *repeating*) — the doctor may prescribe acid-blocking medications. If patients who take these medications feel better, they probably had heartburn.

Sometimes doctors refer patients with heartburn symptoms to gastroenterologists. The gastroenterologist may perform an *endoscopy,* a procedure in which the doctor looks into the esophagus and stomach while the patient is mildly sedated. The endoscopy shows if there's any serious problem. It can also confirm if GERD is present.

According to the book *How to Stop Heartburn: Simple Ways to Heal Heartburn and Acid Reflux,* by Anil Minocha, MD, and Christine Adamec (Wiley), strong painkillers, such as Percocet or Vicodin, can cause or worsen your GERD. So if you're finding that your painkiller or other medication for fibromyalgia seems to worsen your heartburn, let your doctor know so that you can be switched to another type of medication.

Treating gastroesophageal reflux disease

GERD is usually treated with acid-blocking medications. People with GERD are also usually given dietary recommendations, such as no acidic fruit, chocolate, or alcohol.

Many people with GERD also have problems with insomnia, as do people with FMS. A low dose of a sedating antidepressant may help resolve that problem, as may a prescribed sleep remedy. (Read more about sleep in Chapter 14.) In the case of GERD, however, this advice is accompanied with other recommendations, such as to raise the head of the bed and avoid late-night eating. Exercising and weight loss are also common recommendations given to people with chronic heartburn.

Dealing with depression

If you have fibromyalgia, you're at increased risk for depression. *Depression* is a chronic and severely low mood state, in which a person feels chronically sad and has feelings of poor self-worth, appetite and sleep disturbances, and a loss of enjoyment in activities that used to be pleasurable. At worst, the depressed person considers or acts on suicidal thoughts. At best, the person feels sad and distressed. Thankfully, depression is highly treatable.

Diagnosing depression

Many primary-care physicians recognize and treat depression, although they may refer the patient to a *psychiatrist,* a specialist in treating emotional disorders.

One problem that some people with fibromyalgia face is that doctors may see depression as the entire problem rather than one piece of the fibromyalgia symptoms puzzle. Thus, if the depression is treated, the mood disorder may lift, but the pain, fatigue, and other symptoms of the fibromyalgia may continue on, unabated and unrelenting. If you feel as though you're being shuttled off to a shrink when you urgently need help for your pain, maybe you're right. Speak up for yourself.

Treating depression with medication or therapy

Depressive disorders are usually treated with antidepressants and therapy. Doctors have many different types of antidepressant medications to choose from. If a drug from one category doesn't work, another medication may be effective.

The older and less expensive antidepressant drugs such as Elavil (generic name: amitriptyline) may be useful in treating pain syndromes; consequently, you may get the impact of "two for the price of one" if you take such a drug. However, newer drugs such as Cymbalta (generic name: duloxetine) have proven to be very useful as well.

Depression is often treated effectively by therapists using *cognitive-behavioral therapy* (CBT), sometimes known as "talk therapy." With this therapy, the therapist teaches the person to consider *how* he's thinking about his problems. (That's the "cognitive" part.) The therapist shows patients how to challenge erroneous assumptions — the "behavioral" part of CBT.

The CBT therapist can help you identify ill-serving assumptions about yourself (which you may never have challenged or even noticed before), replacing them with better ones. Such as replacing negative thoughts with something like: "I do *not* deserve to have this medical problem, and I *can* feel better! And I really deserve to be well!"

Then you can work toward finding and implementing effective ways to help you work toward your own much-deserved wellness. I offer many ideas in this book for you to try in order to reach that important goal!

Chapter 3

Understanding Possible Causes of Fibromyalgia

In This Chapter

- Considering physical traumas
- Catching fibromyalgia: When it's triggered by an infection
- Analyzing environmental causes
- Pondering hormones or chemical imbalances
- Thinking about whether it's in the genes
- Speculating about a combination of causal factors

Lisa was in a very bad car crash; the air bag was released so explosively that powder from the air bag flew under her contact lenses and temporarily damaged her eyes. She recovered from the accident — or thought she did — but then Lisa began suffering from severe and widespread pain and fatigue. Her symptoms continued to baffle her doctors for several years before one of them finally diagnosed her with fibromyalgia.

Jamie, on the other hand, has had no accidental injuries, and she really can't trace the onset of her fibromyalgia. In fact, she says that she doesn't know when she did *not* have the symptoms of fibromyalgia. As long as she can remember, she's suffered from pain, fatigue, and *fibro fog* (memory problems and confusion associated with fibromyalgia). Jamie has forgotten exactly how many doctors she may have seen before her condition was finally diagnosed. She does know that her sister, mother, and aunt all have similar symptoms, and she's pressed them to ask their doctors if they could have fibromyalgia, too. Jamie believes that fibromyalgia has a genetic basis because it seems to run in her family.

Both Lisa and Jamie have fibromyalgia syndrome (FMS), although the probable causes for each woman's current condition are apparently different. A trauma to the body can sometimes cause a long-term effect that translates into fibromyalgia, as in Lisa's case. And some people may have a genetic predisposition to developing fibromyalgia, as Jamie believes. Her assumption that her family members have FMS may not be correct, but she *is* right in actively urging them to obtain the medical help that they need.

Research has shown that fibromyalgia can be triggered by injuries (especially neck injuries), infections, and traumatic events. So I begin this chapter discussing these causes, moving afterward to more speculative causes for fibromyalgia, such as environmental causes, Gulf War syndrome, chemical imbalances, immune problems, and other causes. However, I can't tell you which single cause is the "right" one for all people. In fact, fibromyalgia probably doesn't have one single cause; it may instead have multiple causes.

I can tell you that research on fibromyalgia and its causes is actively ongoing and will, I hope, bring us the needed knowledge to uncover the underlying causes of this syndrome. Keep in mind that discovery is an ongoing process. Science continues to march forward, sometimes lurching sideways, to make unexpected new findings that help us.

From injuries and other forms of physical trauma to infections, environmental causes, and severe stress causing post-traumatic stress disorder (PTSD) to the effects of genetics, in this chapter I discuss the primary causes for why some people develop fibromyalgia.

Down But Not Out: Physical Trauma

A physical trauma may be severe enough for some people to ultimately develop FMS. In addition to an accidental injury, some researchers have argued that the onset of fibromyalgia can be attributed to physical or sexual abuse that occurred in childhood or in adulthood. Unfortunately, some people are abused both in childhood and in adulthood, increasing their risk for a variety of health problems.

In these cases of fibromyalgia, the afflicted people were basically healthy before the traumatic injuries occurred, and they had no or few symptoms of fibromyalgia. However, at some point after the accidental injury or physical or sexual abuse, fibromyalgia moved in and seemed to make a permanent home for itself in their bodies.

Although current studies seem to indicate a relationship of FMS with a previous trauma, future large, prospective studies need to be conducted to definitively prove this relationship.

Looking at types of trauma that may cause fibromyalgia

What kinds of physical trauma may trigger fibromyalgia? The syndrome can result from an injury due to a car crash, or it may stem from a serious accidental injury that happened at work. Even a major slip and fall causing an injury can be enough to produce the symptoms of fibromyalgia in some people. For other individuals, a medical crisis or surgery may trigger the development of FMS. A medical crisis is something like a severe infection, surgery, or diabetic crisis.

No one knows how often severe traumas actually lead to the development of fibromyalgia, but probably no more than half (at most) of all cases of FMS stem from physical trauma.

Severe accidental injuries

Debbie was in a car crash, and although she didn't break any bones, she had a great deal of soft-tissue damage. She says that she was covered from head to toe with bruises and people were shocked at the very sight of her. After the accident, Debbie began experiencing severe headaches and extreme overall pain. She had been a successful computer programmer, but ultimately she had to give up her much-loved programming career. Debbie says that she couldn't write programs anymore, and she couldn't even *read* or comprehend what was on the computer screen most of the time, nor could she make any sense of written instructions off the screen. She struggled — and mostly failed — to stay on task because of so much difficulty with reading instructions and remembering what she was doing. It wasn't until Debbie's doctor finally diagnosed her FMS that she began to start picking up the pieces of her life again.

Rebecca, another person whose FMS apparently stemmed from a physical trauma, began experiencing fibromyalgia pain and symptoms after a very bad fall. She slipped and fell, breaking her leg, heel, and toes. In addition to the FMS symptoms, she developed very severe pain in her knee, which her doctors diagnosed as arthritis. Following the advice of her doctors, Rebecca had a knee reconstruction. Her knee felt better after the surgery, but her overall body pain then began in earnest. Rebecca says that she had enormous trouble sleeping, and, at best, she was clocking three or four hours of sleep per night. She also had trouble walking around. Sometimes these difficulties became extreme, and Rebecca says that she had to go to the hospital emergency room 12 times in one year. Rebecca was finally diagnosed with fibromyalgia by a doctor who actually listened to her description of her symptoms, performed a thorough physical examination, ordered laboratory tests to rule out other illnesses, and then correctly deduced that the problem was fibromyalgia (probably caused by the fall) and began to treat it.

Injuries from car crashes or other accidents can trigger fibromyalgia in some people. You can't help it if you were in a car crash or you fell down, but you can deal with the aftermath of fibromyalgia symptoms, when they occur.

Physical or sexual abuse

Physical or sexual abuse is another type of trauma that may lead to fibromyalgia. Some people were subjected to physical or sexual abuse during their childhood, while others are abused in adulthood. Jeanne calls herself an "incest survivor" because a family member sexually abused her when she was a little girl. Jeanne says that she also suffered from extreme stress that stemmed from the abuse, and she later developed fibromyalgia as well.

In another case, Sara, who was physically abused by her husband, says that various doctors suspected that her fibromyalgia was triggered by a near-death beating that she suffered, during which she also suffered a serious head injury and neck trauma.

Some people who were abused as children continue to be abused as adults by their spouses or other individuals. All that physical battering can eventually take its painful toll on the human body, and sometimes the "price" is fibromyalgia.

REMEMBER

Because of these associations, your doctor may ask you probing questions pertaining to sensitive areas of your personal life, including the existence of any current or past abusive relationships, sexual abuse, or physical trauma. Try not to be offended — your doctor is just trying to understand your clinical situation more clearly.

TIP

Being treated and getting counseling for factors such as domestic violence or childhood abuse may be as important in your therapy as any medicinal treatments.

Extreme life-threatening illness

Tammy says that she was fine until, for some reason, she developed a serious brain aneurysm that burst and required emergency surgery. Fortunately, the brain surgery was successful — or so she thought. But shortly afterward, Tammy began experiencing severe fatigue, muscle aches, a hard knot at the top of her left shoulder, and other symptoms — all of which were later diagnosed as fibromyalgia. Since then, she has wondered whether the brain aneurysm may somehow have triggered her fibromyalgia.

Tammy's illness is an example of how physical trauma to the body, including from an extremely severe medical condition, can be a shock that precipitates the development of fibromyalgia. Long after the cause of the illness has passed, as with Tammy's brain aneurysm, the effects of the trauma still remain and must be dealt with.

Injuring yourself on the job

Could your symptoms stem from a work injury? A *repetitive strain injury* (an injury that stems from repeated motions, such as from work on an assembly line) may trigger the development of fibromyalgia. (The most commonly known repetitive strain injury is *carpal tunnel syndrome,* which is damage to a nerve in the hand that results from repeated motions.) An accidental injury at work may also cause fibromyalgia.

Post-traumatic stress disorder and fibromyalgia

Unusual stress and traumas may ultimately trigger fibromyalgia. This reaction is known as *post-traumatic stress disorder* (PTSD). The body and mind apparently go into a hyper-aroused state, and the individual may suffer from extreme anxiety that continues long after the distressing incident occurred. People who suffer from PTSD can develop physical symptoms that lead to fibromyalgia either soon after the incident or after six months or more.

PTSD may be caused by such horrors as witnessing the violent death of another person, experiencing rape or severe physical abuse, or being threatened with death. Soldiers who have served in combat, such as in Afghanistan and Iraq, have an increased risk for PTSD. Not surprisingly, PTSD is the most common disability associated with military service. Other causes of PTSD are torture, natural disasters, severe car crashes, or being told that you have a life-threatening illness. The person who suffers from PTSD frequently reexperiences the distressing event in his mind, including the anguish and pain that he felt when it actually happened. He tends to actively avoid anything that may remind him of the terrifying incident, including the people or places associated with it. PTSD can affect the person's performance at work as well as his social functioning.

PTSD has some basic symptoms, according to the *Diagnostic and Statistical Manual of Mental Disorders, DSM-IV-TR* (a book used by mental health professionals), published by the American Psychiatric Association. When a person has PTSD, the following symptoms become present and were *not* there before the traumatic incident:

- Sleep disorders, such as trouble falling asleep or frequent awakenings
- Angry or irritable outbursts
- Problems with concentration
- *Hypervigilance* (The individual is always on the watch for danger to appear on the horizon and has an extreme startle response. Someone touches him unexpectedly, and he jerks far more violently than normal.)

If you think that your fibromyalgia may stem from an injury that occurred while you were at work or as a result of the work that you perform, you may be eligible for worker's compensation. In a precedent-setting 1999 Illinois case *(Waldorf Corporation v. Industrial Commission),* a worker whose job was to stack cartons in repetitive motions was diagnosed by a rheumatologist with fibromyalgia, and she sought worker's compensation. She won at the lower level, but the case was appealed by her employer. The lower court's ruling was later upheld. (Read more about work and fibromyalgia in Chapter 17.)

Other traumas

Even a very difficult pregnancy may trigger fibromyalgia in some susceptible people. Rose says that she was always a sickly child with FMS-like problems, but her really major symptoms didn't develop until after she became pregnant. She didn't get better after her child was born; instead, she became increasingly ill. Finally, and to her great dismay, Rose became completely bedridden with fibromyalgia when her daughter was about 6 years old.

Keep in mind that Rose's case is a severe one. Most people don't become this disabled from fibromyalgia.

Investigating how physical trauma can trigger fibromyalgia

No one knows for sure how physical trauma or abuse can trigger fibromyalgia. But what may happen is that the body's stress response is shocked into a sort of hyperdrive. The stress response system may rush to help the body resist the trauma by mobilizing *hormones* (chemicals created by the body, such as cortisol and adrenalin) as well as *neurochemicals* (chemicals created by the brain, such as serotonin or noradrenalin) and other body chemicals. The body may hyper-react to the extent that, when the incident is all over, the biochemical reactions still continue on.

For example, imagine your body as a sort of living house. Intruders break into the house and attack it. They smash the windows and slash the carpet. They throw paint on the walls. If a house were alive, it would try to repair itself after the attack ended and the intruders were gone. It would also be vigilant. If the house could somehow give itself burglar alarms and a security system, it would do so.

Imagine if the live "house" decided to *really* protect itself from any future attacks, by surrounding itself with razor wire, armed guards on alert with machine guns, and killer dogs. This protection would be an overreaction, just as sometimes after a trauma, people's bodies go into a hypersensitive and overreactive mode, too.

Catching Fibromyalgia

Some experts have hypothesized that fibromyalgia may result from a bacterial or viral infection, which somehow triggers the FMS symptoms. In some cases, the infection may cause the immune system to go into hyperdrive. Research has borne out that infections apparently can trigger the development of fibromyalgia in some people.

In a study reported in a 2001 issue of the *Journal of Rheumatology,* Danish researchers compared the presence of antibodies (chemicals the body created to kill invading bacteria or viruses) to *enterovirus* (a common viral infection) in 19 people with an acute onset of fibromyalgia to 20 subjects with a slow onset of FMS. They found that half the people with a sudden onset of FMS tested positive for the antibodies, but only 15 percent of the subjects with a slow onset of fibromyalgia had the antibodies in their systems. Based on these results, the researchers concluded that some patients with fibromyalgia may have different immune responses. Although this theory may sound far fetched, it's certainly possible.

Some preliminary pharmaceutical research with *interferon* (a human immunity-boosting chemical) has demonstrated that some people with FMS respond well to the drug, indicating that an immune-system problem may be at work in at least a portion of the people who have fibromyalgia. However, further research is indicated before interferon can be used to treat fibromyalgia.

Interestingly, some people (mostly women) have an immune system that apparently becomes hyperactive, turning on itself. This is called an *autoimmune reaction,* and it may be a cause of fibromyalgia. This may explain why a large number of patients with the autoimmune disease systemic lupus erythematosus (SLE) also have fibromyalgia. Conversely, other people may have lethargic immune systems that are basically run down. Both extreme paths may ultimately lead to fibromyalgia.

From a viral infection

Carla says that a virus may have triggered her fibromyalgia. She was very healthy until she came down with a severe mosquito-borne virus that she contracted in Australia. At the same time, her marriage also failed, and she faced extreme stress from that breakup. The physical and emotional factors, together with the damage to her body caused by the infection, may have thrown Carla's entire body into a turmoil, or so her doctors hypothesized.

In another case, Janet's fibromyalgia symptoms began several months after she'd recovered from a bout with mononucleosis, which may have triggered her FMS.

For both Carla and Janet, an infection appears to have played a role in the development of their FMS. Thus, indirectly, their fibromyalgia was "catching."

From an autoimmune reaction

An FMS sufferer may have had an actual infection to the body, but the person's body hyper-reacted to the bacterial or viral invader by creating an excessive response of the immune system, generating high levels of antibodies. Those high levels of antibodies may have continued to act well after they were still needed, leading to the damaging condition known as fibromyalgia.

This theory makes particular sense, especially when considering that many people with an already-diagnosed autoimmune disease, such as lupus, may also suffer from a form of fibromyalgia. Therefore, all people being diagnosed with fibromyalgia should have an evaluation to make sure that they don't have a recognized autoimmune disorder that's precipitating their FMS symptoms.

From hepatitis B or hepatitis C

Fibromyalgia may be triggered by an infection with hepatitis B (a viral infection transmitted by body fluids that attacks the liver) or by hepatitis C (a less common bloodborne infection that also attacks the liver). According to the Centers for Disease Control and Prevention (CDC), there were 5,494 reported active cases of hepatitis B in the United States in 2005, compared to 671 cases of hepatitis C.

A study of the frequency of fibromyalgia among carriers of hepatitis B, reported in a 2005 issue of the *Journal of Clinical Rheumatology,* suggested that chronic hepatitis B apparently increased the risk for the incidence of fibromyalgia. Among 50 hepatitis B carriers, 26 percent met the criteria for FMS, compared to 4 percent among the control group of subjects who didn't have hepatitis B. The patients with hepatitis B also had a much greater level of fatigue (40 percent) compared to the control group (12 percent) and sleep disorders (36 percent in the FMS group versus 8 percent in the control group). Diffuse musculoskeletal pain was present in 48 percent of the hepatitis B carriers, compared to 6 percent of the patients in the control group who didn't have hepatitis B. Other clinical characteristics that were sharply higher in the hepatitis B subjects were morning stiffness, headache, anxiety, menstrual-cycle disorder, and irritable bowel syndrome. The researchers did not know if the association between hepatitis B and fibromyalgia was directly due to the viral infection, altered liver function, or other causes.

Because many schoolchildren in the United States are now immunized against hepatitis B, this may help to decrease the incidence of fibromyalgia in the future.

Hepatitis C is also linked to FMS. In a study reported in a 2003 issue of *Rheumatology International,* the researchers found that 18 hepatitis C patients (19 percent of their patients) also had fibromyalgia. Hepatitis C is mainly transmitted through blood, while hepatitis B can be contracted through body fluids or intimate physical contact. As a result of their study, the researchers recommended that physicians who suspect that their patients may have fibromyalgia should rule out hepatitis C as a possible cause of the medical problem. If hepatitis C is found, the disease (hepatitis C) can be treated with the appropriate medications (such as interferon and ribavirin, an antiviral drug) as well as with other recommendations that the physician may have.

This evidence doesn't mean that everyone or even most people with fibromyalgia have hepatitis B or C. Instead, it means that hepatitis *may* cause fibromyalgia-like symptoms, and, thus, hepatitis may need to be considered as the cause of these symptoms. This need for testing is particularly true if the individual experienced a blood transfusion before 1990. (After 1990, testing to screen for hepatitis C was developed.) Testing is also necessary if the individual has injected illegal drugs, because hepatitis C is transmitted through the blood.

From other infections

Some experts say that some patients with fibromyalgia may have been previously infected with viruses such as the *Epstein-Barr virus* (a common virus that causes infectious mononucleosis), human immunodeficiency virus (HIV), parvovirus, or *Lyme disease* (a tick-borne illness that was originally discovered in Lyme, Connecticut). In the case of Lyme disease patients who develop FMS, their fibromyalgia symptoms typically don't improve with the normal antibiotic regimen that's prescribed for Lyme disease.

Regarding Gulf War Syndrome

Unexplained musculoskeletal pain, fatigue, and sleep problems have been observed after every military conflict as far back as the Civil War. To date, researchers haven't been able to identify any specific environmental agent as the cause or the trigger of the particular symptoms experienced by the veterans. The one thing they *do* all have in common is the stress that occurs during war times. It is likely that this stress is responsible for their medical problems.

After the Gulf War in 1991, similar to many other military campaigns throughout history, as many as half of the military people who had served in the Persian Gulf reported suffering from symptoms of muscle pain, headaches, difficulty with memory, and fatigue. Among their military compatriots who did *not* serve in the Gulf War region during the same time frame, only about 15 percent reported similar complaints. In retrospect, many of the veterans' complaints, also generically known as *Gulf War syndrome,* may have been consistent with a diagnosis of fibromyalgia. However, despite intensive research, no one could find any specific toxins, like nerve gas, that would explain the Gulf veterans' symptoms.

Female veterans and PTSD

A survey of 1,259 female veterans who received care at a veterans' facility in Puget Sound, Washington, was reported in *Archives of Internal Medicine* in 2004. The researchers found that 21 percent of the women (266 women) were positive for PTSD. The women with PTSD were significantly more likely to have fibromyalgia, irritable bowel syndrome, chronic pelvic pain, premenstrual syndrome, obesity, and other health problems than were the female veterans without PTSD. For example, of the female veterans with PTSD, 19.2 percent had fibromyalgia, compared to 8 percent of the women veterans without PTSD.

Clearly, PTSD is a risk factor for fibromyalgia.

Some researchers have speculated that the military people who served in the Gulf during the war may have contracted a viral or bacterial infection that could have led to their symptoms, perhaps one that was further aggravated by the heightened stress of undergoing warfare in another country. Others think that the severe stress of a combat situation alone could have been sufficient to induce the medical problems that the veterans suffered from. Soldiers in combat have an increased risk of developing post-traumatic stress disorder (PTSD), which itself increases the risk for the development of fibromyalgia and other medical problems.

In one study of Gulf War veterans (104 men and 21 women) who complained of a variety of symptoms, the researchers at Oregon Health Sciences University in Portland, Oregon, found that 27 percent of the veterans met the diagnostic criteria for chronic fatigue syndrome and 14 percent met the diagnostic criteria for fibromyalgia.

In another study published in 2005 in the *Annals of Internal Medicine,* researchers compared the health of 1,061 individuals deployed to the Persian Gulf in 1991 to nondeployed people in the military after ten years. The goal was to determine if there were any long-term effects in deployed veterans versus nondeployed veterans. Although the risk for fibromyalgia was low, the researchers found that veterans who had been deployed to the Gulf were nearly twice as likely to have fibromyalgia (2 percent) than the nondeployed veterans (1.2 percent). They also found that the deployed veterans had an increased risk for chronic fatigue syndrome, skin rashes, and *dyspepsia* (chronic stomach upset).

What about veterans who have been deployed to Afghanistan or Iraq in the 21st century? It's too soon to tell, but it seems likely that at least some of these veterans will develop fibromyalgia, for many of the same reasons as seen with veterans of the Gulf War and other wars.

Homing in on hormonal changes in fibromyalgia

Researchers have found that military veterans with fibromyalgia have low levels of *growth hormone,* a hormone that works to repair muscle tissue. Some civilians diagnosed with fibromyalgia have been found to have similarly low levels of this same hormone.

Researchers say that stressful conditions can inhibit the production of growth hormones. (It's not only children who produce growth hormone. All through your life, some levels of growth hormone are produced by the body.) So, perhaps the military veterans who were in a state of heightened stress under war conditions produced less growth hormone, which then led to the development of fibromyalgia. This theory remains unproven, but it's an intriguing possible explanation for the higher-than-normal incidence of chronic pain and fatigue among the military veterans who have served in the Gulf War.

Helping Gulf War veterans

No one may be able to explain why veterans return from war with symptoms of chronic illnesses, but that doesn't mean that these veterans can't get help. Veterans who served in the Gulf and who have since been diagnosed with chronic illnesses — such as chronic fatigue syndrome (CFS), irritable bowel syndrome (IBS), or fibromyalgia — may be eligible, and should apply, for financial benefits that are available through the Veterans Administration (VA).

Congress passed a law in 1994 to cover military veterans with symptoms of medical problems, such as chronic fatigue syndrome and fibromyalgia, but many veterans were denied benefits. In January 2002, a law was passed to broaden the coverage to more veterans of the Gulf War. The application deadline for these benefits is September 30, 2011. About 3,200 veterans were approved for compensation prior to 2002. (For further information, contact the nearest Veterans Administration office; go to `www1.va.gov/directory/guide/home.asp` to locate a VA facility near you.)

Studying Chemical Imbalances

Research has shown that, among people with fibromyalgia, some important body chemicals are significantly lower than normal, while others are significantly higher. For example, a 2006 study published in the *Journal of Psychiatric Research* compared the levels of brain-derived neurotrophic factor (BDNF) in people with FMS and people without fibromyalgia. (BDNF is a protein in the central nervous system.) The researchers found that BDNF concentrations in the blood were significantly higher in the 41 patients with fibromyalgia than in the 45 patients without fibromyalgia. However, *why* the BDNF levels were higher in patients with fibromyalgia is unknown, and further research is still needed.

Some experts believe that the cause of excessive or deficient levels of body chemicals is due to a brain abnormality related to the interaction between important organs that regulate body chemicals, such as the hypothalamus, pituitary gland, and adrenal glands. What is generally accepted is that excessive or deficient levels of certain hormones from the hypothalamus, thyroid, pituitary, and adrenal glands could contribute to or cause fibromyalgia-type symptoms.

Impairments in these glands that cause deviations from the normal level of body chemicals can lead to troublesome difficulties with sleep, an increased risk for pain, and greater degrees of muscle pain, especially morning stiffness. They may also cause other symptoms that are commonly associated with fibromyalgia, such as fatigue and brain fog, and hormonal abnormalities may worsen other medical conditions.

REMEMBER

No one knows for sure what causes fibromyalgia, although a wide array of theories abound. Evidence is mounting, however, for profound central nervous system abnormalities in FMS. Much of the scientific data strongly implicate stress-related factors that result in abnormalities of the autonomic nervous system as well as neuro-endocrine axes (brain-hormone axes include the pituitary-adrenal gland connection) of FMS patients. Fibromyalgia is not just an extreme form of chronic musculoskeletal pain in the general population. For people with fibromyalgia, speculating on *why* they've developed FMS is certainly an interesting topic — but it isn't as important as actively working with doctors and other health-care providers on a good plan to minimize the pain, fatigue, and other symptoms.

Substance P = Pain

Substance P is a brain/pain neurochemical with the main purpose of sending pain messages to the body. "It's time to hurt! Say 'ouch!'" Normally, this pain message isn't a bad thing, because people *need* to feel pain when they experience harm, so that they can take the appropriate action to resolve the situation. The problem with fibromyalgia, however, is that the pain signal that the individual feels is way out of proportion to minor injuries or illnesses. (Read more about pain in Chapter 4.)

Researchers have demonstrated that people with FMS generate abnormally high levels of Substance P. In fact, studies have shown that some people with fibromyalgia have as much as three times the levels of Substance P in their *cerebrospinal fluid* (a special fluid found in the backbone) than is found in people who don't have fibromyalgia.

Experts don't know whether excessive levels of Substance P are the *cause* of fibromyalgia symptoms or the *result* of them. And, actually, experts don't even know *if* Substance P is either the cause or the result of FMS at all. The high amount of Substance P could just be a by-product of other biochemical processes. (Yes, I know that trying to categorize the cause of this elusive fibromyalgia syndrome can be very frustrating — sort of like trying to nail down Jell-O. Just when you think you have it figured out, it slips away.)

Everyone's body releases some amount of Substance P as a normal course of events when painful stimuli occur. But you certainly don't want to have excessive levels of Substance P in your body. Unfortunately, you can't flip a "halfway" or a "low" switch in your brain to scale things down if your body is churning out too much of this chemical. For now, your brain's control panel is currently inaccessible. Instead, medications and treatments must be used to counteract the effects of Substance P and the accompanying array of symptoms that are associated with fibromyalgia.

Actions that can make fibromyalgia worse

This chapter focuses on possible *causes* of fibromyalgia, but you should also know some basics about what can aggravate an existing case of FMS in many people. So here's a quick list of watch-out-for items for you to consider:

- **Consuming copious quantities of alcohol:** You may think that alcohol will help you fall asleep, so why not have a few drinks before going to bed? The reality is that you may pass out from drinking, but you'll usually wake up in the middle of the night feeling awful. (Read more about alcohol and fibromyalgia in Chapter 15.)
- **Staying up very late and skimping on your sleep time:** In fact, some experts believe that inadequate sleep can actually *cause* FMS, not just worsen it. (When you read Chapter 14, you find out why sleep deprivation is so bad. But the short answer is that inadequate sleep can *really* worsen existing fibromyalgia for most people.)
- **Stressing out in a major way about your personal, work, or family problems:** Stressing out on just about anything, in fact, can really aggravate your symptoms, making it important for FMS sufferers to figure out how to relax. (Read more about depressurizing yourself in Chapter 13.)
- **Consuming only junk food, like soda, chocolate, and sugary foods and drinks:** Ouch! You're going to regret it when the pain kicks in. (Chapter 15 offers good advice on good foods and bad foods.)
- **Experiencing changing weather conditions:** You can try to wish bad weather away, but it won't work. However, you can anticipate its effects on you. (See Chapter 2 for more information on weather sensitivity.)

Neurochemically affecting your pain or symptomatic levels

Some studies of people with fibromyalgia have indicated that other neurochemicals, in addition to Substance P, may be possible causes or contributors to the problem. Thyroid hormone is a critically important hormone that regulates the body's energy expenditure and metabolism. Some people who suffer from chronic fatigue, wide-ranging muscle pain, and sleep disturbances are ultimately found to have elevated or depressed levels of circulating thyroid hormone. This can occur for many reasons, but, in most instances, can be appropriately controlled, leading to improvement in symptoms.

Cortisol is an important hormone that's secreted by the adrenal glands in a circadian rhythm. Most of your cortisol is produced early in the morning (around 3 a.m.), but dips to low levels in the evening. It maintains blood pressure, blood sugar, and other important biological functions that help people cope with stress. Studies indicate that some people with FMS have abnormal circadian rhythms of cortisol secretion resulting in low levels of cortisol during daytime (making them feel fatigued) and too much cortisol at night (causing insomnia).

People with fibromyalgia sometimes experience below-normal levels of brain chemicals, such as *serotonin,* a calming brain chemical. Also, some people with fibromyalgia have below-normal levels of growth hormones, which are hormones that even adults have that perform basic repair work at the cellular level. Insufficient growth-hormone levels may mean that damaged cells stay damaged longer, causing pain and other symptoms.

Examining Environmental Causes

Maybe some people's bodies react to an allergy quite extremely by exhibiting fibromyalgia symptoms, or maybe some people consume a substance and react negatively to it, causing the FMS symptoms to occur. Doctors don't know for sure, so the studies continue.

Considering an allergic reaction

Another theory about FMS is that it may result from the body's allergic reaction to something else in the environment, whether it's chemicals, smoke, or other irritants. This may be why antihistamines can make some people with fibromyalgia feel better — the antihistamine drugs quell the action of the body's *histamines* (chemicals released by the body when confronted with an allergic agent).

Experiencing a hypersensitivity to chemicals

Some people may be overly sensitive to many chemicals in their environment. Most people in the United States are constantly exposed to a barrage of chemicals, but their bodies can usually cope with them. However, some people may go into a sort of "systems overload." They don't actually die, but their bodies react so strongly that it may lead to the pain, sleep difficulties, muscular stiffness, and other problems that are characteristic of fibromyalgia. Some people respond very severely to cigarette smoke, perfumes, and industrial chemicals.

Feeling the effects of phosphates

Some people are convinced that people with fibromyalgia build up storage areas of chemicals in their bodies that clog up their systems with substances that the kidneys are unable to excrete fast enough. They see the primary culprit causing fibromyalgia as a series of numerous, heavy deposits of *phosphates* — chemicals stemming from products containing the element of phosphorus.

The theory is that substances containing salicylate, including aspirin itself, generate phosphates; it is also believed by some that topical ointments containing aspirin and other products also proliferate phosphates. This is why guaifenesin has been advocated to help break up the phosphates that are supposedly present.

Guaifenesin is a drug that's available in both prescribed and over-the-counter dosages; it's normally taken to treat coughs. Guaifenesin users believe that doses of this medication can eventually alleviate the pain, fatigue, and other symptoms of FMS, although clinical studies have yet to bear them out. (Read more about the use of guaifenesin in treating fibromyalgia in Chapter 9.)

Suffering from hyper-arousability

Some people with fibromyalgia, for whatever reason (hormonal, viral, or something else), become extremely sensitive to loud noises, strong light, and other stimuli. Carol says that she stopped sleeping with her husband because he snores. So, now, she sleeps in another room with a big blanket over the closed window to keep out the noise and the light. Carol also got rid of a ticking clock in the room, the noise of which she says drove her "wild." Her children call Carol's new bedroom her "sensory-deprivation room." Carol says spending time in this room makes her feel much better. And it certainly enables her to sleep better.

It's almost as if Carol, as well as some other people who have fibromyalgia, have lost some of their basic sensory screening-out abilities. Or perhaps they're too sensitive, for whatever reason. Either way, they feel nearly as overstimulated as a person suffering from *autism,* a disorder in which the individual feels completely bombarded with stimuli, even in a low-key situation. The slightest touch, sound, or other stimulus causes irritation in the autistic person, and as the stimulus increases in intensity, it causes physical pain. (Of course, people with fibromyalgia are rarely autistic — I'm offering this example only as a comparison.)

Exploring Other Theories

Other theories also try to explain why fibromyalgia strikes some people and not others. For example, maybe it's in the genes, and you inherit this propensity from your parents. Or FMS may result from too much or too little exercising. Fibromyalgia may also be caused by a structural defect at the cellular level. I explore all these possibilities in the following sections.

Linking genetics and fibromyalgia

Can something in your genes cause fibromyalgia? Can you really inherit the risk for developing fibromyalgia if other people in your family are diagnosed with the syndrome? Based on the reports of most FMS sufferers, fibromyalgia seems to run in families. It's also true that almost all chronic medical problems have a genetic basis.

Today, many doctors believe that numerous people may have a genetic predisposition to a wide variety of different medical problems; however, something in the environment (contracting a virus, being involved in a car crash, or facing other types of severe trauma to the body) may have to actually trigger this predisposition to developing fibromyalgia or other medical problems.

Doctors and researchers are working very hard to map the human genetic codes and to try to determine which genes weaken the body and lead to medical problems and which ones work to protect the body and prevent serious illnesses. But the genetic link (if one or more particular links even exist) is still unknown.

Despite this lack of evidence, many people are still convinced that fibromyalgia must be a hereditary medical problem. For example, Denise says that she has always had fibromyalgia symptoms, and her mother and her two sisters have them as well. Their symptoms flare up when they become very stressed out and upset. But Denise is the only family member who has been diagnosed with fibromyalgia so far.

Denise has three children, and two of them — teenage girls, ages 14 and 16 — have the very same overall painful symptoms that Denise and her sisters suffer from. Denise thought that her daughters were too young to have fibromyalgia, but she's rethinking her position and plans to take the girls in for medical evaluations. (Read more about children and adolescents with fibromyalgia in Chapter 20.)

A shared environment

One potential problem with the genetic-cause theory is that people in nuclear families (adults and children, usually two generations) generally also have a shared environment. Because they live together and are in close contact with each other, they come down with the same viruses and are exposed to the same chemicals. They eat the same foods. They also share the same lifestyle — for example, being very active or more on the sedentary side. As a result, if more than one family member has fibromyalgia, the medical problem may actually derive from some undefined element from within their shared environment, rather than from a shared gene pool.

A research link

Dr. Muhammad B. Yunus at the University of Illinois College of Medicine in Peoria, Illinois, has studied 40 families with fibromyalgia and looked at possible hereditary factors at work. His research has found a weak correlation between the development of fibromyalgia in the *HLA allele,* a specific genetic location. Dr. Yunus and other researchers are continuing to look for specific genetic markers that may lead to the development of fibromyalgia among family members.

Looking at who is most at risk in your family

Because fibromyalgia is generally more prominently found among females than males, if FMS does actually run in families, you may expect to find it more frequently in your mother, sisters, aunts, grandmothers, and other female blood relatives rather than in your father, brothers, uncles, grandfathers, and other male blood relations. But keep an open mind. Men can have fibromyalgia, too, so it doesn't hurt to ask.

Even if practically everyone in your family seems to have all or most of the symptoms of fibromyalgia, this doesn't mean that you or your other relatives have FMS. And even if there *is* a genetic predisposition to FMS, this merely means that some people in the family may develop fibromyalgia, and others will not.

Exercising too little or too much

Some doctors and experts theorize that another underlying cause of fibromyalgia may be related to an extreme decrease or extreme increase in activity.

Basically, this means that playing the role of couch potato can transform a person into an unhappy fibromyalgiac. At the other end of the spectrum, a person can excessively exercise to the point that he has overstressed his body and inadvertently caused the onset of fibromyalgia symptoms.

In general, people with fibromyalgia have a lower pain threshold and a greater sensitivity to painful stimuli, and they also feel pain significantly longer after a painful event than people who don't have fibromyalgia. What causes this hypersensitivity to painful stimuli is not entirely clear, but it's apparent that this extreme pain sensitivity can impair a person's overall functioning, causing a negative downward spiral unless and until the cycle is broken. (Read Chapter 4 for more information on pain issues and fibromyalgia.)

As a result of this pain sensitivity, both under-exercising and over-exercising can worsen fibromyalgia pain. For example, Lethargic Lucy rarely exercises because it hurts too much. She's gotten very out of shape, which in turn has caused her pain to worsen. At the other end of the spectrum, Dynamic Diana, an overly enthusiastic exerciser with fibromyalgia, is far more fit than Lethargic Lucy. But she's also more likely to incur injuries, along with the pain she incurs from excessive exercising. (Read Chapter 15 for important advice on exercise when you have FMS).

Considering muscular or structural abnormalities

Some researchers, using expensive high-tech electronic microscopes and other very specialized equipment, have studied tissue samples from people with fibromyalgia. They've found that FMS patients are more likely to have damaged muscle tissue than people who don't have fibromyalgia. Research continues on this high-tech front.

Suffering from a combo platter of illnesses

Maybe fibromyalgia results from a variety of different causes that interact with each other in a bad way. For example, perhaps some families have a genetic predisposition to an allergy. If that genetic propensity interacts with allergy-inducing substances, then the result may be FMS. On the other hand, maybe some families have less effective immune systems, and its members

Analyzing your family tree: What to ask

In attempting to determine whether members of your extended family (primarily your parents and siblings) have fibromyalgia, it's best to avoid asking them directly if they have FMS. They may never have heard of it. Instead, ask them if they frequently have lots of muscle pain, particularly around the neck, shoulders, and back areas. Then ask if the pain seems to move around a lot, sometimes it's in the neck, sometimes in the shoulder, and so forth. (Fibromyalgia pain often moves from place to place.) Keep in mind that older relatives (over age 65) may have pain in those areas, but it could be pain that's associated with arthritis.

Then ask your relatives about any problems with continuous and severe fatigue. Make sure they understand you're not talking about simple tiredness from a hard day but rather a constant and extreme fatigue. If you receive another "yes," continue on with the other symptoms that often appear with fibromyalgia, such as sleep problems, chronic headaches, irritable bowel syndrome, and so forth. Do not, however, announce to your relatives who seem to "qualify" that you *know* that they have fibromyalgia, even if they say "yes" to every symptom, and it seems glaringly obvious to you that, of course, they *must* have FMS. Many medical conditions can be confused with fibromyalgia, and only a doctor can really determine whether a person has FMS (see Chapter 6 for more information).

are more at risk for contracting viruses and bacterial infections — and this combination together may cause fibromyalgia. It may also be true that some families tend to have overactive immune systems, and their members are more at risk for experiencing a triggering of abnormal immune responses to viruses and bacterial infections, which may cause fibromyalgia. There are many possible combinations of circumstances that may lead to the development of fibromyalgia.

Looking to the Future

You can drive yourself crazy trying to pin down the actual cause of fibromyalgia in yourself or other people. Research is actively ongoing, and I anticipate many important breakthroughs in the near future.

For now, researchers and doctors can only theorize about what may cause fibromyalgia. We do know, however, that whatever the causes, fibromyalgia is a *real* syndrome that causes pain and suffering to millions of people, and it needs to be taken seriously.

Chapter 4

Understanding Fibromyalgia Pain

In This Chapter

- Recognizing that pain has both bad and good (really!) roles in life
- Seeing how fibromyalgia pain is different from non-fibromyalgia pain
- Understanding that not all pain can be eliminated — nor should it be
- Discovering what pain management is and how it can help
- Keeping a pain/symptom diary

Pain is bad. But pain is also good. And yes, these seemingly contradictory statements are both true. I know that the idea of pain as a useful thing is very hard to wrap your mind around when you're suffering from frequent and severe pain. And yet, gaining an understanding of both the pros and the cons of pain is important. Why? Because knowledge about your pain is one giant step toward mastery over it. And wouldn't you like to be more in charge of your fibromyalgia pain?

The main problem with fibromyalgia syndrome (FMS) is that your pain is out of control, like the proverbial headless chicken. Another problem with fibromyalgia is that chronic and sustained pain, such as the kind that many people with fibromyalgia most frequently experience, can be very bad for the body. The key with fibromyalgia pain is to control it, keeping it from a scream to a whisper.

In this chapter, I describe the purpose of pain — and it really does have a purpose (actually, more than one). I also talk about pain management and its importance. You may not (and usually can't) succeed at wiping out all your fibromyalgia pain forever. But you can tame it from a raging wild stallion to a sort of gentle nag, and, in most cases, you can also lead a far more normal life than you may be experiencing right now.

Grasping Pain and Why People Have to Have It

If you have fibromyalgia, you know what pain is because you feel it probably every day and at differing levels of intensity. You'd probably like to "grasp" your fibromyalgia pain and throw it out the window forever. But before you explore ways to get rid of pain, you first need to understand pain: what it is and why you feel it.

Pain defined

Pain (mild to severe discomfort stemming from an injury, an illness, or from unknown sources) comes from one of two types of stimuli:

- **An outside stimulus:** The "Ouch! That hurts!" pain response from a paper cut, for example.
- **An internal stimulus:** Tightened muscles, for example.

Pain can be chronic or acute:

- **Acute pain** is pain that's always temporary.
- **Chronic pain** is pain that is sometimes worse and sometimes better, but it's basically always hanging around at some level.

With fibromyalgia, the pain is chronic no matter what caused the initial trauma to the body — whether it was an outside stimulus, such as an accidental injury, or an internal stimulus, such as a virus or something else altogether.

Its advantages and disadvantages

I know it's hard to believe, but pain plays a crucial and good role in your life. Here are the primary advantages of pain to human bodies:

- **Pain provides an early warning system of harm to the body and helps you detect damage or medical problems before they get out of control.** For example, if you have pain with urination, this pain may indicate a bladder infection. If you have chronic headaches, the cause may be sinusitis or a more serious medical problem. If you have constant pain after eating, you may have chronic heartburn or another medical condition. In each of these cases, your pain warns you to see your doctor for further evaluation. Without pain, a medical problem can worsen without your knowledge.

- **Pain enables us to take action now to stop the pain.** Of course, you can't go rushing off to the doctor every time you have a minor ache or pain. But if your pain is severe and/or chronic, your body is sending you a message. It's telling you that something is wrong. Do something about it right now! Ignoring your pain can be perilous to your health.
- **Pain allows you to avoid worse pain.** When you know that something continues to bother you, you can (with your physician's help) work on treating the problem and try to identify patterns that seem to worsen the pain. Armed with that information, you can then avoid (or try to avoid) the painful stimulus in the future. For example, if you know that a bear hug is going to make you ache for days (because it's happened before), you can warn people ahead of time that they really need to be gentle with you.

Pain can be very problematic, not only because pain *hurts* but also because it may lead to some long-term problems. In general, pain can be bad for your body for three main reasons:

- **Chronic pain wears down the body.** Like a truck spinning its wheels in the mud, smoke pouring from the engine, your body starts to break down under the added strain of chronic pain.
- **People who have chronic pain are prone to other illnesses.** Their immune systems may become weakened, and they may become more at risk for contracting the flu or the latest virus making the rounds among their family, friends, and co-workers. If you find yourself getting a strep throat and then the flu and then a bladder infection, you need your doctor's help to break out of this pattern. One way to break away is to accept the fact that chronic illness and pain are part of your problem, ask for help, and then work on rebuilding your health.
- **Pain can harm your quality of life.** When pain is the pervasive influence in your life, you may find it hard to think about anything else or to achieve much of anything. When you're in severe pain, you may have trouble simply getting out of bed, let alone going to work to put in your eight or more hours. Pain also seeps into (or maybe floods into) other aspects of your life. For example, you can't help your child with his homework when you're overwhelmed with pain, nor can you pay attention to your partner or your friends.

Don't start doubting yourself when people say that they can't find anything wrong with you. Causes for chronic pain are frequently hard to detect. But the pain itself is always real. You don't feel chronic pain solely because you're upset or depressed or anxious or annoyed. You may be all those things — especially when people imply that your fibromyalgia pain is imaginary! But the pain itself is an independent and very real entity.

My pain studies on fibromyalgia

My FMS research over the last ten years has clearly shown that patients with fibromyalgia are very sensitive to very mild pain stimuli, like pressure or heat. Why? Because the nerve endings in their muscles and other tissues have become sensitized over time. A small reason for this change in the nerve endings is genetic, but the major reason is acquired tissue changes over the years.

Most people's overall pain sensitivity briefly goes up when they're hurt with minor injuries, and most often this change in sensitivity is very small. But if you have FMS, this increased pain sensitivity has a very hard time reverting back to normal, so you become more and more sensitive to everyday bumps and bruises. Similar to people with frequent infections, your defenses are down — not your defenses against bacteria and viruses, but your defenses against pain.

This concept is a very important one, because, just as you can strengthen your immunity to infections, you can strengthen your pain defenses. You can become more resilient to pain and feel more like a person without FMS. As you may imagine, strengthening your pain defenses may be a slow process and it will require some work — but you *can* do it.

When you have fibromyalgia, your first order of business is to keep your pain from getting any worse. Avoid the daily common mistakes many people with FMS make, like not stretching, not exercising, or not sticking to a healthy diet.

Find out what helps you fight your pain the *most,* so that you can use those techniques to decrease it. Some of the techniques you may try include improving your sleep, making aerobic exercise a part of your day, reducing your stress, and taking medications and medical treatments.

Use your own individual pain fighters to help you reduce your long-term pain level. Identifying your most effective pain fighters is not always an easy process, but it's worth it because the major payoff is that you'll feel significantly better.

Regarding the Different Kind of Pain That's Fibromyalgia

Based on my research and the research of others, I can tell you that the pain that comes with fibromyalgia has three primary aspects. Very basically, people with fibromyalgia feel pain

- **Faster than others do:** FMS sufferers have a lowered pain threshold, meaning that, for example, if someone stuck a pin in you and another one in Susan (who doesn't have fibromyalgia), you'd probably yell before she would. (Read Chapter 3 for possible causes of this heightened pain.)
- **Worse than others do:** When you have fibromyalgia, you feel the pain more strongly. In fact, some light touch that wouldn't bother Susan at all

may really aggravate you. Some people with fibromyalgia say that when they're feeling bad, even something as normally benign as a cat rubbing up against them actually hurts.

- **For a longer time period than others do:** The pain keeps going and going and going, like the Energizer Bunny of pain. Suppose that Susan was pricked with a pin 20 minutes ago, and she's already forgotten about it and is outside raking leaves or talking on the phone with her friends. But you, with your fibromyalgia, are still sitting there, and you're still hurting.

Working with Your Doctor to Manage Fibromyalgia Pain

Some pain can be cured permanently, but most chronic pain, such as the pain of FMS, can't be eradicated altogether and forever. Instead, the goal should be to manage FMS pain by radically decreasing it to a tolerable level. You can attain this goal through pain management. With the help of a good doctor (or two or more — sometimes, you need the help of a specialist as well as your regular doctor), you can beat most pain into submission.

Pain management refers to all the actions that you and your doctor take to decrease (but usually not altogether eliminate) your fibromyalgia pain. It can be an action as simple as taking Tylenol or as complicated as combining medication with acupuncture, exercise, massage, and other options. The bottom line is that you were *up* at *here* (wherever that pain level was) when you started, and then you go *down* to *here* (a lower level of pain) if the pain management has worked for you.

The best way to get pain relief is to work with a caring and knowledgeable doctor who listens to you and works to act in your best interests. And yes, such doctors are out there! If your doctor isn't helping you, you need to think about moving on to a doctor who *will* help you. (Read Chapter 7 for help on finding a good doctor.)

Define your terms

The first step in managing the pain is to find out exactly how your doctor defines pain management. I know what *I* mean by *pain management,* but the term doesn't mean the same thing to all doctors. To one physician, pain management may mean that you're radically improved. To another, it may mean that you aren't calling her anymore, so you must be better. And the term has still other meanings to other doctors.

Find out how your doctor defines pain management by asking the following questions:

- **Does pain management mean a cure?** In most cases, doctors will say "no." If the pain could be eliminated, it wouldn't need to be "managed." So, if the doctor says, "Yes, I can cure you," find another doctor.
- **Can most patients get some pain relief?** The right answer is nearly always "yes," "usually," or "in most cases." If the doctor says "no," you can't get any pain relief for your fibromyalgia, find another doctor.
- **What do you consider "success" in pain management?** I don't have the space here to evaluate the many possible answers you may hear. Just listen carefully to what your doctor says, and determine whether her answer makes sense to you.

After you and your doctor agree on what pain management is and what to expect from it, ask him to help you formulate a plan to set you on the right path to managing your pain.

Plan a course of treatment

The doctor can't feel your pain, so she'll usually ask you how bad it is, on a scale of 1 to 10 — with 1 being minor pain and 10 being extremely severe pain. When your doctor knows how much pain you're in, she'll decide upon a course of action for you to try. She may prescribe medication, along with a hands-on therapy (such as heating or icing the painful area; I cover both options in Chapter 11).

Generally, the doctor will want you to follow her recommendations for a given period of time — which may be days or weeks — and will advise you to come back after that time for a follow-up visit. Listen carefully to what your doctor recommends (it doesn't hurt to take notes!), and follow her instructions as closely as possible. If the recommendation doesn't work at all and your pain is still severe, tell the doctor, and she'll work on seeking other solutions for you.

Chart any changes

Part of working with your doctor is making sure that you report when you feel worse or better. Don't assume that your doctor somehow knows that this new drug or treatment is great or terrible for you. Physicians are smart, but they aren't mind readers. Let your doctor know about the bad and the good. If something helps you, it may help others who are in fibromyalgia hell.

Studies on women and pain

If you're a woman with fibromyalgia who thinks her pain may be undertreated, you may be right. In their article for a 2001 issue of the *Journal of Law, Medicine & Ethics,* authors Diane E. Hoffmann and Anita J. Tarzian analyzed studies of how men and women perceived pain, as well as how their pain was regarded by doctors and nurses. The authors said that because women have pain more often than men and they're more pain sensitive, it would seem as though they'd be treated by doctors at least as well as men are. And yet, they aren't. Instead, women who report pain are *less* likely to be taken seriously and also less likely to receive adequate treatment for their pain.

Other researchers have shown that women experience fibromyalgia pain more and longer than men do. If you're a woman with fibromyalgia, don't let anyone tell you that your pain isn't real. (You can read more about women and fibromyalgia in Chapter 5.)

One way to help you track whether you're getting better, getting worse, or staying about the same is to document in a special diary how you feel. Without this diary, you can very easily forget and think that you felt much worse (or maybe think you didn't feel that bad, when you did). Having a written record is essential.

To help you track how you feel, I've created a simple pain and symptom diary for you to use (shown in Table 4-1). Photocopy it or you can just copy the entries elsewhere, such as in a spiral notebook. If you love computers, you can create a spreadsheet. The key is to choose a format that's easy enough for you to use that you'll use it every day.

Table 4-1 A Sample Pain and Symptom Diary

	Mon	*Tues*	*Wed*	*Thurs*	*Fri*	*Sat*	*Sun*
Level of pain (0–10)							
New treatments							
Stress							

Between visits to your doctor, try to make updates in your diary daily. At the end of each week, carefully look at your pain diary for patterns. Share your diary and any patterns that you notice with your doctor at your next visit.

I suggest that you make entries in your pain diary even if you don't have any pain or much pain on one particular day, so that you'll have an accurate record. (Perhaps your pain management treatments are working. You'll want to record that.) You should also list any moderate to serious stress you faced, ranging from trouble at work or home to anything else that you know causes you to feel distressed.

For example, say that Tom, who's recently been diagnosed with fibromyalgia, started keeping his own pain diary. His first week's entries might look like the diary in Table 4-2.

Table 4-2 Tom's Pain/Symptom Diary

	Mon	*Tues*	*Wed*	*Thurs*	*Fri*	*Sat*	*Sun*
Level of pain (0–10)	9	6	7	5	5	5	7
New treatments	Started new pain drug	No	No massage	Had	No	No	No
Stress	Usual	Usual	Boss yelled	Usual	Usual	Easy day, rested	Mom sick, am worried

As you can see from his chart, on Monday, Tom had severe pain at a level 9. That was also the day he started a new pain medication. On Tuesday, Tom had some pain but felt much better, and his pain was down to a 6. Nothing much else happened that day, so Tom wrote "no" for new treatments and "usual" for stress.

Then on Wednesday, Tom's pain went up a little to a 7. That was also the day his boss yelled at him, which he noted in his diary. (Stress can increase pain, but it can't create it.) Tom's pain was down to a 5 on Saturday but then went back up to a 7 on Sunday, when he was worried about his mother's health. All told, however, a 5 or a 6 is much better than a 9 on the pain scale (which is where Tom started out). Consequently, the medication was a success.

Move on to Plan B

Sometimes, when your doctor recommends a drug or a treatment, even if he's certain that this option is *the* most wonderful remedy on the planet, it just won't work for you. Give it a fair trial, though. Don't expect instant results from anything.

Are you a painiac?

If pain is completely dominating your life and it's also impairing your work and your relationships with others (as is the case for many people with fibromyalgia), you're probably also distressed and upset much of the time. I've coined the very tongue-in-cheek term *painiac* to denote a person whose life is dominated by pain and its effects. Many people with fibromyalgia can easily slip into painiac status, but they shouldn't have to. They need to ask, or, if necessary, *demand* some help from their doctors.

Take this brief self-test to find out if you may qualify as a painiac. Answer "true" or "false" to the following questions and then read further for an analysis of your answers:

1. **I turn down most invitations, including those to events I'd otherwise like to go to, because the pain is too great. Or I fear that it *could* become bad, so I say no.**
2. **If someone I care about needs help with a project, whether it's sewing on a button or asking me to read a term paper, I usually decline because of the pain.**
3. **I have few (or no) pain-free days.**
4. **I have given up physical activities that I used to enjoy.**

Now, you need to analyze your answers. If you answered "true" to question 1, you've indicated that you may be at painiac status now. After the pain is under control, most people can return to socializing and other activities they like.

In question 2, if you answered "true," you're at risk for painiac status.

If you answered "true" to question 3, your life is dominated by pain. It's beyond time for you to step up and recognize that you've got a problem, and it's likely that you are a painiac. If your doctor can't or won't help you, find another doctor. (Turn to Chapter 7 for help on identifying a good physician.)

If you answered "true" to question 4, you're at risk for becoming a painiac. Talk to your doctor about it and ask for help.

Some treatments may take days or weeks, and others may take months before you feel significantly better. How do you know how long is long enough before you should move on to Plan B and try something else? This decision really varies depending on the treatment. But to evaluate whether your pain management is having a significant effect, consider the following:

- **Have you followed the doctor's recommendations or treatments?** If the doctor told you to take a medication daily for a month and you took it once or twice, you didn't give it a fair trial.
- **How long did the doctor tell you it would take for you to have any improvement?** If the doctor said you'd feel better in several weeks, and that time has passed and your pain is still unabated, it isn't working. But if it's only been a few days, give it some more time.

Sometimes, people with fibromyalgia (or their doctors) attribute virtually any pain to their fibromyalgia. Your head hurts, and you think it's your fibromyalgia. Your back acts up — it's that pesky fibromyalgia again. Your toe aches, so it must be fibromyalgia. But people with FMS can have pain from problems other than fibromyalgia. If you experience any of the following, contact your doctor right away — these problems may indicate a medical condition that has nothing to do with your FMS:

- The pain is sudden and far more extreme than it has ever been before.
- The pain is accompanied by symptoms that you haven't seen before, such as dizziness, a racing pulse, weakness, or mental confusion.
- You experience bleeding or visible body changes, such as extreme paleness or redness.

Part II

Finding Out Whether You Have Fibromyalgia

The 5th Wave By Rich Tennant

"I was just surprised you put the word 'marriage' next to the question asking if you suffered from a chronic condition."

In this part . . .

If you think that you're alone with your fibromyalgia, well, think again! About 6 million people in the United States (mostly women, but also some men) and millions more worldwide know exactly what you're going through. Who *are* these people? I'm glad you asked that question because that's the subject of Chapter 5, where I describe patterns found among people most likely to suffer from fibromyalgia.

Part II is about discovering whether *you* have fibromyalgia, and part of that process is ruling out medical problems that may be impostors for your real problem of fibromyalgia. These conditions include chronic fatigue syndrome, myofascial pain syndrome, thyroid disease, forms of arthritis, and a few other illnesses that may surprise you, such as Lyme disease, lupus, and Raynaud's phenomenon (all discussed in Chapter 6). Then I move into diagnosing fibromyalgia. A good doctor is crucial to diagnosing and treating fibromyalgia, and I discuss the important role that doctors play in Chapter 7. I also offer advice on working with your regular doctor and, if that doesn't work, finding a new doc. Then I cover what actually happens (or *should* happen) during your physical exam to find out whether you have fibromyalgia.

Chapter 5

Who Gets Picked to Have Fibromyalgia?

In This Chapter

- Understanding why women are most afflicted
- Analyzing the impact of age and other factors
- Considering fibromyalgia in men

Maybe you're a woman who has fibromyalgia. In addition to you, your sister has it, your daughter has it, and you think that your mother probably has it as well, although she hasn't been diagnosed yet. All the key women in your family seem to have fibromyalgia syndrome (FMS). Not only that, but your brother who served in the Gulf Wars or in Afghanistan is also experiencing some symptoms that sound an awful lot like the ones you and your female relatives all share: widespread pain, fatigue, sleep difficulties, and other shared symptoms.

Almost anyone can develop fibromyalgia. But there *are* general patterns among the people who are the most likely to be diagnosed with FMS; for example, women are much more frequently found to have fibromyalgia than are men (although men can and do have fibromyalgia, and there are indications that men may have FMS more often than realized in the past). Adults are more prone to being diagnosed with fibromyalgia than are children, although children can also have FMS. (Read more about children and adolescents with fibromyalgia in Chapter 20.)

This chapter covers the types of people most likely to develop fibromyalgia. At the same time, it includes information on men with fibromyalgia who may be even less likely to receive a diagnosis than women. In addition, I discuss a possible explanation for *why* women may suffer from fibromyalgia more than men: In general, women actually experience pain more acutely than men do.

Looking at the Numbers: Who Has Fibromyalgia?

About 6 million people in the United States and millions more worldwide have fibromyalgia, and most studies indicate that the overwhelming majority of people who are diagnosed with FMS (80 percent to 90 percent) are adult women roughly of childbearing age (about 20 to 45 years old), although some men and some children and adolescents also suffer from and are diagnosed with fibromyalgia. Many women diagnosed with fibromyalgia are white women, although women of any race may develop fibromyalgia.

There are several possibilities to consider here. These numbers may exist simply because they're valid, and because most of the people who actually do have fibromyalgia really are young and middle-aged Caucasian females. On the other hand, many physicians may not be *looking* for FMS in children or teenagers, just as they may not be looking for it in males, in women under age 20 or over age 45, in nonwhite women, and so forth. Simply put, if FMS isn't in the doctor's constellation of possibilities, often, he's just not going to find it among his patients.

It's not that he's a bad doctor. Instead, FMS simply isn't the first (and maybe not the second, third, fourth, and so on) thing that a physician usually looks for among people who fit into these other groups — even when a male or a teenager of either sex exhibits symptoms that seem consistent with a diagnosis of fibromyalgia (widespread pain, muscle stiffness, tender points, chronic fatigue, sleep problems, and so on).

As a result, if you don't fit into the basic patterns of people who usually have fibromyalgia, you may want to ask your doctor if you could possibly have this medical problem, even though you're generally regarded as "too young" or "too old" to be considered a candidate — or even though you're a man or a nonwhite woman.

Wondering Why Women Suffer More than Men from Fibromyalgia

Research has shown that women are significantly more sensitive to painful stimuli than most men are, and this pain sensitivity is particularly true with regard to the soft tissues and muscles that are examined by physicians. (Soft tissue and muscle pain can stem from damage or defects to the musculoskeletal system, such as strains, tears, or fractures. Rarely, it comes from infections or organic defects or damage, such as heart attack or stroke.) Studies have also revealed that women are often more likely than men to seek out doctors when they feel pain, and they're also more likely than men to complain when they experience pain.

Some experts believe that women's higher level of pain sensitivity may well be what causes females to become much more at risk for developing fibromyalgia than men. Or, as the authors of *Muscle Pain: Understanding Its Nature, Diagnosis, and Treatment* put it, "The greater sensitivity of women to painful stimuli may help to explain why there are approximately seven times as many women as men with fibromyalgia." They also added, "It comes as a surprise to many male practitioners that women frequently experience more pain that do men in response to the same stimulus."

It's not that doctors don't appreciate the pain that many women suffer from. Instead, the reality is that many physicians, along with most people in the general public, haven't learned yet about studies indicating a greater pain sensitivity among women. But medical school professors like me are working hard to find out why some women actually hurt more than some men do. And until more studies are performed to determine gender pain differences among men and women with fibromyalgia, the issue remains up in the air.

Considering How Fibromyalgia Relates to Women's Ages

FMS is most commonly diagnosed in women who are between the ages of 20 and 45. In this section, I give you more information on how age and FMS correlate in women of different ages, from young adulthood and middle age to women in their 50s and older.

Young and middle-aged women and menstruation

Young and middle-aged women may both suffer from fibromyalgia. Young women may find that they're experiencing the onset of their fibromyalgia symptoms, or they may have had FMS for years. (I'm defining *young women* as females who are ages 18 to about 39, after which they can be better defined as women who are in their middle years.) Young women also may be prone to trying hard to ignore the problem, concentrating instead on the demands of their jobs and their children, and trying to work despite their pain and fatigue.

Women with fibromyalgia have an increased risk for metabolic syndrome

Some studies have shown that women with fibromyalgia are more likely to be overweight or obese than other women and to have more medical problems. One study, reported in a 2007 issue of *Metabolism Clinical and Experimental,* found that among 109 women with FMS, they had a 5.6 times greater risk of having *metabolic syndrome* than women without FMS. Metabolic syndrome is a serious health condition that is characterized by *abdominal obesity* (a body shape like an apple instead of a pear), high triglycerides, high blood pressure, low levels of *high-density lipoprotein* (HDL, the good cholesterol), and high fasting *glucose* (blood sugar) levels. The researchers also found that higher urinary levels of norepinephrine and cortisol were associated with a risk for metabolic syndrome.

Many women in early middle age (I'm defining *middle age* as 40 to the mid-50s) are more likely to experience problems with obesity and the onset of other health problems, such as arthritis. Fibromyalgia and its symptoms may be a burden that's laid on top of other emerging and serious health problems that middle-aged women experience.

FMS doesn't seem to be linked to *perimenopause* (the onset of menopause, or the cessation of menstruation), although studies need to be done to determine if such a link may exist. However, stress is strongly linked to fibromyalgia, and many women, especially in their late 40s or 50s, are members of the "sandwich generation" — they're responsible for teenage children as well as caregiving for their aging parents. The stress that comes with this difficult role may trigger fibromyalgia in women who are predisposed to the problem.

WARNING!

Putting off acknowledging that you have FMS is a mistake. You're better off if you work on your medical problems when they first develop because you have a good chance of preventing them from getting much worse. You can't stop yourself from aging. But if you know that you have fibromyalgia as a young woman, with the help of your physician, you can work on creating a good plan of exercise, weight loss, and pain control. This plan may help you to shortstop a future that's clouded with much greater pain and more limitations than you currently face.

Older women and menopause

No one knows how many older women (and men) may suffer from fibromyalgia, but it seems likely that at least some do. In fact, one isolated study indicated that FMS actually *peaked* at age 70, after which it appeared to drop off in incidence. However, more studies need to be performed to determine the extent of fibromyalgia among older women.

One possibility is that older people may have FMS, but they also may have other medical problems that are so severe that they require a great deal of attention, such as a history of stroke, cancer, heart attack, severe osteoarthritis, diabetes, or other ailments. As a result, fibromyalgia may not seem like such a big deal to physicians in comparison to these other, often life-threatening, medical problems. (Although FMS is very painful, it's not a life-threatening condition.) It's also true that sometimes FMS symptoms may be ignored or even diagnosed as "you're just getting older" by some physicians.

For more on menopause, turn to *Menopause For Dummies,* 2nd Edition, by Marcia L. Jones, PhD, Theresa Eichenwald, MD, and Nancy W. Hall (Wiley).

Fibromyalgia and Men: It Isn't Just a Woman Thing

Although the overwhelming majority of people who are diagnosed with fibromyalgia are women, it's definitely possible for a man to have FMS, too. In fact, considering the major difficulty that some women report that they've had to go through in getting a diagnosis of fibromyalgia, a man with the same medical problem may have an even *harder* time receiving an accurate diagnosis of his condition.

One study, reported in the *Journal of Clinical Rheumatology* in 2006, looked at the incidence of fibromyalgia based on actual diagnoses made in medical claims from 1997 to 2002. The results were surprising: The researchers found that although women were more likely to have been diagnosed with fibromyalgia than men, it was by a much lower ratio (by 1.64 times) than reported in many other studies. They also found that patients with FMS (male and female) were from two to seven times more likely than patients without fibromyalgia to also have other conditions, such as headaches, depression, anxiety, irritable bowel syndrome, rheumatoid arthritis, and lupus.

Some men with fibromyalgia are military veterans, particularly from the Gulf Wars. (For more information on this topic, read Chapter 3.) Whether they're veterans or nonveterans, however, the symptoms that men experience are generally the same as the symptoms felt by women, although some men with fibromyalgia report that their fatigue is far more troublesome than the pain.

The trouble with "women's troubles"

Laurie has had fibromyalgia symptoms her entire life. But they've always been perceived as symptoms that were related to her gender. She says that when she first started getting her period, the symptoms were always attributed to menstruation — because she was going to get her period or because she had her period or even because her period had just finished. Somehow, the pain in her body was always related to the bleeding, according to the doctors. When she got older, the problem became, basically, "getting older." Laurie suspects that at some point in the future, when she goes through menopause, doctors will say that menopause is causing all her body aches. Laurie says that it's almost like being female is a disease. (If you think that your doctor regards womanhood as a disease like Laurie's doctors did, be sure to read Chapter 7 on dealing with your doctor or finding a new physician.)

Tom is 42 years old and says that he had a difficult time obtaining a diagnosis. It wasn't until Tom asked his doctor if his problem could be the same thing as his sister had (she'd been diagnosed with FMS) that it occurred to the physician to consider fibromyalgia. After the doctor started thinking about FMS as a possibility for Tom's tender points, fatigue, and other symptoms, he said that it seemed very obvious that fibromyalgia was the correct diagnosis for Tom's condition. The possibility just hadn't occurred to him before, because Tom wasn't a woman.

Men who think that they may have fibromyalgia should ask their doctors about it, because some men do suffer from FMS. Fibromyalgia isn't an unmanly disease — although most men (like most women) would prefer not to have it.

Chapter 6

Identifying Diseases Often Confused with Fibromyalgia

* * *

In This Chapter

- Understanding why fibromyalgia is often misdiagnosed
- Considering chronic fatigue syndrome
- Identifying myofascial pain syndrome
- Analyzing arthritis
- Thinking about thyroid disease
- Going through the other contenders

* * *

You may wonder *why* you should care about other medical problems that can be confused with fibromyalgia syndrome (FMS) and why I've devoted a chapter to this topic. Self-empowerment is the reason. If you're diagnosed and treated for one of these other problems but you're not getting better, you may have fibromyalgia instead. In addition, many people with fibromyalgia suffer from one or more medical conditions described in this chapter.

Yet, sometimes, doctors diagnose *only* your arthritis or *only* your thyroid disease, and not your fibromyalgia. The reverse is also possible. You may be diagnosed with *only* fibromyalgia when you could have thyroid disease, arthritis, or another medical problem. Awareness of these other health problems can help you be a more informed health partner.

I start my discussion with medical problems that can be fibromyalgia imposters (problems with symptoms like fibromyalgia, which may confuse or delay the diagnosis) or fibromyalgia cohabitors (conditions that you may have along with fibromyalgia) such as chronic fatigue syndrome or arthritis.

In addition, I cover several conditions with symptoms similar to fibromyalgia, including Lyme disease, infectious mononucleosis, lower-back conditions, and multiple chemical sensitivities syndrome.

Understanding the Uncertainty

Lauren's doctor had explained to her that her X-rays, along with her symptoms of pain and muscle stiffness, clearly indicated that she had arthritis. Using her X-rays, he illustrated the problems in her neck and back.

Lauren faithfully followed her doctor's recommendations of medication and exercise, and felt *some* better. Yet a lot of pain was still there and, oddly, it sometimes moved from place to place. Could arthritis do *that?* Lauren also had trouble sleeping at night. And she was very tired, all the time.

Lauren went back to the doctor and asked him to reconsider her condition. Could something more than arthritis be at work? Her physician carefully reviewed Lauren's symptoms, her lab tests, and her medical history and came to his diagnosis. The doctor told Lauren that she really did have arthritis — *and* fibromyalgia. The pain that moved from place to place, along with her other symptoms of insomnia and fatigue, tipped him off to the fibromyalgia.

Doctors should easily be able to distinguish FMS from all other medical conditions, shouldn't they? After all, they're smart and they're trained in the scientific method. It should be a piece of cake for them, right? Unfortunately, this viewpoint has several gaping problems.

One problem is that many different symptoms overlap between fibromyalgia and an array of other frequently occurring medical problems. In fact, even trained physicians often initially confuse fibromyalgia with several other medical problems that may be present in their patients, such as chronic fatigue syndrome, myofascial pain syndrome, arthritis, or thyroid disease.

To muddy the water further, many people don't have *only* fibromyalgia; they have other medical conditions along with the fibromyalgia, as in Lauren's case. In these circumstances, the other medical problems can distract the physician from diagnosing fibromyalgia. As a result, you shouldn't be surprised that some people are underdiagnosed — even by good physicians.

Happily, most physicians are increasingly adept at identifying and distinguishing fibromyalgia from other medical problems, and are also getting better at effectively treating patients with FMS. But, to be on the safe side, consumers should gain a basic general understanding of other diseases that become confused with FMS, as well as attain an understanding of the differences between fibromyalgia and these other problems. Such knowledge may give readers confidence to ask doctors more questions, as Lauren did.

Chronic Fatigue Syndrome

Chronic fatigue syndrome (CFS) is characterized by severe and long-term fatigue and exhaustion. It's also known as *chronic fatigue/immune dysfunction syndrome* (CFIDS). According to the Centers for Disease Control and Prevention (CDC), more than 1 million people in the United States have CFS, although at best, 20 percent are diagnosed. Women have about four times the risk of suffering from CFS as men.

I start with CFS because it's probably the condition most frequently confused with fibromyalgia. This confusion results partly from the fact that patients with chronic fatigue syndrome often share many of the same symptoms as people with fibromyalgia.

Although the two syndromes have many points of intersection, fibromyalgia and chronic fatigue syndrome are different illnesses. However, diagnosis can be difficult when the patient is burdened with symptoms of *both* fibromyalgia and chronic fatigue syndrome — which happens all too often. According to the CDC, 30 percent to 70 percent of patients with CFS have FMS.

About chronic fatigue syndrome

The prevailing symptom of chronic fatigue syndrome is an extreme and overwhelming long-term exhaustion. Some research indicates that there may be both a genetic and environmental basis to CFS, particularly with genes that direct the body's response to hormones and with neurotransmitters generated during times of stress and/or injury. However, specific genetic markers have not been identified to date. One study found that childhood trauma increased the risk of an adult developing CFS from three to eight times.

Patients with chronic fatigue syndrome say their exhaustion goes way beyond the mere tiredness that most people without CFS feel sometimes. People who have CFS feel completely overwhelmed and drained of all energy, even when they haven't been doing anything that would normally cause minor fatigue.

With FMS, in contrast, the fatigue that patients feel is often listed as their second worst problem, or may be even farther down on their list of symptoms. Instead, pain is the paramount complaint for people with FMS.

Besides fatigue, many other symptoms are associated with having chronic fatigue syndrome, such as an overall malaise, a hypersensitivity to lights and noise, and chronic headaches in people who never had frequent headaches prior to their onset of CFS. People with chronic fatigue syndrome may also suffer from *hypotension* (low blood pressure) and *syncope* (fainting).

In addition, many patients with CFS are prone to developing *irritable bowel syndrome* (IBS), which means that they have varying degrees of belly pain with diarrhea or constipation. These problems are also common to people who have fibromyalgia, so physicians may have a hard time determining whether CFS or fibromyalgia is the appropriate diagnosis.

How chronic fatigue syndrome differs from fibromyalgia

The difficulty in distinguishing CFS from fibromyalgia is sometimes complicated by the fact that some people alternate between *both* medical conditions. As a result, the physician may find it hard to diagnose each individual medical problem. In addition, CFS is a diagnosis that doesn't exclude other diseases. Although there is no specific laboratory or imaging test for CFS, your doctor will generally order an *erythrocyte sedimentation rate* (ESR) blood test, a nonspecific test for inflammation also used to detect the presence of rheumatoid arthritis, Lyme disease, and other diseases.

In general, if pain is the main complaint and the patient has other symptoms common to fibromyalgia, such as *tender points* (specific areas of the body that are sore, described in detail in Chapter 8), the medical problem is probably fibromyalgia.

In contrast, if the patient's key complaint is extreme fatigue, followed by other symptoms, such as pain and sleep difficulties, CFS is more likely to be diagnosed as the prevailing problem.

Because these two syndromes are more frequently confused than other medical problems that I discuss in this chapter, I provide a chart (Table 6-1) comparing key symptoms of fibromyalgia and chronic fatigue syndrome.

Table 6-1 Comparing Fibromyalgia with Chronic Fatigue Syndrome

Symptom/Finding	*Fibromyalgia*	*Chronic Fatigue Syndrome*
Pain	Primary symptom	Secondary symptom
Fatigue	Secondary symptom	Primary symptom
Muscle pain	Yes	Yes
High spinal-fluid levels of Substance P	Yes	No
Physical brain changes	No	Maybe (cortical white matter lesions)

Symptom/Finding	*Fibromyalgia*	*Chronic Fatigue Syndrome*
Abnormal growth-hormone levels	Yes, in some patients	No
Difficulty concentrating	Yes	Yes
Chronic or frequent sore throat	No	Yes
Problems with short-term memory	Yes	Yes
Tender lymph nodes	No	Yes
Chronic low-grade fever	No	Yes
Weight gain	Yes	Yes
Chronic headaches	Yes	Yes

Treating chronic fatigue syndrome

Although chronic fatigue syndrome currently has no cure, the condition eventually appears to improve in most people — but how long it takes to feel better varies from person to person. In the meantime, physicians can treat CFS patients with nonsteroidal anti-inflammatory drugs and low doses of antidepressants. Patients with anxiety and sleeplessness may be treated with anti-anxiety medications such as Klonopin (generic name: clonazepam) or Ativan (generic name: lorazepam). (Read more about medications in Chapters 9 and 10.) Some physicians place their patients with CFS on antiviral regimens or antibiotics.

Doctors may give patients with CFS lifestyle recommendations, such as advice on exercising and, if needed, weight loss. ***Note:*** Because people with CFS are easily overtired, they should exercise at a slow rate. Walking and mild aerobic exercises are usually best for individuals with chronic fatigue syndrome. The individual may also benefit from psychological counseling, because depression or anxiety often accompanies CFS.

TIP

For further information and the latest findings on chronic fatigue syndrome, contact the CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398 (phone: 704-365-2343; Web: `www.cfids.org`). Also, check out *Chronic Fatigue Syndrome For Dummies,* by Susan R. Lisman, MD, and Karla Dougherty (Wiley).

Considering cortisol

Could *cortisol* (a hormone released by the adrenal glands that helps to control blood pressure, blood sugar, and other major body functions) be the key to both the cause of chronic fatigue syndrome and its solution? Researchers who performed a study of 32 CFS patients reported on their findings in the British medical journal *Lancet* in 1999. The researchers found that about one-third of their subjects significantly improved upon taking low doses (5 or 10 milligrams per day) of oral hydrocortisone, a synthetically made form of cortisol, and felt much more energetic.

The researchers hypothesized that *hypocortisolism,* or a below-normal rate of the cortisol hormone produced by the adrenal glands, may have been responsible for the fatigue experienced by the patients. However, hydrocortisone is an experimental treatment, and further studies need to be done before hydrocortisone can be considered an acceptable treatment for patients who have chronic fatigue syndrome.

Myofascial Pain Syndrome

Another condition that may be confused with fibromyalgia is *myofascial pain syndrome* (MFS), which is primarily characterized by *regional pain* (pain confined to one particular area). This type of pain differs from the widespread pain characteristic of patients with fibromyalgia. The doctor can also identify painful areas when he probes them, because they feel like knotted ropes.

Experts say that many cases of MFS have gone undiagnosed, despite the severity of the case. Yet, this medical problem is usually treatable with medications and other therapies.

About myofascial pain syndrome

MFS may be caused or worsened by mechanical stress or strain on the muscles, such as from heavy lifting or a physically traumatizing event, or by overstressing the muscles of the body in some other manner. Whatever caused the muscle groups to become stressed, they stay that way and cause pain.

MFS occurs about equally among women and men, in contrast to patients with fibromyalgia — a medical problem dominated by female patients.

Pain caused by MFS occurs most commonly in the head, shoulders, or lower back (and usually not in all those places, as is common with fibromyalgia). Pain from neck muscles can radiate into the skull, although any muscles anywhere in the body can develop trigger points.

Trigger points are areas of pain characteristic of myofascial pain syndrome. A trigger point is a ropey or nodular muscle area that causes pain that can be felt in one or more areas of the body by the doctor when she probes the painful area. They're very different from the *tender points* of fibromyalgia.

With fibromyalgia, your painful areas, or tender points, are very sore to the touch, but the physician doesn't usually feel anything during your physical examination, even when directly probing areas that cause you pain. In fact, the person with FMS feels basically the same to the doctor as a person who does not have FMS, even in the sore areas. Of course, the pain *is* there when you have fibromyalgia, it's just not related to specific muscle abnormalities.

Several other key features characterize myofascial pain syndrome:

- **Regional, rather than widespread, pain:** The person with FMS may feel pain in her neck, shoulders, upper back, lower back, other sites, or all these areas. The pain may also alternate from one site to another. With myofascial syndrome, the pain takes up permanent residence in one or several different hurtful places, and stays there for a long time.
- **A limited mobility of motion:** With myofascial pain syndrome, you may have local pain with movements. With FMS, on the other hand, moving around a lot may hurt, but the pain is usually scattered and widespread.

How myofascial pain syndrome differs from fibromyalgia

If someone has told you that myofascial pain syndrome and fibromyalgia are really the same condition, remember what I'm telling you here: They're not. Although FMS and myofascial syndrome have many overlapping features and you can actually have *both* medical conditions at the same time, the reality is that they're two very different medical problems.

Emotional problems, such as depression and anxiety, occur more frequently among people with fibromyalgia than among people who have MFS. This doesn't mean that patients with MFS are never depressed or anxious. It just means that they're less likely to have these emotional problems than are people with fibromyalgia.

Another difference, as mentioned earlier, is that myofascial pain is usually more localized than the pain from fibromyalgia, which is widespread.

Even though myofascial syndrome is different from fibromyalgia, it does share the common denominator of pain. In addition, many people with MFS also have problems with fatigue and sleep difficulties. However, the *fibro fog,* or major difficulty with concentration characteristic of many people who have fibromyalgia, is found less frequently among patients with MFS.

Treating myofascial pain syndrome

Studies indicate that day laborers regularly performing physically demanding manual work are much less prone to developing trigger points than are individuals who are basically sedentary and then suddenly engage in physically demanding tasks. As a result, although exercise and physical activity are generally good for most people, people who are out of shape and have MFS need to build up slowly from a sedentary level to a more active level. In fact, this policy is good for sedentary people without MFS.

Because specific and identifiable trigger points can be found in myofascial pain syndrome, the condition may be treated with trigger-point injections, made directly into the painful areas. (These injections often use medications that can slightly hurt at first, but the pain dissipates quickly, and relief moves in. Most patients consider the relief worth temporary discomfort.)

Patients with MFS may gain good relief with trigger-point injections, as well as a variety of medications, such as muscle relaxants, nonsteroidal anti-inflammatory medications, and painkilling drugs. (I discuss these medications in Chapters 9 and 10.)

Biofeedback therapy may also be helpful to patients with myofascial pain syndrome, in that it can help very tense patients receive training in how to relax overstressed muscles that are causing them such pain. Relaxation therapy may help as well. (Read more about these therapies in Chapter 13.)

Arthritis

Some people with fibromyalgia may be told that they have arthritis — and the doctor may be right, because arthritis is commonly associated with FMS. Very generally, arthritis is a disease of the joints and the surrounding tissues. Arthritis has many different forms, but two primary types are the arthritis leaders: *osteoarthritis* and *rheumatoid arthritis.*

Physicians may sometimes assume that patients have one of these forms of arthritis, particularly osteoarthritis (because it's so common), when the primary problem may be fibromyalgia instead. Also, patients may actually have osteoarthritis along with fibromyalgia, or may have both rheumatoid arthritis and fibromyalgia.

There are also less common forms of arthritis which may be associated with fibromyalgia, such as lupus and polymyalgica rheumatica (pronounced pah-lee-my-*al*-jih-kuh roo-*mat*-ih-kuh). Patients may have one of these disorders alone or may have one alongside FMS.

About arthritis

The long-term damage caused by osteoarthritis (and sometimes by rheumatoid arthritis as well) can be so severe that the affected person will eventually require joint replacements, usually of the knee or hip joints.

The key characteristics of arthritis are pain and inflammation, and clinical tests, such as X-rays, blood tests, or the doctor's visual observation of apparent swelling and damage of a patient's joint, usually show some abnormalities. In general, people with fibromyalgia and no arthritis have normal X-rays and normal blood-test results, and their friends and relatives drive them crazy by telling them that they look "just fine."

Boning up on osteoarthritis

Osteoarthritis is the most prominent form of arthritis: About 21 million Americans ages 25 and older have osteoarthritis. Before age 45, more men than women have the disease; after age 45, women pass men in osteoarthritis incidence.

Osteoarthritis is a degenerative, wear-and-tear disease of the bones. Although people often think of older people when they think of osteoarthritis, you don't have to be a senior citizen to be diagnosed with osteoarthritis; middle-aged or even younger individuals may also be diagnosed with osteoarthritis.

As people with osteoarthritis age, their pain increases, and their X-rays usually show increased deterioration. In fact, the damage can become quite severe, although treatment can often delay the progression of this disease.

Regarding rheumatoid arthritis

The other common form of arthritis is *rheumatoid arthritis* (RA), an inflammatory form of arthritis that causes swelling, stiffness, and the eventual deformity and destruction of the joints. About 2.1 million adults in the United States suffer from this debilitating disease.

Rheumatoid arthritis is an *autoimmune disorder* (a disorder in which the person's immune system mistakenly attacks its own tissues as if they were foreign invaders, like a virus or bacteria). Rheumatoid arthritis causes pain, inflammation, and damage to the joints. In many people, RA becomes progressively worse with age.

Severe morning stiffness is a common symptom of RA, as is debilitating joint pain. Rheumatoid arthritis usually has an onset in patients ages 20 and 45, although it can develop earlier or later in life. Women have about four times the risk of developing rheumatoid arthritis as men, related to the fact that, in general, women are more likely to experience autoimmune disorders.

Laboratory tests can usually (about 60 percent of the time) detect particular blood factors that are indicators for the presence or likelihood of rheumatoid arthritis. In addition, the damage to the person's joints, which may be swollen and distorted, may be clearly visible to the physician as well as the layperson.

In the early stages of the condition, however, the diagnosis of arthritis may be missed, particularly if the patient was previously diagnosed with fibromyalgia. And the reverse is true: If the patient was previously diagnosed with arthritis, the diagnosis of fibromyalgia may be missed.

Looking at lupus

Lupus, also known as *systemic lupus erythematosus,* is an autoimmune disease that usually appears in patients in their 20s or 30s. About 90 percent of people with lupus are female. Lupus is caused by antibodies (produced by the body) that attack the skin, kidneys, joints, nervous system, and other parts of the body. It is unknown what triggers these antibodies. If lupus affects the joints and muscles, causing pain, it may be misdiagnosed as fibromyalgia.

The most common symptoms of lupus are a red rash on the face, severe fatigue, painful joints, and swollen glands. The painful joints and extreme fatigue may generate a diagnosis of FMS if the physician does no further investigation. For example, people with fibromyalgia are not sensitive to sunlight, but patients with lupus are photosensitive. In addition, patients with lupus often have an unexplained fever, not a symptom of fibromyalgia. Symptoms of lupus come and go; an onset of symptoms is called a *flare.*

For further information on lupus, contact the national office of the Lupus Foundation of America, Inc., at 2000 L St. NW, Suite 710, Washington, DC 20036 (phone: 800-558-0121; Web: `www.lupus.org`).

Pondering polymyalgia rheumatica

Polymyalgia rheumatica (PMR) is another disease sometimes confused with FMS because it causes muscle pain, shoulder and neck pain and stiffness, and hip pain and stiffness, as well as fatigue. The patient's pain and stiffness are particularly severe in the morning. (Often patients with other forms of arthritis are stiff in the morning, so don't think that you must have PMR if you have this symptom.)

An estimated 700 of every 100,000 people (less than 1 percent of the population) age 50 and older develop PMR. The disease nearly always develops suddenly in people age 50 and older, and older women are about twice as likely to develop PMR as men. The person with PMR has an elevated erythrocyte sedimentation rate (ESR) in their blood test for inflammation, but other tests are normal. Anemia may be present, as well as unintentional weight loss. The symptoms usually decline within one to four years. People with PMR are treated with medications for their pain and stiffness.

It is unknown what causes PMR, although some experts theorize that it may be triggered by infection, because the symptoms occur so suddenly. If PMR is caused by an infection, the bacteria or virus has not been isolated to date.

Women have about twice the risk of men of developing PMR. The diagnosis and treatment of PMR is important because about 15 percent of those with PMR develop giant-cell arteritis, a more severe disease which may cause blindness and stroke. Giant-cell arteritis causes arteries in the head, neck, and arms to narrow and reduce blood flow.

How arthritis differs from fibromyalgia

How can osteoarthritis or rheumatoid arthritis, the most common forms of arthritis, possibly be confused with fibromyalgia? This confusion can occur in two primary cases:

- **The osteoarthritis or rheumatoid arthritis may be an early case, and damage is not yet detectable in lab work or X-rays.** In the early stages of arthritis, the disease causes pain, muscle stiffness, overall achiness, and fatigue. Patients may also experience depression and anxiety, as they also do with fibromyalgia. The doctor may assume that if the patient’s symptoms sound like arthritis, it *must* be arthritis.
- **Many people with fibromyalgia have osteoarthritis or rheumatoid arthritis (or less commonly, lupus or PMR), because arthritis is a common medical problem.** As a result, the diagnosis of arthritis may be correctly flagged by the physician, but the identification of fibromyalgia may be altogether missed.

What if a person has *only* fibromyalgia? Can she be misdiagnosed with arthritis? Yes, this can happen, primarily when the mistaken diagnosis is osteoarthritis, primarily because osteoarthritis is so commonly found. Even if no extensive damage can be found in X-rays, physicians may assume that the person is suffering from a “touch” of arthritis, which usually means that the patient has indications of early osteoarthritis. But the correct diagnosis may be fibromyalgia instead.

Treating arthritis

If you’re diagnosed with arthritis, your doctor should be able to help you improve how you feel. However, keep in mind that, as with fibromyalgia, arthritis is a chronic disease, and no magic pills are out there that can eradicate it forever.

Whether you have rheumatoid arthritis, osteoarthritis, lupus, or PMR, the key elements of help are medication, exercises to improve your stiffness and your range of motion, and basic lifestyle changes, such as weight loss (when needed) and a nutritious diet. Physical therapy may also provide some relief.

For more on coping with arthritis, check out *Arthritis For Dummies,* 2nd Edition, by Barry Fox, Nadine Taylor, and Jinoos Yazdany (Wiley).

Medicating arthritis

People with osteoarthritis generally need medications in a class known as *nonsteroidal anti-inflammatory drugs* (NSAIDs). These medications reduce pain that stems from inflammation. As the name stipulates, they aren't steroid drugs. NSAIDs are available in both over-the-counter and prescribed strengths. Their primary side effect is to cause stomach upset, and their continued use may cause stomach ulcers.

Although most anti-inflammatory drugs and mild painkillers provide pain relief to patients with rheumatoid arthritis, most patients need to take disease-modifying antirheumatic (DMARD) drugs, such as methotrexate sulfasalazine or hydroxychloroquine. Doctors may suggest prescribing a DMARD drug early in the course of the disease because these drugs can prevent serious joint damage.

Newer drugs for rheumatoid arthritis include Enbrel (generic name: etanercept), Humira (generic name: adalimumab), and Remicade (generic name: inflixamab), all drugs that work to block inflammation. Patients may also be given drugs in the *COX-2 inhibitor class* to block inflammation and pain, such as Celebrex (generic name: celecoxib). Other newer therapies include medications such as Orencia (generic name: abatacept) and Rituxan (generic name: rituximab).

The treatment for patients with lupus is tailored to their problem. If the patient is in remission, aspirin may be sufficient. If the patient is suffering from a flare, she may need painkillers as well as anti-malaria drugs such as Plaquinil (generic name: hydroxychloroquine) and steroids.

What about PMR? Patients with PMR are given steroids such as a low daily dose of prednisone. The prednisone is reduced as symptoms go away. Nonsteroidal anti-inflammatory drugs such as ibuprofen and aspirin may be taken daily. Prednisone can cause weight gain, fluid retention, easy bruising, and a round face. It may also lead to diabetes, glaucoma, and stomach irritation. Patients with PMR need to be followed carefully by their doctors.

Considering other needed treatments

The patient with rheumatoid arthritis may also need to "rest" a joint, with splints or braces. Some patients in the later stages of rheumatoid arthritis may be so impaired that they may require a walker in order to move about.

People with the forms of arthritis discussed in this chapter can gain considerable benefit from cold or heat therapy or massage therapy (as described in Chapter 11), as well as relaxation therapy (covered in Chapter 13). Aquatic exercises and swimming may improve problems with physical mobility and pain. (Read more about how exercise can help fibromyalgia symptoms in Chapter 15.) They may also benefit from massage therapy and acupuncture. (Read about massage therapy in Chapter 11 and acupuncture in Chapter 12.) Low doses of antidepressants, described in Chapter 10, may decrease pain and improve sleep among those with sleep problems.

These are all therapies, which, coincidentally, also benefit people with FMS. As a result, if you happen to have the dubious honor of having both arthritis and fibromyalgia, such therapies can help you to improve both conditions.

Thyroid Disease

Now, arthritis and fibromyalgia seem to go together quite well. But how could anyone possibly confuse thyroid disease with fibromyalgia? One is an endocrine disorder, and the other is a musculoskeletal problem — two seemingly disparate medical issues.

The key reason why thyroid disease can be easily confused with fibromyalgia is that *hypothyroidism,* or low thyroid function, leads to fatigue and may cause painful and aching muscles and even widespread pain — the symptoms experienced by most people with fibromyalgia. Hypothyroidism is common, yet is often undetected. However, testing for low thyroid isn't difficult.

TIP

If you think that you may have fibromyalgia, ask your doctor for a thyroid-function blood test. If you have an underactive thyroid, a small thyroid pill taken once a day usually rectifies the problem.

About hypothyroidism (low thyroid)

The thyroid gland is an important organ located in your neck. It produces thyroid hormone, a hormone needed for survival. This hormone controls a person's basic energy level and affects many aspects of the body, such as blood pressure, heart rate, and even fertility and mood states. People need thyroid hormone to live, whether it's derived from their own thyroid gland or from thyroid-supplement medications that they take.

Sometimes, people develop thyroid problems that cause low or high levels of thyroid hormone to circulate in the body, and this malfunction directly affects the individual. Thyroid disease is almost always treatable, although people with thyroid problems should consult an *endocrinologist,* a physician who specializes in endocrine diseases like thyroid disorders.

When someone has a thyroid disease that doctors may confuse with fibromyalgia, it's nearly always hypothyroidism because symptoms more commonly associated with low levels of thyroid, such as low energy, fatigue, and body aches and pains, are also symptoms of fibromyalgia.

The specific screening test for thyroid disorders is the *thyroid-stimulating hormone* (TSH). If your thyroid gland isn't producing enough thyroid hormone to meet your needs, your pituitary gland will react and raise the level of TSH in your blood. A repeat TSH test is usually done to confirm hypothyroidism before medication is started. There are other thyroid tests, but most doctors consider the TSH the gold standard of thyroid tests. If you have a thyroid disease, you'll need periodic blood testing to ensure that your medication is at the right level.

Treating thyroid disease

Hypothyroidism is readily treatable by experienced physicians. Thyroid disease is best treated by *endocrinologists,* physicians expert in treating thyroid diseases and other medical problems related to the endocrine system.

Hypothyroidism is treated with prescribed synthetic or natural thyroid hormone, available at virtually any pharmacy. The medication is usually taken once daily, and is best taken on an empty stomach for full potency.

When thyroid disease is first diagnosed and treatment has begun, the TSH is usually repeated several times the first year of treatment, to ensure that the person doesn't need a higher or a lower dosage. After apparent stabilization, TSH testing may be limited to an annual test, if the doctor decides that's sufficient. If thyroid medication is taken during pregnancy or menopause, a woman may require a change in the dosage of the drug.

For more on treating thyroid disease, check out *Thyroid For Dummies,* 2nd Edition, by Alan L. Rubin, MD (Wiley).

The Other Suspects

In addition to the diseases and medical conditions that I discuss earlier in this chapter, the specific medical problem that causes pain, fatigue, and other symptoms characteristic of fibromyalgia may be caused by another underlying disease or condition.

There are too many possibilities to name them all here, but several are worth discussing, including Lyme disease, Raynaud's phenomenon, various medical conditions that cause back pain, and infectious mononucleosis.

Being ticked off by Lyme disease

Lyme disease is an infection caused by an organism with a tongue twister name: *Borrelia burgdorferi.* It's spread by tiny, dot-like ticks that typically feed off animals but aren't opposed to a human treat. If they latch onto you, you could get the disease.

Lyme disease was originally believed confined to the northeastern United States and was first identified in Lyme, Connecticut. However, subsequent clusters of Lyme disease were identified in most states, as well as in France, Germany, and Switzerland, and other countries worldwide.

Lyme disease can be cured if treated early on, but if the disease goes undiagnosed for months or longer, then it usually becomes a chronic illness.

You don't need an up-close and personal encounter with an animal in the forest in order to be afflicted by Lyme disease. You can become a tick's host if you walk in deep grass or interact a lot with your pets that go outside. What if you never saw any ticks on your body? Does that mean that you're safe from Lyme disease? No, it doesn't. Experts say that most patients who tested positive for Lyme never recall seeing a tick on themselves.

Some symptoms of Lyme disease may resemble those of fibromyalgia, such as widespread joint pain, fatigue, difficulty concentrating, and so forth. Flu-like symptoms occur in the first stage of Lyme disease, and a characteristic rash typically occurs. The symptoms generally escalate weeks or even months later to musculoskeletal pain, arthritis, and swelling. These symptoms may be clinically confused with fibromyalgia or with osteoarthritis.

As with the other medical problems described in this chapter, patients can have both FMS and Lyme disease. However, unlike with rheumatoid arthritis or fibromyalgia, the arthritis of Lyme disease is usually limited to one joint, most often the knee, and it is difficult to overlook.

One laboratory indicator of possible Lyme disease is an elevated *erythrocyte sedimentation rate* (ESR), a blood test for inflammation. Doctors may suspect that Lyme disease is present, based on your symptoms and the ESR, but the illness can only be confirmed with further testing that the doctor orders.

In most cases, doctors order a blood test called a *Lyme titer,* a special test that checks for Lyme disease. If this test is positive, other confirming tests are also often ordered. The Lyme titer does have some false negatives, especially if the person just contracted the disease, but false negatives aren't common.

Making sure that people actually have Lyme disease before treatment is initiated is important because treatment can be long and costly, particularly when the disease is identified in the late stages. In the early stages, patients may be treated with oral antibiotics for two to three weeks. However, if the disease has progressed to a later stage, patients must take antibiotics intravenously for at least several weeks — possibly for several months.

Reflecting on Raynaud's phenomenon

Raynaud's phenomenon is also associated with FMS. Raynaud's phenomenon, present in about 3 percent of the population, primarily affects the fingers and toes, causing them to hyper-react to cold temperatures, become pale, throb, and tingle. (No bare feet for anyone with Raynaud's!) Raynaud's phenomenon is associated with increased sympathetic tone, which may cause or contribute to fibromyalgia pain. Often Raynaud's phenomenon is diagnosed, while the FMS is not.

Most people with Raynaud's complain of cold hands and feet but rarely develop skin ulcers in their toes and fingers. Occasionally other parts of the body are affected, such as the nose, ears, and lips.

Raynaud's has a genetic link, but may also be caused or worsened by chronic stress. Chemotherapy for cancer may induce Raynaud's, as may some drugs for high blood pressure (beta blockers) or migraine headaches (drugs with ergotamine). In addition, even over-the-counter cold medications may cause Raynaud's. The autonomic nervous system (which controls heart rate and breathing) plays a major role in Raynaud's. Tests for autonomic dysfunction include heart rate and blood pressure measurements as well as tilt table testing (lying on a table flat or upright). Simple methods like biofeedback and stress reduction can often calm an overactive autonomic nervous system.

Tests such as a cold challenge are used to detect Raynaud's phenomenon. With this test, the physician may put your hands into cold water for a few seconds. If this manipulation causes your fingers to turn blue or white, you may suffer from Raynaud's phenomenon.

People with Raynaud's should avoid the cold and should wear socks. (If it's very cold, several pairs of socks may be needed.) They should also wear a hat in cold weather so body heat is maintained. They should also avoid smoking and caffeine, both of which make blood vessels constrict, and they should be careful around air-conditioning, which can aggravate the condition. (Don't sit next to or directly under an air-conditioning vent.)

Some medications that help people with Raynaud's disease are Procardia (generic name: nifedipine) and Norvasc (generic name: amlodipine). Both of these drugs are calcium-channel blockers, which relax the smooth muscle and help to enlarge small blood vessels. Some patients also improve with Minipres (generic name: prazosin) or Cardura (generic name: doxazosin), both high-blood-pressure medications that are alpha-receptor blockers.

Evaluating other possibilities

Your doctor may consider a variety of other ailments when trying to make a diagnosis when pain is present. Ailments that cause low-back pain are one possibility. Other far less common medical problems are multiple chemical sensitivities syndrome and infectious mononucleosis.

Low-back pain

The majority of all adults experience pain in their lower backs at some time in their lives. If the pain is chronic, it may indicate some minor or moderate damage to the spine. The underlying problem causing your symptoms may be arthritis. Or it could be a disk problem, infection, or something else. The causes of low-back pain are numerous.

Low-back pain may indicate fibromyalgia, particularly if other symptoms are present, such as pain in other parts of the body, fatigue, and sleep difficulties.

When patients complain primarily of low-back pain, doctors try to determine if a recent injury, such as a fall or car crash, occurred. If not, they try to determine other possible causes, such as a kidney infection, bladder infection, or another internal problem.

Physicians usually order a complete blood count and a urinalysis to detect bacteria or blood in case the underlying problem is a kidney or a urinary tract infection. They may also order spinal X-rays to help determine if the pain is coming from damage to the spinal cord or from arthritis. However, it is important to know that spinal X-ray changes correlate poorly with your degree of back pain. This means that you may have only minimal changes on your spinal X-ray but *major* pain, whereas some people with lots of spinal arthritis have no pain at all!

If low-back pain has continued without any relief for weeks or months and the physician suspects a serious problem (or wants to rule one out), he may order a *magnetic resonance imaging* (MRI) scan. An MRI is an expensive special test that is noninvasive and provides many details of bones, muscles, tissues, and internal organs. If you have normal laboratory tests, normal X-rays, and, if ordered, a normal MRI, then the problem may be fibromyalgia.

Multiple chemical sensitivities syndrome

A very controversial diagnosis, *multiple chemical sensitivities syndrome* (MCSS) means that the patient has seemingly become extremely sensitive to many different substances that never bothered him before, such as numerous odors, foods, and other common items found in most environments.

Items like perfumes, household detergents, and cigarette smoke can induce severe symptoms, such as migraine headaches, insomnia, joint pain, and mental confusion. These symptoms also can occur in someone with FMS.

This syndrome is sometimes confused with the "boy in the bubble" situation, a very unique situation in which a child had virtually no immune system and lived confined in a bacteria-free environment because any germs would've killed him. But people with MCSS still have working immune systems, even though it may seem that everything bothers them and causes symptoms.

Pinpointing the causes of what's aggravating their fatigue and pain and other symptoms can be a challenge for the patient and doctor. No current blood tests or other laboratory measures screen for multiple chemical sensitivities syndrome; consequently, this diagnosis is generally made based on the physician's observations — long after other possible causes are ruled out.

Infectious mononucleosis

Can adults contact *infectious mononucleosis,* a virus once known as the "kissing disease"? Yes, people of any age can contract mononucleosis, the infection obtained through the Epstein-Barr virus. But remember, most people have been exposed to Epstein-Barr during childhood, and this virus remains with you for life.

The basic symptoms of mono are fatigue and flu-like aches and pains, symptoms also found in fibromyalgia. However, unlike fibromyalgia, the person with mononucleosis often has a sore throat and swollen glands. Fortunately, mononucleosis does eventually go away, with rest and treatment. (Although people can contract mononucleosis more than once.)

The illness is easily screened for with a blood test. If the test is negative, the person usually doesn't have mononucleosis.

If a patient doesn't improve with time, the doctor should consider the possibility that the underlying problem may be fibromyalgia or other medical problems.

Chapter 7

Working with a Good Fibromyalgia Doc: You Need a True Believer

In This Chapter

- Talking fibromyalgia with your primary-care doctor
- Analyzing specialists who treat fibromyalgia
- Finding a good specialist or a new primary-care doctor

Linda saw an internist, a family practitioner, and two rheumatologists before she was finally diagnosed with fibromyalgia. Sam says that he saw five different doctors. He's forgotten what all their specialties were, but it wasn't until he saw a pain-management expert that he was finally diagnosed with fibromyalgia. Amy was lucky compared to most people who are ultimately diagnosed with fibromyalgia syndrome (FMS): She hit the jackpot on her second try and was diagnosed with fibromyalgia about eight months after the first symptoms hit her hard.

Linda, Sam, and Amy all really needed a good doctor, but connecting with one took considerable time. In fact, some people with fibromyalgia are probably never diagnosed or are misdiagnosed for years. Why does this happen? One reason is that a lot of doctors still don't understand fibromyalgia, while some continue to believe (wrongly) that FMS is a meaningless diagnosis for people with imagined symptoms. Yet you really need a good, caring, and knowledgeable doctor to help you cope with the pain, fatigue, and other troubling symptoms that fibromyalgia causes.

This chapter is about working with your primary-care physician, and it's also about finding another doctor or locating a specialist if you need one. A key point to keep in mind is that you need a doctor who's familiar with the diagnosis and treatment of musculoskeletal pain syndromes like FMS. Many primary-care physicians have experience with FMS, but, sometimes, a specialist like a rheumatologist or a neurologist is required to make the diagnosis.

Working with Your Primary-Care Doctor

In many cases, your “regular” physician can readily diagnose and treat your fibromyalgia, and you won’t need to see any other doctors to receive specialty knowledge or instructions. Over the last several years, most physicians have begun to realize and accept that FMS is a valid diagnosis (although some skeptical doctors and also some total nonbelievers are still out there).

Sometimes, however, your primary-care doctor may need to look up a few things about fibromyalgia, and he may also want to consult with colleagues for their opinions. If so, that’s understandable and okay. You may also need a referral to see a specialist, such as a rheumatologist or another type of physician who has more expertise in treating FMS than your primary-care doctor possesses.

Ideally, your doctor already knows about fibromyalgia, is treating other patients who have FMS, and is seeing some improvements in them. I’ll call this physician “Dr. Wonderful.” Dr. W. is also aware of the many other ailments that are often associated with FMS. (Read Chapter 2 for a complete discussion of the other medical problems that often accompany fibromyalgia.)

In addition to this basic knowledge about fibromyalgia, Dr. W. is also aware of the medications and treatments that usually work best for people with fibromyalgia. (Check out Chapters 9 and 10 for info on FMS-related medications and Chapter 11 for hands-on treatment options.) At the same time, Dr. W. is careful to avoid taking a one-size-fits-all approach because FMS symptoms vary from person to person. Dr. Wonderful is also open to new ideas regarding treatment while retaining a healthy skepticism about new treatments. (I discuss alternative remedies and treatments in Chapter 12.) You’re consulting with Dr. W. not only for medical expertise but also for good judgment.

Unfortunately, finding out that your doctor has little experience with FMS is a common problem. Your primary-care physician may be great for just about everything that ails you. But for some reason, fibromyalgia has her thrown for a loop. Introducing Dr. Good Enough. If your doctor isn’t Dr. Wonderful, you’d rather have Dr. Good Enough than Dr. Awful. Dr. Good Enough may work well for you, if she’s open-minded, caring, and willing to listen and learn.

Is every doctor like Dr. Wonderful (or even Dr. Good Enough)? Sadly, the answer is no. Therefore, I must introduce you to Dr. Awful. Dr. Awful is the kind of person who doesn’t know much about FMS and won’t take the time necessary to get to know you and treat your symptoms.

Some doctors continue to see FMS as a nebulous medical problem. Those doctors haven’t caught up on the latest scientific data about fibromyalgia. Because they can’t see a specific clinical abnormality or result on a lab test or an X-ray, or in some other quantifiable test, they may have trouble making the diagnosis of FMS. They may send off people who suffer from symptoms of chronic pain and fatigue (but who have normal lab results) for psychological counseling only, and they won't prescribe the important comprehensive therapy that's necessary to treat FMS.

Janet is a physician who suffers from fibromyalgia. She says that when she went to medical school, she was taught that fibromyalgia was a problem of neurotic women who constantly felt like they had the flu. Janet isn't surprised, although she's still dismayed, that some people with symptoms of fibromyalgia are sent to mental-health professionals to be treated for a psychiatric disorder when their primary-care doctors receive lab reports that are all marked "within the normal range." If a laboratory finding doesn't come up positive, then such doctors believe that the patient must be imagining the symptoms, according to this mindset.

Janet is right. Patients need to stand up and speak out that musculoskeletal pain can be a very real problem. It isn't something that you invent to get more attention or make the people in your life feel sorry for poor you. FMS sufferers know that they can get attention in plenty of other ways, and they also know that most people do *not* feel sorry for those with FMS. Neither Janet nor the overwhelming majority of the other estimated 6 million people with fibromyalgia are malingerers or hypochondriacs.

Check out Table 7-1 for a comparison of Dr. Wonderful, Dr. Good Enough, and Dr. Awful.

Table 7-1 Comparing Doctors' Approaches to FMS

Dr. Wonderful	*Dr. Good Enough*	*Dr. Awful*
Knows what fibromyalgia is.	Is willing to learn about FMS.	Thinks that FMS is nonsense.
Is open-minded about treatment.	Is open-minded about treatment.	Is resistant to new ideas.
Will help you find a specialist, if you need one.	Is willing to consider a specialist.	Thinks the only specialist you need is a psychiatrist.
Is sympathetic and caring.	Is friendly or neutral.	Is disparaging and nasty.
Is not a sexist.	Is not a sexist.	Believes that women only have fibromyalgia because of hormonal fluctuations* and that men can't have fibromyalgia at all.

(continued)

Table 7-1 *(continued)*

Dr. Wonderful	*Dr. Good Enough*	*Dr. Awful*
Realizes that FMS is often associated with depression and/or anxiety disorders.	Is willing to learn about the association between fibromyalgia and depression/anxiety.	Thinks that people who believe they have FMS are either malingering or seeking drugs.

** Sometimes hormonal changes do cause FMS, but there are many other causes as well.*

Looking Elsewhere for a Doctor: How to Know if It's Time

If you've tried to work with your doctor and you feel like you're just not getting anywhere, and if your pain, fatigue, and other symptoms continue to be moderate to severe or maybe they're getting worse, you may want to consider working with another physician. It may be the only way for you to get the help that you need.

TIP

You have to make your own individual decision about when to seek another medical opinion. But here are some basic points for you to keep in mind before you decide to switch to, or even consult with, another doctor:

- **Have you given your current doctor enough time to evaluate you and treat you?** For example, if you saw the doctor just last week and told him about your problem for the first time, and now you're angry because the first medication didn't work, now's probably too soon to give up on the doctor. In most cases, you should give your physician more time to help you resolve your problem. However, if you've been working with this doctor for months and you don't feel any better at all, it may be time for a change.
- **Do you feel that the doctor is taking your problems seriously?** If the doctor hasn't paid enough attention to your symptoms (or you) or has told you that all you need to do is lose weight, exercise, cheer up, or some other overly simplistic answer, you probably need to think about finding another doctor. These solutions could help you, but they rarely work alone. Instead, most people with fibromyalgia need medications and other treatments.

- **Are your doctor's recommendations making you feel *worse* instead of better or about the same?** If the doctor prescribes medications or treatments that exacerbate your condition, you may actually end up feeling worse than you did before. For example, if the doctor recommends vigorous physical therapy and exercise, you need to tell her if you've tried this approach in the past and it has worsened your pain. People with FMS are very pain sensitive, so they need to exercise at a slower and less intense pace than others who don't have fibromyalgia. (Read more about exercise in Chapter 15.)

Sometimes, sheer persistence may be needed before you identify a doctor who can diagnose and treat your fibromyalgia, although I hope you won't have as much trouble as Joan did. Because of severe stiffness in her neck and shoulders, which seemed to appear around the time she was diagnosed with strep throat, Joan had asked her internist for help with all her symptoms, but he couldn't find anything wrong, other than the strep infection.

Joan changed doctors many times because she felt that they weren't taking her medical problem seriously. In fact, she says that she saw 22 doctors over 18 months until, at long last, she found a rheumatologist who diagnosed her with FMS and treated her. Joan says that the other doctors had told her that her condition was caused by the four pregnancies she'd had and by the onset of menopause. She says she was angry that the doctors didn't listen to her or believe her, but she's very happy that she's found a good doctor now. Joan is glad that she didn't decide to just settle for one of the other doctors. Follow Joan's example: Don't settle.

Considering Types of Specialists

If your primary-care doctor can't or won't treat fibromyalgia or wants you to seek the help of a specialist, not to worry! A variety of specialists treat people with fibromyalgia. In this section, I introduce you to the ones most likely to help you. (***Note:*** Internists and family practitioners treat FMS, too, but they're generally not regarded as specialists.)

TIP

The Fibromyalgia Network is an organization that recommends physicians in the United States and Canada to its members. To find out how to join, contact the organization at P.O. Box 31750, Tucson, AZ 85751 (phone: 800-853-2929; Web: `www.fmnetnews.com`). As a member, you'll also receive the organization's great newsletter.

Regarding rheumatologists

A *rheumatologist* is an internist (a person who specializes in diseases of the internal system) who further specializes in treating arthritis and diseases of the joints, muscles, and soft tissues. Rheumatologists are most prominently at the forefront of FMS treatment and probably have the most knowledge and information about the syndrome. (However, do *not* assume that all rheumatologists are automatically up to date on fibromyalgia. They're not.) A rheumatologist should be able to diagnose and treat you effectively with recommended treatments and medications. He should also be able to give you good advice on lifestyle changes that are tailored to your personal needs and that can make you feel better.

Nerving up about neurologists

Neurologists are doctors who specialize in diseases of the brain and nervous system. Because most people with fibromyalgia suffer from severe pain, at some point in their search for a diagnosis, many patients do eventually consult with a neurologist. Many, but not all, neurologists are familiar with fibromyalgia and how it should be diagnosed and treated. Because neurologists are interested in the brain and spinal cord, they're usually aware of problems with pain and the available array of medications to treat pain — as well as with other therapies and lifestyle changes that could help you.

Considering pain-management experts

Some doctors specialize in treating all forms of pain and start their own pain-management clinics. Often, these doctors are neurologists or anesthesiologists, although doctors of any specialty may start their own pain clinic.

Pain-management doctors may specialize in certain types of pain, such as the severe pain of cancer or other medical problems that are far more readily diagnosed than fibromyalgia. A pain-management clinic may or may not treat a person who has fibromyalgia — the situation varies. Some clinics have told patients that fibromyalgia is "too hard" for them to treat, and they won't accept people with fibromyalgia as patients; others have helped FMS patients a great deal.

Pondering other physician specialists

A *physiatrist* (not a psychiatrist, even though the spelling looks very close!), commonly known as a sports-medicine doctor, is a type of doctor who's familiar with the pros and cons of exercise and physical therapy and who treats injuries that can stem from sports accidents. Sometimes, fibromyalgia results from a physical trauma, such as an athletic accident or a car crash, and physiatrists can help people work on their own rehabilitation.

Orthopedic surgeons also sometimes treat fibromyalgia. They're knowledgeable about broken bones, sprained ligaments, and muscle injuries, and they can help you create a program of recovery. Of course, whatever specialty the doctor has trained in, she needs to be aware of the problems associated with fibromyalgia in particular.

Finding a Good Specialist or a New Primary-Care Doctor

If you decide that you want to consult with a specialist, where do you start in your search for a smart and knowledgeable doctor who can help you alleviate at least some of the pain and strain of fibromyalgia? Here are some basic suggestions, which should help you find a new specialist. If you need to change your primary-care doctor, these guidelines may assist you, too.

Looking at doctors within your insurance network

Although it's not popular to say anything good about health-insurance companies, some of them have thoroughly checked out the doctors that they cover. They often check out malpractice claims, financial records, the doctors' education, and many other aspects of the physicians. They have access to information that's unavailable to most people. Insurance companies don't want to work with doctors who are lawsuit magnets, so they try to screen out these doctors. This is good for patients.

However, some insurance companies merely seek to sign up the doctors who are willing to take a lower payment rate than they would normally accept in order to be in the insurance network. For this reason, sometimes the very best doctors aren't in your particular group or in your health-insurance company's network. As a result, doctors who are out of network shouldn't be regarded as inherently risky or bad. Of course, when you're seeking a new primary-care doctor or specialist, start within your insurance company's network. (Be sure to read more about effective ways of dealing with health-insurance companies in Chapter 17.)

REMEMBER

If you go out of network, you may have to pay a higher percentage of the cost, depending on your health-insurance company's policy.

Asking your own doctors whom they'd see or send a family member to

You've decided that you need to see a specialist for your fibromyalgia, but you have no idea whom you'd like to see, so you ask your primary physician to give you a referral. Your primary physician may have dealt personally with a particular specialist before, but don't assume so. Some physicians simply refer their patients to a specialist whom they've heard about through colleagues or to a specialist who happens to be in the same medical group. You may want to ask your doctor about this specialist and *why* he's referring you to this particular doctor.

When looking for a new specialist or primary-care doctor, talk to *all* your doctors (your pediatrician, gynecologist, urologist, or other docs you know). Don't restrict yourself to solely asking your internist or family practitioner for a recommendation. Asking different doctors can help to broaden the scope of your search. You may also consider asking other professionals, such as your dentist, whom they would recommend for a chronic-pain problem.

Your doctors' recommendations for other doctors will help you narrow the field. But before you get the recommendations, be sure to provide some basic important information to your doctors about what you need and want, in order to help them further gauge whom to recommend. Ask yourself the following questions and then give the answers to the doctors whose recommendations you seek:

- **How far are you willing to travel to see this doctor?** A 20-mile radius? A 50-mile radius? The farther you can go, the greater the pool of doctors to choose from.
- **How long are you willing to wait for an appointment?** Some doctors may be booked for months in advance. However, they may be worth the wait.
- **Do you have any special requirements or other needs?** For example, do you only want to see a female or male doctor? Do you prefer a doctor of a specific ethnicity? The pickier you are, the fewer choices of doctors you'll have.
- **Must the doctor be on your insurance company's list of approved doctors, or are you willing to pay extra to see an out-of-network physician?** Paying extra bucks may be worth it if the new doctor helps you.

In asking your doctors to recommend a specialist, consider asking them the following questions:

- **What physician would *you* go to see if you had this problem?** Most doctors have been asked this question before, but it may still make them stop and think.

- **Would you send your partner, parent, or child to see this doctor?** This question is similar to the first one, but it's still a good question to ask because it'll also make most doctors stop and think.
- **Have you met this doctor in person or ever talked to this doctor at length?** Ideally, your doctor has met and talked to the doctor that's being recommended. If not, at least you'll know.
- **What is it about this doctor that most impresses you?** Listen carefully to the answer and see if it makes sense to you.

Contacting friends and relatives

Many people with fibromyalgia have friends and relatives who also have FMS or are suffering from the apparent symptoms of fibromyalgia. So ask your friends and family members if they know of any doctors who've been effective in treating their fibromyalgia or FMS suffered by others they know.

Keep in mind the basic pros and cons of asking family members for help. Here are some pros:

- They may know many doctors who could help.
- They may be able to help you get an appointment faster.
- They may have other ideas on how you can feel better.

And here are some cons:

- Relatives or friends may try to convince you that you're not really sick.
- They may be annoyed if you don't see the doctor they like.
- They may tell everyone else in the family about your problem, and you could get a lot of unwanted advice.

Check out Chapter 18 for more information on working with your family when you have FMS.

Checking with major medical centers and universities

If you live near a major medical center or in a city with a medical school, in most cases, the doctors there are more likely to be up on the latest diagnoses and treatments. They're also more likely to be well informed on fibromyalgia as a pain disorder. This doesn't mean that if you live in the town of Almost Nowhere, your country doctor can't or won't help you — it's just less likely.

Interviewing Your Physician Candidate: What's Up, Doc?

Imagining yourself interviewing a doctor to see whether she is right for you can be a pretty scary and daunting thought. Who are you, after all, to be interviewing a smart medical doctor? I'll tell you who you are: a person who needs help and who should find the best doctor you can.

Keep in mind that the United States has thousands of doctors with many different types of medical interests and levels of expertise. What you need is a good match between you and your problems and the doctor who will help you to improve your health.

When you're thinking about working with a particular doctor, you should definitely consider making an appointment to ask him specific questions, even if you have to pay for the appointment. One meeting with the doctor should help you to screen the physician to determine whether he may be able to help you.

TIP

Here are a few questions to ask prospective physicians. (I also include a few basic guidelines for you to use in evaluating the doctor's answer to each question.)

- **Is fibromyalgia a prevalent chronic-pain syndrome?** If you get a no or a convoluted and confusing response, this doctor probably isn't the right one for you. If the doctor says yes, that fibromyalgia is common, but she adds that she can't be sure that you have FMS, that's an okay and normal answer. The physician is right that she needs to be able to examine you, take a medical history, and rule out other diseases before coming up with a diagnosis. (Read more about this process in Chapter 8.)
- **Doctor, are you familiar with diagnosing and treating fibromyalgia patients? If so, about how many patients with FMS have you treated?** If it's only one, then don't expect a lot of experience from this doctor. However, many docs are willing to learn about fibromyalgia, so if the doctor admits not knowing much but says he'll investigate further, he may be a "keeper." However, if the doctor says that FMS isn't real, move on!
- **Do your patients with fibromyalgia improve with treatment?** The answer in most cases should be a guarded yes, although most physicians know that they don't have any magical cures or talismans to offer people with fibromyalgia. If the doctor's answer is no, that most FMS patients have no hope of improvement, what's the point of spending any time or money with this doctor? You'd better keep looking.

“Doctor shopping” and fibromyalgia

Sometimes, when you see many doctors over a short period of time, you may get the reputation of *doctor shopping,* or looking for a physician who’ll give you the answer (or the drug) that you seek. When it comes to people with fibromyalgia, it’ s hard *not* to appear as if you’re doctor shopping when you have to deal with the lack of knowledge that some doctors have about FMS.

As a result, when you see a new doctor for the first time, it’s probably a good idea to be very blunt and tell her that you’re not doctor shopping, but you’re looking for someone who can help you feel better. You should avoid proclaiming that nearly every doctor you’ve ever seen before this time was an idiot or incompetent or a monster (even if they were!). Instead, simply say that your previous doctors were unable to help you, for whatever reason. Most doctors can understand and accept that rationale.

- **Do you think that you can cure me if I have fibromyalgia?** If you ask the doctor whether he thinks that you can be *cured* forever of your fibromyalgia and the answer is an unequivocal yes, be very careful about signing up with this doc. Although some physicians may believe that they have the one true answer to the problem, most doctors instead see fibromyalgia as a chronic disease that has its ups and downs.
- **How long do you think it may take for treatments or medications to make me feel better?** When you ask this question, most doctors will honestly say that they don’t know. If the doctor says that you’ll be completely cured in just a few weeks or a month, be very dubious about receiving your medical treatment from this person.

  Of course, your doctor may be able to help you quickly alleviate some of your most severe symptoms, particularly the pain and fatigue, with medications or treatments that you may not have tried before. The key is to retain a healthy skepticism and avoid seeking quick fixes.

REMEMBER

You’re the only one who knows whether this physician has gained your confidence. If you don’t feel comfortable with a particular physician, find someone who is more compassionate and skillful. Finding the right doctor for you may take some time, but it’s definitely worth the search.

Chapter 8

Getting Physical: Your Initial Exam and Diagnosis

In This Chapter

- Understanding what goes into a medical history
- Volunteering information when your doctor doesn't ask for it
- Identifying the tender points of fibromyalgia
- Understanding the necessity of touch in a diagnosis
- Testing as part of the diagnostic process

Many people with fibromyalgia syndrome (FMS) report that they've seen numerous doctors, and obtaining a diagnosis of their illness has taken a year or more. Knowledge is power, and some self-education on the basics of the diagnostic process can help you to help your doctor. Armed with this information, you may be able to shorten the time to reach your diagnosis and treatment.

This chapter tells you about the information-gathering and decision-making process that doctors go through to decide what's wrong with you. You can also find tips on how to talk to your doctor about your symptoms and on how to know when to speak up for yourself. I also cover what tests doctors often use to help them with their diagnosis. In general, laboratory tests and other analyses, such as scans, are negative for people with FMS (meaning that nothing shows up); doctors use the tests to rule out that another condition or disease is causing the symptom.

Diving into Your Medical History: What the Doctor Should Ask You

Most doctors agree that an integral part of an examination for any new patient is the careful taking of a medical history. *Medical histories* usually involve your past and current medical problems as well as any surgeries that you may have had and medications that you currently take. If you're a new patient, you'll nearly always be given a form to fill out regarding this information, or the doctor or a nurse will ask you the questions directly. In fact, even if you've seen the doctor before, it's still a good idea for the physician to perform (or have the nurse perform) at least a quick review of your medical history. Doctors can use this information to check for patterns or clues to help them with your current diagnosis.

You can't possibly know exactly what your physician needs to know to diagnose you. So, instead of trying to screen your answers, just answer all the questions that your doctor asks you honestly, even if these questions don't seem relevant to you, and leave it up to the physician to figure out how to use the information. Provide complete and accurate answers. Something that may seem unimportant to you, such as an operation you had ten years ago, could be relevant to the doctor.

If you have fibromyalgia or think that you may have it, and you've told the doctor about your diagnosis (or your suspicion that you may have fibromyalgia), the doctor should also ask you questions that relate to FMS. Here are a few examples of FMS-type questions that the doctor may ask, although don't expect the doctor to follow my exact wording like a script!

- Does the pain change in intensity, sometimes getting a lot worse or a lot better?
- Does the pain move around, or is it primarily in the same place all the time?
- Do you have morning stiffness? Do you also have stiffness throughout the day? (Most FMS patients have some level of muscle pain, whether in the morning or all day.)
- Do you have trouble sleeping? If so, about how many hours a night do you think that you're sleeping? (Sleep problems are very common among people who have fibromyalgia.)
- Are you experiencing extreme fatigue, beyond the normal tiredness that many people have?

Setting diagnostic criteria for FMS

In 1990, the American College of Rheumatology, a professional organization of thousands of rheumatologists, developed criteria to help doctors determine whether their patients had fibromyalgia. Many (but not all) doctors of all specialties, as well as general practitioners, use these guidelines to help them with their diagnoses. Very basically, these following criteria were offered to doctors:

- Widespread musculoskeletal pain for at least three months on both the right and left sides of the body
- Pain both above and below the waist (for example, in the neck and buttock area)
- Pain experienced when at least 11 of 18 specified tender points are touched with a force of about 9 pounds or less (see “Locating your tender points,” later in this chapter)
- Other symptoms, such as sleep disorders and muscle stiffness

Volunteering Info if the Doc Doesn’t Ask You about It

In most cases, the doctor will ask you questions that elicit the information that’s needed to give you good treatment. Once in a while, however, some facts or complaints may not come out in the course of your encounter with your doctor. Be sure to volunteer any information that you think may be important to your diagnosis.

Whatever happens, make sure that you accomplish the principal mission of your office visit: Communicate *your* chief medical complaints to your doctor. You may find that, for example, the doctor seems primarily concerned about your insufficient sleep and is concentrating on that problem. But you may feel instead that you’re being driven mad by the overwhelming pain you’re suffering from, and the sleep deficit is actually a distant secondary problem. From your own perspective, tell the doctor about your distress with the pain and that it bothers you the most.

Don’t wait until the end of your doctor’s visit to tell your physician what’s really bothering you. “Oh, doctor, I just remembered, I have excruciating pain that goes from my neck to my back, and I also have been passing out a lot.” I’m exaggerating for emphasis (fainting isn’t a usual symptom of fibromyalgia), but, sometimes, patients really do hold off on revealing extremely important information until the doctor is ready to walk out the door. Don’t make this

Laying out common mistakes patients make during physical exams

You want to get better, don't you? Of course, you do! But you may inadvertently make one or more of the common errors that can impair your diagnosis:

- **Telling the doctor that you know what's wrong with you because your mother's friend's cousin said that she has the exact same thing, and her doctor said that it was _____ (fill in the blank).** Doctors can get really aggravated when people assume that a non-physician can make an accurate diagnosis. If a birth relative, such as a parent or sibling, has similar problems, tell the doctor. But let the physician make the diagnostic call.
- **Spending a lot of time on small talk.** Pleasantries are nice, but the doctor's time is usually very limited. Get to the point as soon as possible. Why are you here, and what do you hope the doctor will do for you?
- **Withholding information.** If you're doing something that you think the doctor will disapprove of (such as drinking, smoking, taking drugs, or some other behavior), tell the doctor about it anyway. These behaviors can have a direct impact on your diagnosis, as well as on your treatment. Sure, the doctor may tell you to stop these behaviors. But, well, shouldn't you stop them?

mistake — if you do, you'll be shortchanging yourself by not accentuating your most troubling symptoms or problems early on, when the doctor has sufficient time to consider possible causes of your problem as well as solutions that may help you.

TIP

Before your appointment, write down two or three key points you want to be sure to discuss with the doctor, and bring the list with you to your appointment. Why? Because you may very easily forget what you'd meant to ask the doctor, and you may find that you remember your questions only after you've driven all the way back home again. Of course, you shouldn't bring in a scroll of complaints with you to the doctor's office; keep your list short and simple.

Pay particular attention to volunteering information about your pain, other doctors you're currently seeing, and all medications, vitamins, and supplements that you're taking.

Telling your doctor about your pain

Don't assume that your doctor will somehow automatically know that your pain is very severe. Although most physicians are very smart and very dedicated people who really want to help their patients feel better, they don't have an internal psychic hotline that enables them to read minds and somehow magically know exactly how people feel or what's distressing them the most. So please don't assume that your doctor will always know (or even *should* know) what's bothering you or what you really need or want. Tell the doctor. Also, try to provide specific details, whenever possible. I know that pain can be hard to describe. But is it a burning kind of pain? A pressure pain? A stabbing pain? Provide as many details as possible, so that your doctor can help you resolve your pain problem.

If your pain has become extreme, you may be experiencing another medical problem. Even if it *is* your FMS that's causing you to hurt so badly, severe pain requires treatment. So speak up.

Mentioning the other doctors you see

If you're seeing other doctors in addition to the one who's diagnosing you, tell the doctor about it. Physicians need to know about other doctors you see in case they have any questions that need to be followed up with those other doctors.

Doctors often prescribe medication — that's a fact of life. The diagnosing doc also needs to know about all the other doctors in your life because she needs to know about all the medicines that you're taking — not just the ones she's prescribed for you.

Bringing your medications, vitamins, and supplements with you

If any other doctor has prescribed medications or recommended over-the-counter medications for you, bring them along with you to your doctor's appointment in the original prescription bottle or the over-the-counter container. Why? Because forgetting the dosage of your medicines is very easy — many people do. And doctors really hate it when patients say, "It's the little blue pill — I forgot the name." Do you know how many little blue pills are out there? Too many!

The doctor needs to know what medications, vitamins, and supplements you're taking because he won't want to prescribe a medicine for you that may interact badly when taken in combination with a drug that you already take, and because what you're taking now may affect your lab results. To avoid those problems, the physician must first know what you're taking.

Drugs that you buy in the health-food store or over the counter at the pharmacy are still drugs, even if you don't need a prescription to buy them. "Natural" and over-the-counter drugs can often interact with or even prevent other drugs that you're taking from working properly. So be sure to tell your doctor about alternative remedies that you take (including vitamins). Or better yet — show the doctor.

Patients have nearly died (and some patients *have* died) because they failed to tell their doctor about a "natural" drug they were taking. You really need to inform your doctor about *everything* that you're taking, natural or not.

Getting All Your Questions Out in the Open

Some people believe that if any information is important, the doctor will automatically provide it to them. Based on that belief, they don't ask questions and are passive patients. But doctors *can't* always know exactly what you're most concerned about or what you don't understand. That's why asking questions is important. Don't be shy! If you don't understand something or your doctor hasn't covered the topic that you're most keen on knowing about, just ask her.

If you're concerned that maybe the doctor wasn't listening to you or didn't hear something that you said that was important to you, don't agonize within your mind about whether she did or didn't hear you. Just say it again. Make sure that the doctor is looking at you when you say it and isn't jotting down notes, talking on the phone, or doing some other multitasking chore. To get the doc's attention, say her name and wait until she looks at you. If necessary, say the name *again,* even if it's when she's walking out the door. "Dr. Smith, I have one more question!" If the doctor has a name that's hard to pronounce, use the first letter of the last name. "Dr. Z., I need to know. . . ." Most people, including doctors, find it hard to ignore people who are calling them by name.

Identifying the Tender Points of Fibromyalgia

Another very important part of the diagnosis of fibromyalgia, after ruling out other medical problems that you may have had, is for physicians to consider whether or not you have tender points. In fact, the existence of tender points is one of the hallmark features that help doctors to diagnose fibromyalgia.

Tender points, a key diagnostic feature of fibromyalgia, are specific areas of the body that are very painful when gently probed. (Tender points aren't the same as *trigger points,* also covered in Chapter 6, which are lumpy or ropey muscular knots or inflammations.) With tender points, the patient feels pain when the area is touched, but the doctor himself can't feel any apparent abnormalities, nor can he detect the presence of inflammation or disease. When the problem is fibromyalgia, the doctor typically sees nothing unusual about the body except for the patient's reaction — typically, wincing or cringing.

Some patients find out about their tender points for the first time during an office visit. For example, Lucy learned about tender points in a very un-tender way. But first, here's some background on Lucy. She says that for years, every time she saw any doctor, she asked the physician to explain to her why she was so sore in the area that would be covered by an elbow-length shirt — most of her upper body (neck, arms, back, chest). But none of the doctors seemed to know or care what the cause of her soreness was. Then one day, Lucy was seeing her family doctor, and she asked him if he thought that she might have fibromyalgia. He suddenly and very unexpectedly poked her very hard in one of the tender spots between her neck and shoulder. It hurt so much that Lucy screamed, and she says that she nearly passed out. How did the doctor react? He told her yes, she did have fibromyalgia. Fortunately, most doctors aren't as insensitive as Lucy's (former!) doctor was.

Touching is part of the process

Doctors need to touch their patients in most physical examinations, if only to check their basic reflexes. But touching the patient is even more important if a person may have fibromyalgia because physical pain is a key problem faced by most people with FMS. The doctor needs to see if it hurts when you're touched, as well as *where* it hurts, and *how much* it hurts.

TIP

If you try to be really brave and avoid wincing or reacting at all when the doctor presses a tender point, or any other part of your body that hurts, how can your doctor know that it hurts you? Don't try to play Ms. or Mr. Stoic. Wincing is okay. In fact, you may find it hard not to. So don't even try.

Locating your tender points

The tender points that doctors use to help them diagnose fibromyalgia (as developed by the American College of Rheumatology) are primarily located on the upper torso, although a few can be found on other parts of the body, such as in the knees. Check out Figure 8-1 for a drawing of the locations of these tender points. All these tender points add up to a grand total of 18.

TECHNICAL STUFF

How do doctors diagnose people?

In general, most doctors diagnose patients with a process that is called a *differential diagnosis,* which means that they consider all the possible things that may be wrong with you, based on your symptoms, gender, age, geographic location, and other factors. They then narrow the diagnosis down to the most likely one.

For example, if you're a woman living in Peoria, Illinois, you're unlikely to have malaria. If you're a man, you flat out will *not* have menstrual problems. For possible fibromyalgia sufferers, the doctor considers the location of your pain/discomfort to aid with the diagnosis. If you're suffering from painful cramps in your toes, you may have fibromyalgia — but you may also have a vitamin deficiency or a problem with dehydration. Laboratory tests help the doctor rule out other medical problems and further narrow down the list to what is most likely.

And according to the guidelines established by the American College of Rheumatology, to obtain an official diagnosis of fibromyalgia, you must feel pain during palpation in 11 or more of them. (For more info regarding these guidelines, check out the "Setting diagnostic criteria for FMS" sidebar, earlier in this chapter.) Hopefully, you won't feel pain in all 18 places!

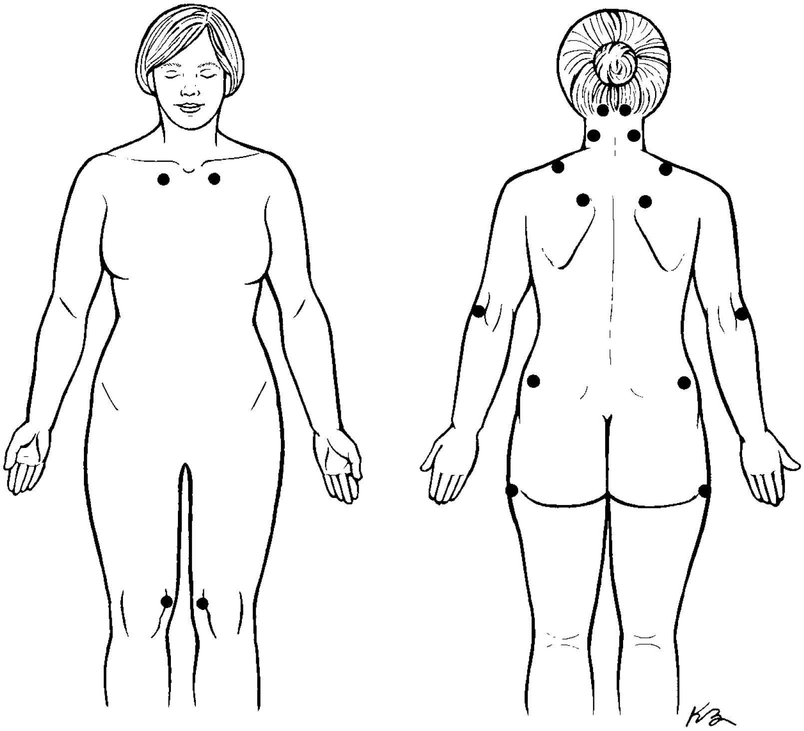


Figure 8-1: The 18 tender points of fibromyalgia. One part of the diagnosis is checking for pain in these specific areas.

Of course, people with fibromyalgia frequently have tenderness that's not limited to these 18 areas. Consequently, if you hurt elsewhere, that pain's probably from your fibromyalgia, too. In addition, some tender points may be very sore on one day and other tender points may even be painful on other days. The specific tender points as depicted in Figure 8-1 were selected by doctors as those areas that are most characteristic of people with FMS, which is why they're often used in the diagnostic process.

Assigning a tender number to FMS

According to the American College of Rheumatology, a person should have some pain in at least 11 of the 18 tender points to be diagnosed with fibromyalgia. Some doctors follow this guideline, while others think that if you have nine or ten tender points (or even fewer) but you meet other criteria, you may have fibromyalgia.

The presence of many tender points indicates a high probability that fibromyalgia exists — if other medical problems have been ruled out and if you also exhibit other symptoms of FMS, such as severe fatigue, difficulty with insomnia, or other sleep problems. Whether the doctor is a stickler for a given number of tender points as a cutoff really depends on the physician.

TIP

Rheumatologists are probably the most likely to consider tender points as very important because rheumatologists were the ones who devised this criteria and also because it's quantitative data in an area where hard data and verification aren't easy to come by.

WARNING!

One problem with using tender points as mandatory diagnostic criteria is that fibromyalgia is a very changeable syndrome. As a result, most people who have fibromyalgia feel better on some days and worse on others. This inconsistency means that some people who really do have fibromyalgia may only "score" with nine or ten tender points on a given day, but the following week, they could have pain in all 18 tender-point areas. It also means that if patients see their doctors on the day they have fewer than 11 tender points and the physicians are very rigid about the tender-points criteria, some cases of FMS won't be diagnosed.

Test-ifying about FMS

Most of the tests that doctors order when they think that you may have fibromyalgia are really tests for other medical problems. Although doctors should take a hard look at the symptoms you exhibit, they can't say for sure that you have fibromyalgia until they're able to rule out those other diseases and conditions. FMS has no specific tests, other than the tender-points criteria described earlier. In the future, doctors may test you for hormones and other body chemicals that may be higher or lower when you have fibromyalgia. But that's not happening right now.

Ordering up a round of lab tests

Part of your physical examination may include laboratory tests, such as blood tests and urinalysis. It's normal for the doctor to want such tests to be done, so don't be alarmed if your doctor orders them.

Ruling out autoimmune disorders

The pain of fibromyalgia may appear to the doctor to be the beginnings of rheumatoid arthritis or lupus, both very serious and deteriorating arthritic conditions. Another possibility is multiple sclerosis, also a serious disease. In addition, the doctor will often want to verify that you don't have a thyroid disease. *Hypothyroidism,* or below-normal levels of thyroid hormone, can also cause fatigue and muscle and joint pain. Sometimes these conditions can coexist with fibromyalgia.

These diseases are known as *autoimmune disorders,* or diseases resulting from the body's immune system actually attacking itself. A blood test will reveal if your blood includes a special factor that indicates that you may have rheumatoid arthritis or lupus. If the blood test comes back negative, you're unlikely to have them. A spinal-fluid examination can detect antibodies that are characteristic of multiple sclerosis.

A blood test can also measure the level of circulating thyroid hormone. If your levels are out of range, you're *hypothyroid* (low thyroid levels) or *hyperthyroid* (excessively high levels of thyroid hormone). The doctor can also check a sedimentation rate to identify inflammation, and he can order a chemistry panel, which will show how well (or poorly) your kidneys and liver are functioning.

Excluding blood diseases

The doctor will also often order a *complete blood count* (CBC), which is a count of your red and white blood cells. It's also a check on whether you may have a blood disease that can cause a person to feel weak and achy, such as anemia or another blood disease. If the CBC comes back normal, in most cases, you don't have such a disease. The doctor will also usually order a test of your blood glucose to rule out *diabetes* (characterized by *hyperglycemia,* or high levels of blood glucose) or, at the other end of the scale, *hypoglycemia,* a condition of unusually low blood sugar.

Verifying it's not a vitamin deficiency

Blood tests can also verify if you're deficient in any major vitamins (such as Vitamin B_{12} or Vitamin D) or minerals (such as calcium, magnesium, or potassium). A vitamin or mineral shortage can cause pain and weakness.

Sometimes, people who take medications for an illness can develop a vitamin or mineral deficiency, which leads to side effects and symptoms. For example, people with high blood pressure (also known as *hypertension*) may need medication, which can lead to a side effect of depleting the body of potassium.

Someone suffering from a potassium deficiency may be able to just eat a few bananas a day to make up for this deficiency, or may need to take supplemental potassium every day to reach normalcy. The blood tests that you have will show whether you have a deficiency and, if one is present, how severe it is.

Counting out infectious illnesses

The same CBC that the doc uses to rule out blood diseases can also show whether you may have an infection, because your white blood cell count will be slightly (or very much) higher than normal — although usually not dangerously higher than normal, as found with a blood disease.

The doctor should also screen your blood for hepatitis B and C, which may cause fibromyalgia-like symptoms. (Read more about these problems in Chapter 3.)

Doctors may also test for Lyme disease, particularly for patients who live in the northeastern part of the United States. (Read more about Lyme disease, which is a diagnosis sometimes confused with FMS, in Chapter 6.)

If you've had blood transfusions in the past or have been engaged in some high-risk behaviors, like taking illicit drugs, your doctor may also check you for HIV (the virus that causes AIDS).

In addition, the urine can be checked for possible kidney disease. High levels of protein in the urine (also known as *proteinuria*) or of other elements that are not normally present may indicate the beginning of a kidney disease that needs to be treated.

Testing the function of your autonomic nervous system

A characteristic abnormality of FMS is hyperactivation of the autonomic nervous system (ANS). This system is in overdrive in patients with FMS. Characteristic changes include increased resting pulse rate (more than

60 beats per minute), dizziness or fainting when standing up, and cold hands or feet. Some easy tests can identify these abnormalities, including pulse and blood-pressure readings while lying down or standing up. A more sophisticated test is tilt-table testing, which measures your heart rate and blood pressure during position changes.

Considering CT scans or MRIs

In some cases, the doctor will decide that you need a special scan of the part of your body that's causing you pain. The physician may order a high-tech X-ray, known as a *computerized tomography* (CT) scan, or may order a *magnetic resonance imaging* (MRI) test. The doctor may also order regular X-rays, if he or she thinks that you may have arthritis or other bone changes.

The CT scan, MRI, and X-rays aren't invasive and they don't cause any pain. However, some people are disturbed by the noise generated by the MRI machine. Because people with fibromyalgia can be hypersensitive to noise, they're also more likely to be distressed by the MRI. Many MRI technicians offer a solution to this problem by giving you headphones to listen to music during the procedure.

Another potential issue with having an MRI is that your body is enclosed in a small area. If you suffer from *claustrophobia,* or anxiety or fear about being in confined spaces, you may want to ask the doctor to give you a mild sedative before you have the MRI. Of course, if you do take a sedative, you'll need someone to drive you there and then drive you home afterward. In some cases, your doctor may be able to order an open-sided MRI for you, avoiding the problem of claustrophobia, although not all insurance companies cover the use of this equipment.

Doctors use MRIs, CT scans, and X-rays to rule out a number of possibilities:

- **Bone diseases:** The X-rays, CT scan, or MRI will check for any fractures or abnormalities of the skeletal system, such as those caused by arthritis or other diseases. And yes, you can have a minor fracture and still be walking around — although you probably won't be walking perfectly normally and you'll have at least some pain.
- **Other diseases:** An MRI can also rule out some diseases, such as multiple sclerosis.
- **Brain abnormalities:** These tests can rule out problems, such as a brain tumor or *aneurysm* (a tiny blood vessel about to burst).
- **Organic problems:** One or more of your major organs may be malfunctioning, anywhere from your thyroid gland to your colon to any other organ in any system of your body.

Using ultrasound for diagnosis

An *ultrasound* is a special device that uses sound waves to create outlines of an organ. Along with other tests, it can be helpful with diagnosis. A pregnant woman typically has at least one or two ultrasounds of her baby during the course of her pregnancy, so that the obstetrician can make sure that the fetus is developing normally.

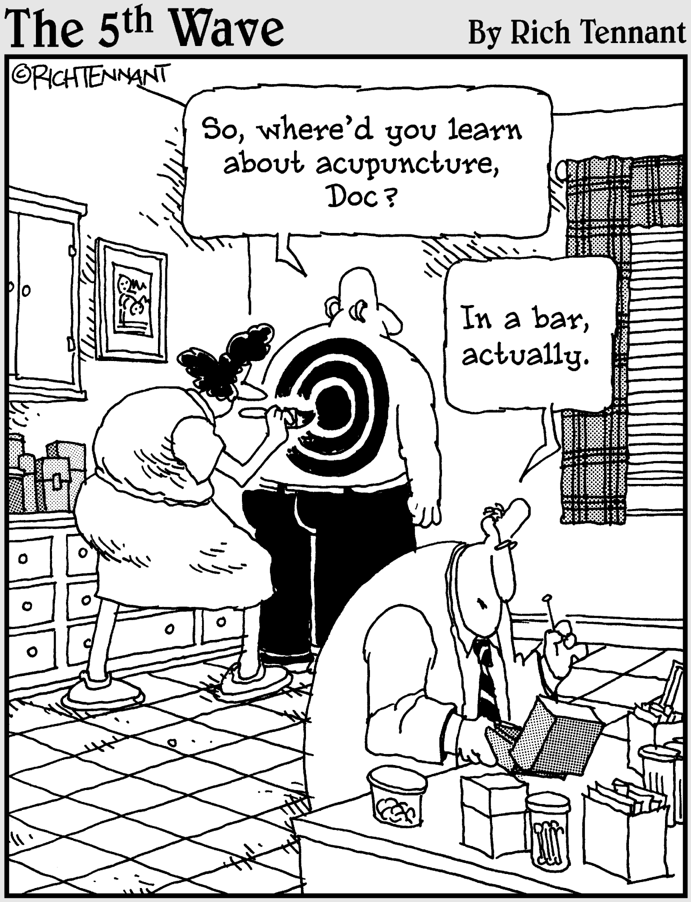
An ultrasound isn't invasive and is usually not painful, unless the ultrasound wand is pressed against an area of the body that's hurting. The ultrasound technician will be as gentle as possible.

An ultrasound can detect the following:

- **Organic abnormalities:** The doctor will usually order the ultrasound to check areas of the body that are most prone to problems. For example, could you have a problem with your gall bladder, stomach, or colon? A combination of the physical examination, your answers to the doctor's questions, and the laboratory tests and ultrasound will together help rule out organic abnormalities that are causing your medical problem.
- **Tissue/nerve problems:** Is there inflammation? With fibromyalgia, patients do *not* have any inflammation that's detectable in standard laboratory tests. If your ultrasound reveals inflammation or tissue damage, you have another medical problem rather than (or in addition to) fibromyalgia. If no inflammation or tissue damage is apparent from an ultrasound, most doctors will perform a neurological exam, which includes testing your reflexes and your responses to pressure and touch. It may also be important to test your muscle strength because some rare muscle diseases can mimic fibromyalgia.

Part III

Looking At All Your Treatment Options



In this part . . .

After you know that you really *have* fibromyalgia, the next order of business is to figure out what to do about this aggravating problem — and that's the purpose of Part III, which covers a broad array of treatment options. I include the latest information on over-the-counter drugs, under-the-counter drugs (just kidding — I mean prescribed medications), and what I call *hands-on therapy,* which is basically therapy that touches your skin and muscles such as icing and heating, massage therapy, topical ointments, and other options.

And I don't forget alternative remedies! Some good (and some less-than-good) alternative remedies exist for people with fibromyalgia, and I cover the gamut. I review the latest information on supplements, homeopathy, acupuncture, Botox injections, magnet therapy, and a few other intriguing choices. I offer my expert opinion on each option.

Chapter 9

Medicating the Problem: Over-the-Counter Drugs May Help

In This Chapter

- Regarding guaifenesin: A cough medicine used by some for fibromyalgia symptoms
- Optimizing over-the-counter painkillers
- Considering antihistamines or cold remedies that may help
- Talking about topical remedies

Guaifenesin (pronounced gway-*fehn*-ih-sin) is a cough medicine promoted by some patients and doctors as a treatment for fibromyalgia syndrome (FMS).

Tina says that she feels so much better since she's started taking guaifenesin to treat her fibromyalgia. According to Tina, she still has plenty of back pain, fatigue, and other symptoms of fibromyalgia. But compared to how she felt *before,* Tina says that she's radically better now. Marcy, on the other hand, has been taking guaifenesin faithfully for two years and has yet to see any results. But Marcy figures that the positive effects should kick in anytime now, so she's continuing to take the drug. Tom took guaifenesin for a month, but didn't notice any improvement in his condition, so he gave up on it.

Anecdotal recommendations are usually worthy of consideration when it comes to finding a plumber or even a doctor. But I think a far better way to consider whether to take medications such as guaifenesin, as well as other over-the-counter (nonprescribed) remedies for fibromyalgia, is to look at existing clinical studies, as well as consider patient comments. I provide both objective data and subjective anecdotal information on guaifenesin in this chapter.

TECHNICAL STUFF

I include guaifenesin as an over-the-counter (OTC) drug, because it's available in an OTC strength, and many people who take it rely on OTC guaifenesin. An *over-the-counter drug* is a medication that doesn't require a prescription from your doctor, but it's still regulated by the Food and Drug Administration (FDA), and the FDA can pull it off the market if problems develop. However, guaifenesin is also available in a prescribed strength, as are some of the other medications described in this chapter.

In this chapter, I also cover antihistamines (cold-medicine-type remedies), painkilling remedies (such as Tylenol, aspirin, and ibuprofen), and topical pain-relief remedies (ointments, creams, and so on that you can rub into your skin, allowing — you hope — at least a temporary reprieve from your pain).

Considering Guaifenesin

Guaifenesin is an *expectorant,* a drug that thins out and loosens your mucous, making it easier to cough up. Guaifenesin is also one ingredient found in popular cough syrups; however, individuals who support taking guaifenesin for the symptoms of fibromyalgia believe that it's best to take guaifenesin alone, without other added drugs.

Some guaifenesin supporters take an over-the-counter dose of the drug; others take a prescribed level. Some individuals supplement prescription guaifenesin with OTC guaifenesin. And still others take a prescription-level dose of guaifenesin by taking many OTC guaifenesin tablets. I don't recommend this practice at all — I believe that your doctor should monitor prescribed drug strengths.

WARNING!

Taking high doses of OTC drugs can be very dangerous, and people have accidentally died this way. It can be harmful to act on the mistaken belief that if two pills would be good (if recommended on the bottle), then four would be twice as good. Don't make this mistake.

REMEMBER

Guaifenesin is not an FDA-approved treatment for fibromyalgia. So far, clinical studies have *not* proven that guaifenesin is an effective treatment for people who have fibromyalgia or any other ailment beyond a serious cough or chronic asthma. (Take a look at the "Studying guaifenesin" section in this chapter for some info on the one clinical study of guaifenesin.) So what's the real deal on guai, as its proponents affectionately like to call it?

Looking at some background info

Guaifenesin as a solution to fibromyalgia was the brainchild of Dr. Paul St. Armand, an endocrinologist from California. Dr. St. Armand believes that people with fibromyalgia build up caches of chemicals (phosphates) in their bodies, and these deposits cause pain and other symptoms characteristic of fibromyalgia.

Dr. St. Armand also believes, based on personal and anecdotal observations of his patients, that the regular taking of guaifenesin can slowly rid the body of these chemical deposits and that it will eventually make patients with fibromyalgia feel dramatically better. Some people are said to feel well more quickly than others; supposedly, some patients may wait a year or longer before gaining noticeable benefits from taking the drug.

Studying guaifenesin

Some doctors take a neutral stance about the use of guaifenesin, and others are more negative, saying that because the use of guaifenesin for FMS isn't backed up by clinical studies, it should never be used to treat fibromyalgia. Other physicians believe if the drug doesn't cause identifiable harm, it's okay for patients with FMS to try, as long as competent doctors follow the patients.

Clinical studies to date haven't validated the use of guaifenesin as a treatment for fibromyalgia. Dr. Robert Bennett, a highly respected rheumatologist and clinical researcher in Oregon, performed a one-year clinical study on guaifenesin among 40 women diagnosed with fibromyalgia. (The study wasn't published in a journal, but it's available at `www.myalgia.com/guaif2.htm`.)

Dr. Bennett subsequently concluded that guaifenesin didn't significantly improve the subjects' fibromyalgia symptoms, compared to the effects of the *placebo* (sugar pill) on the control group. Dr. St. Armand, an advisor to the researchers of the clinical study, has disputed the study findings. But to date, no other clinical studies have been performed that support or refute Dr. Bennett's research. No one can definitively state that guaifenesin *doesn't* help fibromyalgia, based on just one study that refutes its value. Nor can anyone say with certainty that guaifenesin helps FMS symptoms. The only thing that's absolutely clear is that further studies are needed.

Joining the fan club

Although guaifenesin has no clinical proof that it works, there is a lot of anecdotal evidence that the drug helps some patients. These testimonials come from individuals convinced that guaifenesin has played a major role in their improvement. For example, Susan, a long-time sufferer of FMS, says that guaifenesin has given her back a normal life — one she thought had been lost forever. Last year, Susan says that she could barely climb a flight of stairs. But now, she goes up and down stairs several times a day effortlessly, the way most adults unthinkingly use stairs.

Kathy is another fibromyalgia sufferer, and she says that the only drug that has given her any symptomatic relief whatsoever has been guaifenesin.

Susan and Kathy believe that guaifenesin has been a life changer for them. But others say that guaifenesin hasn't helped at all, or made them feel worse.

If you want to contact supporters of the use of guaifenesin and discover their information about its use in treating fibromyalgia, you can go to a Web site of a support group at `www.psha-inc.com/guai-support/`. Or go directly to the site of the doctor who promotes guaifenesin as a fibromyalgia therapy at `www.guaidoc.com`.

Ordering guaifenesin

If you decide to try guaifenesin, you may have a hard time finding the drug by itself in your local drugstore, because it's usually one ingredient in OTC cold remedies. However, you can ask your pharmacist to order you an OTC dose of guaifenesin alone.

You can also order an OTC dose of guaifenesin over the Internet, but generally, you're better off working with your local pharmacist. State medical boards strongly disapprove of doctors and pharmacies who prescribe drugs for people they have no direct personal relationship with, because they worry about possible overdoses or side effects. For this reason, I advise against ordering from anyone who sells drugs over the Internet.

Don't take guaifenesin on your own without discussing it with your doctor. Combined with other medications that you may take, or with other medical problems that you may have, guaifenesin may be inadvisable for you.

Weighing the pros and cons of guaifenesin

In this section, I offer a brief overview of the advantages and disadvantages of guaifenesin use as a treatment for fibromyalgia.

Accentuating the positives

Simply put, here are the basic advantages of guaifenesin treatment:

- It's generally an inexpensive medication.
- Guaifenesin has few or no side effects for most users, although some side effects are listed later in this chapter and in Appendix B.
- You won't need a prescription for the low doses of the drug.

Looking at the drawbacks

The key disadvantage of taking guaifenesin is that it may not make you feel any better. The only way to know whether some drugs work is to take them and see what happens.

Another disadvantage is that many people who support taking guaifenesin won't believe you if you say it's not helping you. These individuals may say that if guaifenesin isn't working for you, it's your fault — you're not taking enough of the drug or you're doing something else wrong. If you rely on such views, you could find yourself in a confused or self-blaming state — neither of which is helpful.

Along the same lines, hard-core guai supporters will tell you the drug *is* working regardless of how you feel. Ironically, if you feel *worse* when you take guaifenesin, guai supporters believe this is "proof" that the drug is working because it's allegedly ridding your body of pain-inducing chemicals, such as phosphates. If you feel better, that means that the drug's working, too. And if you don't feel anything, don't worry: Supposedly, you'll soon feel better or worse, and you'll know that it's working.

WARNING!

Although guaifenesin has few side effects, some people have bad reactions to it. Here are some of the more common reactions:

- The drug may cause skin itching and rashes.
- It sometimes causes nausea and vomiting.
- Guaifenesin may also cause drowsiness in some individuals.
- Some people say that it exacerbates their symptoms of fibromyalgia.

REMEMBER

I can't rule out guaifenesin as a possible remedy for fibromyalgia until further studies are performed, but I can't support it as a surefire remedy, either.

Relieving Pain with Painkillers

Your doctor may prescribe painkilling medications or other types of drugs to help you cope with the aching, stiffness, and overall pain of fibromyalgia. (Read Chapter 10 for more information on prescribed medications.) But if your symptoms have lessened somewhat and you still feel like you need something for pain relief, an over-the-counter painkilling medication may be the right answer for you. In the following sections, I cover a few options.

Acetaminophen

You probably know this drug by a different name, Tylenol. (There are also generic forms of acetaminophen.)

The simple short-term benefit of taking over-the-counter Tylenol is that it may give you a temporary respite from widespread body aches and pains. Many people see Tylenol as extremely safe, and it generally *is* a safe medication. However, long-term and heavy use of Tylenol can damage the liver — the organ that breaks down the drug. You may be better off, at least once in a while, taking ibuprofen instead.

WARNING!

Don't consume *any* alcohol when taking Tylenol (including any form of Tylenol, whether over-the-counter Tylenol or prescribed medications with Tylenol in them like Tylenol 3, which is Tylenol and codeine). When Tylenol is combined with alcohol, it can cause serious damage to your liver. Livers come only one to a customer, and you can't live without your liver. So be extremely careful about your alcohol/Tylenol consumption. The best way to do that is to not drink when taking Tylenol.

Aspirin

Aspirin can be a very effective painkiller, and it's also often used (usually at very low daily doses) by people who are at risk of suffering from heart attacks or strokes or from having another stroke.

WARNING!

But aspirin can also cause serious gastrointestinal upset, and it may even lead to stomach bleeding as well as the development of *gastritis,* an inflammation of the stomach. Don't assume that aspirin is always "safe" just because you've been taking it all your life. It's still a drug. Use aspirin with caution.

Ibuprofen

Ibuprofen is the generic name for Advil, Motrin, or other forms of the drug. It's a painkilling drug that's available over the counter. The primary benefit of ibuprofen is the pain relief that it can bring.

WARNING!

The main drawback of ibuprofen is that it can cause serious gastrointestinal distress, including ulcers, gastritis, gastrointestinal bleeding, and so forth. Other possible side effects that may occur include headaches, *tinnitus* (ringing in the ears), and dizziness. These side effects usually don't occur except with high doses over a long period, but some people are more sensitive than others and may develop problems sooner.

Naproxen

Naproxen is the generic name for Aleve, the only over-the-counter form of naproxen approved by the FDA. Aleve is available in tablet form and should be taken with milk or food to avoid stomach upset. Like most painkillers of this type, it should be taken for only a short time without recommendation by a doctor. Its key benefit is pain relief.

WARNING!

Naproxen's primary drawback is that it may slightly increase the risk of heart attack and stroke, especially if taken long-term. The risk for gastrointestinal disease is also increased, including such problems as heartburn, ulcers, and gastritis. Other side effects that may occur with naproxen include diarrhea or constipation, mouth sores, headache, dizziness, ringing in the ears, and lightheadedness. As with ibuprofen, some people are more susceptible to side effects than others.

Warming Up to Cold Remedies for Fibromyalgia

Fibromyalgia is very different from the common cold, unless you want to factor in the generalized aches and pains of a severe flu into your "cold" equation. (Many people say that fibromyalgia feels like a semipermanent case of the flu to them, with periodic breaks of feeling a little better.)

Despite this difference, some remedies that are given to people with colds, bronchitis, and related ailments may be helpful to people who have fibromyalgia. I cover guaifenesin (a remedy that's effective in coping with cough) at the beginning of the chapter, so here I move on to other cold remedies that people with FMS have tried.

Dealing with dextromethorphan

Some studies have researched whether taking regular doses of *dextromethorphan,* an anticough medication, could help some people cope more effectively with their symptoms of fibromyalgia. Some researchers who've studied dextromethorphan, such as Dr. Robert Bennett, a prominent rheumatologist, initially found that low levels of dextromethorphan were ineffective in subjects with fibromyalgia. However, when the dosage of dextromethorphan was increased, the research subjects reported that their pain had significantly decreased.

Another study (one I conducted) found that dextromethorphan decreases pain sensitivity of FMS patients. Using this drug can reduce the achiness that many FMS patients feel. To get this effect, the drug must be used at prescription strength (60 mg to 90 mg twice per day), which requires a prescription from a doctor.

TECHNICAL STUFF

In one study of the effectiveness of dextromethorphan, the drug was found to *potentiate,* or boost the effect of Ultram (generic name: tramadol), a prescribed painkilling medication. But further studies are needed before I can recommend dextromethorphan as an OTC remedy for fibromyalgia.

WARNING!

Some people are trying dextromethorphan now. People who follow this course should discuss it first with their physicians to make sure dextromethorphan won't interact with other medications that they take and will be safe for them.

Locating a source for dextromethorphan tablets as a stand-alone drug may be difficult because it's usually an ingredient in cold medicines. You can ask your pharmacist to order it for you in the OTC strength. (Obviously, the pharmacist won't give you the prescribed strength without a prescription from your doctor.) Another possible option is to purchase Delsym (generic name: dextromethorphan polistirex). This OTC drug comes in a liquid form, and supposedly is chemically akin to dextromethorphan. (Delsym does include a small amount of alcohol and, thus, may be sedating.)

Trying antihistamines

In addition to cough medicine, some other drugs that are normally classified as *antihistamines,* or "cold medicines," may give some people with fibromyalgia some (or even a lot of) relief from their overall aches and pains. The most popular examples are Benadryl and Tylenol PM.

Cold or allergy medications may help some people with fibromyalgia because they may affect the serotonin levels, much as some antidepressants also can alleviate some of the pain and other symptoms of fibromyalgia by affecting the circulating levels of *neurochemicals* (brain chemicals such as serotonin, norepinephrine, or dopamine, which may affect mood and pain). Substance P is another neurochemical that can affect your pain level.

WARNING!

Because many antihistamines make you drowsy, they may also help with sleep problems. Be careful with driving or activities that require alertness when you take these drugs, unless they specify that they're "non-drowsy."

Talking about Topical Remedies

Can you gain pain relief from an over-the-counter ointment that you merely rub into your skin? Sometimes topical remedies *can* help, even if the relief lasts a few hours. Often these drugs work for people with arthritis, but they can be beneficial for people with fibromyalgia, too. (Read about Lidoderm, a prescribed skin patch that helps many people with FMS, in Chapter 10.)

Considering your options

Skin ointments are available in any pharmacy and most supermarkets, and there are too many brands to list here. Most are creams, but there are a few spray-on remedies. Most contain minor anesthetics such as the following ingredients:

- **Capsaicin (derived from chili peppers):** When it works, capsaicin can anesthetize parts of your body where you've rubbed it on your skin by reducing your level of Substance P (the pain neurochemical) and also by dulling the pain receptors at the level of your skin's surface.
- **Cayenne (comes from hot peppers):** Like capsaicin, cayenne can cause the skin to heat up, thus causing the muscles to relax.
- **Eucalyptus (taken from the tree that is the major diet of koala bears):** This substance can act as a mild stimulant to the skin, causing tense muscles to loosen up.
- **Menthol:** You may find that menthol "cleans out your sinuses" with its very pronounced aroma. It may also provide you with temporary relief from your minor muscle pains and strains.
- **Methyl salicylate (derived from aspirin):** Many topical ointments include salicylate, an aspirin-based substance. These drugs may act as *both* a combination painkiller and an anesthetic when rubbed into the skin. They also bypass the gastrointestinal system, so if you've found that aspirin hurts your stomach, that won't likely be a problem for you with a skin rub.
- **Peppermint oil:** Often thought of solely as a flavoring, peppermint oil can also be a mild painkiller for sore and tense muscles.

In addition to these ointments, a variety of other ingredients can help numb muscle pain that's close to the surface of the skin. (Your doctor can also recommend prescribed topical agents. They may include the same types of ingredients, but at a significantly greater strength.)

When you or anyone else uses a topical ointment, make sure that the person who's doing the rubbing thoroughly washes his hands directly afterward. You don't want this substance to be accidentally applied to your eyes or to anyone else's, or to any other body part that may be sensitive to burning.

Deciding which topical remedy is best

One of the main difficulties with topical remedies lies in choosing which one to buy! You have many different ones to choose from and may find it hard to decide which one's right for you. Don't go by price only: The cheapest ointment isn't always the best choice — nor is the most expensive ointment necessarily the most effective.

When looking at various brands of topical ointments to help you ease muscular aches and pains, here are a few pointers to consider:

- **Have you bought this brand before?** If it worked for you before, it may work again. If it didn't work before, no matter what new and dramatic promises are made in advertisements, it probably still won't work now.
- **Is this drug odor-free or will everyone within 500 yards know you're coming if you use this product?** If you want to be unnoticed in the world, choose the drug without an obnoxious aroma. If it doesn't matter because you're going to bed, and don't care what you smell like as long as you get pain relief, skip this criterion.
- **Can you buy a small tube or "sample-size" container in case you haven't tried this drug before, and don't know if it'll help?** If you don't like the medication, you won't have wasted your money on the larger size. If a small or sample size isn't available, you may have to risk money if you think the product may work for you.
- **What are the ingredients in this medication?** Does the drug have ingredients you want to avoid? Some people want to stay away from drugs that include salicylate (aspirin). Perhaps, you don't like another ingredient. Also, be sure to check for ingredients that you're allergic to.
- **Is this drug reasonably priced, and can you afford it?** When you're in severe pain, almost any amount may seem reasonable. But don't let yourself get ripped off by people taking advantage of your desperation. Check the label for the ingredients. The expensive stuff may include the same ingredients as the lower-cost drug.

Chapter 10

Prescribing Health with Medications

In This Chapter

- Musing about muscle relaxants
- Overcoming pain with painkilling medications
- Knocking out stiffness and pain with non-steroidal anti-inflammatory drugs
- Using antidepressant drugs against fibromyalgia
- Waking up to what sleep remedies can do
- Considering other prescribed medicines
- Anticipating future medications

Natalie has had fibromyalgia for about ten years, and says that she absolutely could not get through a single day without her pain medication. Natalie honestly believes that she'd be suicidal from the pain by now if it weren't for her medications. The few times that Natalie has waited until the last minute to refill her prescriptions and had to go a day before she got her medicine (because the pharmacy had just run out of the drug), were not days that you'd want to be around her, she says.

Is Natalie a drug addict, or maybe a hypochondriac? No, she fits neither category. Natalie isn't a drug addict, because she's taking her medication to alleviate her pain and not to induce pleasure. Nor is Natalie a hypochondriac. Hypochondriacs misinterpret their symptoms and worry about imagined illnesses, but fibromyalgia pain is undeniably real, and it can be very severe. Natalie says that the medications she takes don't take *all* the pain away — they make her pain tolerable, so she can lead a relatively normal life.

Dave also has fibromyalgia, but he takes medications intermittently. Sometimes, the pain is severe, and he needs a strong painkiller. Other days, he's able to forego taking any medication altogether.

You may be more like Natalie, needing to take medications daily, or maybe you're more like Dave, who doesn't need medicines every day. But when you have fibromyalgia, at some point in time, you'll need prescribed medications. The purpose of this chapter is to discuss the key drugs that doctors prescribe for fibromyalgia syndrome (FMS) and the benefits and risks associated with these drugs. I talk about muscle relaxants, painkilling medications, nonsteroidal anti-inflammatory drugs, anticonvulsive drugs, anti-anxiety medications, sleep remedies, and other drugs, as well as some treatments you may see in the future. So read on and discover how you can combat the pain.

Relaxing Your Fibromyalgia: Muscle Relaxants

Many people with fibromyalgia complain of muscle aches and pains, so many physicians prescribe *muscle relaxants.* These drugs do more than just what they sound like: They soothe your overtensed muscles and reduce your pain — but they often do more than that, such as improve sleep and decrease depression.

WARNING!

Be sure to avoid alcohol when you're taking muscle relaxants. One muscle relaxant, Soma (generic name: carisoprodol), can cause an opium-like high in some people when it's combined with alcohol. Also, even if you *don't* drink, avoid driving when taking any muscle relaxant. The sedating effects of the muscle relaxant can cause you to become an impaired driver.

Naming names

Flexeril (generic name: cyclobenzaprine) is the most commonly prescribed muscle relaxant. This drug often also acts as a mild antidepressant because Flexeril increases the level of serotonin in the bloodstream. People who have been prescribed Flexeril generally take this medication in the evening because it can cause major sleepiness. Flexeril may work well for you, or it may not. Often, the only way to know is to try it and see what effect it has on your aching body. One study of 120 patients with fibromyalgia indicated that 84 percent of the patients who took Flexeril significantly improved. They experienced decreased pain, improved sleep, and a reduction in the number of their tender points.

Here are some examples of other muscle relaxants that are often prescribed to treat FMS pain (again, they may be effective for you, or they may not be):

- Baclofen (generic name: liorisol)
- Norflex (generic name: orphenadrine citrate)
- Skelaxin (generic name: metaxalone)
- Soma (generic name: carisoprodol)
- Zanaflex (generic name: tizanidine HCl)

A combination of Soma and acetaminophen is also available. It's called Soma Compound.

Weighing the risks and benefits of muscle relaxants

The primary benefits of muscle relaxants are that they may provide temporary pain relief. In addition, the sedating action of most muscle relaxants can help FMS patients with trouble sleeping to avoid yet another sleepless night.

On the negative side, the chief side effect of many muscle relaxants is *gastrointestinal distress,* such as stomach pain and diarrhea. This gastrointestinal problem may range from mild to severe, depending on the particular drug and the particular patient. At the extreme end of side effects, muscle relaxants can damage the stomach, as with *gastritis* (an inflammation of the stomach) or even stomach ulcers or *duodenal* (small intestine) ulcers.

Although one drug in a class of medications may cause side effects, sometimes another drug in the same class may not cause the same side effects. Thus, if your doctor orders another muscle relaxant even after you tried one muscle relaxant that caused side effects, you should try the second one because you may have better luck with another drug.

Easing Pain with Painkillers

Most people with fibromyalgia *need* to take prescribed painkilling medications, at least some of the time, in order to cope with the widespread pain and stiffness — symptoms that are so characteristic of FMS.

Of course, some people with fibromyalgia may not need to take their painkilling medications every single day. Also, on some days, muscle relaxants, milder painkillers, or even over-the-counter *analgesics* (painkillers) may be sufficient to manage the pain for many people who have fibromyalgia.

Considering key pros and cons of prescribed painkilling medications

TIP

The most obvious benefit of taking a prescribed painkilling medication is that, if it works, the medication makes your pain go away or makes it more tolerable. But painkilling meds have a few other benefits as well:

- **If you take a painkilling medication at the same time as your pain is continuing on its upward path, you can often thwart the pain from getting any worse and prevent it from ever reaching the high scream-zone of agony.** In that way, your painkilling medication is acting as a preventive medicine.
- **Taking painkillers when you're in severe pain can also aid your immune system.** How? Basically, your body won't need to divert so much effort and energy to concentrating so hard on coping with the pain. With pain relief, your immune system can work much more efficiently.

WARNING!

Taking painkilling medications also has some disadvantages that every person should consider before taking these drugs.

- **Side effects may be problematic for you, causing you to feel drowsy and unable to drive yourself to work, school, or anywhere else that you want to go.** Painkilling drugs can also be very constipating, causing you to need to change your diet (eating more fiber, fruits, and vegetables, and drinking more water) or to take laxatives.
- **Your doctor may be hesitant to prescribe painkilling medications because of state and federal laws designed to curb drug abuse.** You may feel as though your doctor regards you as a drug addict simply because you asked him for pain medication to give you some relief. Read more about why some doctors are hesitant to prescribe painkillers in the "Prescribing painkillers: The dilemma" section, later in this chapter.

Investigating controlled/scheduled drugs

Some painkillers, including narcotics, fall into controlled-drug categories. (All narcotics are controlled drugs.) A *narcotic* is a painkilling drug classified as having a significant risk to cause addiction. Many narcotics are opium based (such as morphine and codeine), while others are synthetically derived, such as Duragesic (generic name: fentanyl) and methadone. From a patient's perspective, the key benefit to a narcotic is the pain relief that it provides and the return of physical and social functioning.

Scheduled drugs and fibromyalgia

Under the Controlled Substances Act, passed by Congress in 1970, controlled drugs fall into five *schedules* (or categories) of drugs, based on the risk for addictiveness, with Schedule I having the highest risk of addiction and Schedule V the lowest risk of this group:

- **Schedule I:** Drugs categorized as having major potential for drug abuse. Drugs such as heroin and LSD are in Schedule I. These drugs have no value to patients who have fibromyalgia. They are all illegal drugs.
- **Schedule II:** These drugs also have potential for abuse, albeit less than the drugs in Schedule I. Cocaine is included on the Schedule II list (some doctors have legitimate uses for the drug), as is methadone. Some fibromyalgia patients may take methadone for pain control, and others take Percocet or Percodan (both are forms of oxycodone). Some people with fibromyalgia have also used Duragesic patches and found them beneficial, in large part because of their timed-release benefit. Unfortunately, Duragesic has become a popular drug for people wanting to abuse drugs to get high. As a result of this problem, legitimate patients sometimes have a hard time getting prescriptions for Duragesic patches.
- **Schedule III:** This category includes medications such as Tylenol 3 (Tylenol with codeine), Vicodin or Lortab (two forms of hydrocodone), and barbiturate medications, such as Fiorcet (butalbital). Some fibromyalgia patients take these drugs for pain control.
- **Schedule IV:** Patients with fibromyalgia needing an anti-anxiety drug may take Valium (generic name: diazepam) or Xanax (generic name: alprazolam), which both fall under this schedule, as do other anti-anxiety medications.
- **Schedule V:** Some medications that include codeine, such as cough syrups with codeine, are categorized by the DEA as scheduled drugs. These drugs are generally less helpful for people with fibromyalgia.

The U.S. federal agency known as the Drug Enforcement Administration (DEA) has designated specific medications as *scheduled drugs* because they can be dangerous, addicting, or habit forming. Drugs designated as scheduled drugs require more monitoring and record keeping by doctors and pharmacists because of their high potential for abuse. Some scheduled drugs are painkillers that help people with fibromyalgia, while others are used only for abuse, such as heroin, LSD, or crack cocaine.

Narcotics aren't the only drugs that have been identified by the DEA as potential drugs of abuse. Amphetamines, anabolic steroids, and other types of drugs are also addicting drugs "scheduled" by the DEA (see the nearby "Scheduled drugs and fibromyalgia" sidebar).

A serious side effect of narcotics is addiction, but that problem rarely occurs among people taking narcotics to alleviate their pain rather than to attain an artificial high. The side effects that often do occur, however, are sedation, nausea, dry mouth, and constipation.

At very high doses, such as those taken by patients with terminal cancer, narcotics can cause considerable mental confusion or anxiety and may even result in *hallucinations* (seeing, hearing, or feeling things that aren't really there). They may also cause *delusions* (believing things that aren't true) — for example, that aliens have landed in the backyard, or the government has planted secret listening devices in newspapers. Narcotic-induced hallucinations and delusions cease when the dosages are decreased or the drugs are out of the person's system.

Prescribing painkillers: The dilemma

For some people with fibromyalgia, their pain is constant and severe, and it can only be made bearable by taking painkilling medications. Some people with fibromyalgia say that their doctors are reluctant about prescribing any painkilling medications, telling them to take regular Tylenol or ibuprofen if they have pain. Others say that as long as the drug isn't on the scheduled-drug list, their doctor will give it to them.

Judy says that she could probably score cocaine easier than she could convince her doctor to give her a prescription for Ultram (generic name: tramadol), a mild *analgesic* (painkiller) not even on the scheduled-drug list. And she says that she knows she can totally forget about ever asking her doctor for a scheduled drug. She tried once, and Judy says that the look of horror on his face made it very clear where he stood in terms of prescribing narcotic painkillers.

Many people with fibromyalgia find it degrading to plead and beg with their doctors for painkillers. Even worse, if a doctor reluctantly provides a small number of painkillers, the contrast between the relatively pain-free existence and the return of the pain when the limited supply of pills is gone can be maddening.

Tom says that his doctor prescribes narcotics that he can take when the pain becomes severe, but his physician keeps a close watch on his dosage and asks Tom plenty of questions, such as where the pain is, how bad it is, and so forth. Tom is very careful about taking strong drugs, and he uses them only for very bad pain. Otherwise, he relies on milder medications. Tom feels that his doctor has just the right balance of compassion combined with careful control.

Painkillers, particularly narcotics, are not drugs to take lightly, and any doctor who does so isn't the physician for you.

In my experience, the problem usually isn't a doctor who dispenses painkillers freely; instead, the opposite is usually the problem: Some doctors are resistant to prescribing painkilling medications. Why are doctors often reluctant to prescribe strong painkillers for relief of fibromyalgia-related pain?

- **Doctors disagree on whether narcotics are effective at treating the pain of fibromyalgia.** Many doctors think that narcotics are usually ineffective; others think that they can relieve at least some of the severe pain.
- **The side effects associated with narcotic painkillers concern many doctors.** (See the "Investigating controlled/scheduled drugs" section earlier in this chapter.)
- **Many doctors fear having to deal with law enforcement agencies.** Law enforcement agencies in many states are concerned about the abuse of prescription medications, particularly of scheduled drugs. Drug abusers don't take scheduled drugs for pain control. They take them to attain an artificial high, or because they've become addicted to the drug (often because they originally took the drugs to get high). Sometimes, people in severe pain also become addicted to painkillers if their physicians don't monitor them very carefully. Addiction to narcotics is more likely to occur if you're a smoker, or if you've had other addictions in the past to substances such as alcohol or marijuana.

Drug abusers develop such an overwhelming need for the drug that they may forge prescriptions, steal drugs from pharmacies, or buy them on the street. These people are the ones whom law enforcement agencies are concerned about.

Unfortunately, some patients with severe pain are the victims of overzealous law enforcement and frightened physicians. Drug addicts and those who seek illegal highs will find their drugs somewhere. Hurting patients who need legitimate pain relief don't have that alternative, unless they're willing to acquire the medications illegally.

Fighting pain with non-narcotic pills

Ultram (generic name: tramadol) is a non-narcotic drug (not overseen by the Drug Enforcement Administration) that's effective at alleviating pain for many people with fibromyalgia. *Ultracet* is a medication that combines Ultram with Tylenol (acetaminophen). It's not clear exactly how these drugs work, but they appear to work similarly to a narcotic drug in inhibiting pain, although in a milder and less dangerous way.

TIP

So what can you do if you're in pain, but your doctor seems (or definitely is) hesitant to prescribe narcotic painkilling medication? You can use several tactics:

- **Ask your doctor bluntly if she's concerned that you'll become addicted to medication.** Whether she says yes or no, you can point out that you've never developed an addiction in the past. (If that's true.)
- **Tell your doctor that you're seeking medication to combat pain, not to go off on some sort of high.**
- **Give one or two examples of what your pain is preventing you from doing.** Maybe you can't drive your children to soccer practice anymore, even though it's really important to you, because you're hurting so bad. Or perhaps you feel like a prisoner in your house because the pain is so overwhelming.

If your candor and your examples don't seem to matter, and your doctor can't or won't give you a reason that makes sense to you for why she won't prescribe a painkiller, it's probably time for you to read Chapter 7, my chapter on how to find a new physician.

Lessening Pain with Lidoderm

A relatively new entry in the pharmaceutical arsenal against pain, Lidoderm (generic name: lidocaine, 5 percent) is a transdermal skin patch that the patient applies directly to the painful area after removing the protective backing from the patch. Without its backing, the patch is very sticky and adheres to the skin. The drug soothes muscles and can provide major pain relief to many patients with fibromyalgia; the drug's effects last for about 12 hours. Up to three patches can be used on the body at the same time. The patches are used 12 hours on, and then 12 hours off (no patches). The patch may cause skin irritation in some patients, but many patients respond very well.

TIP

You can cut the patch into smaller strips if you don't need the larger-size patch.

Reducing Inflammation with Non-Steroidal Anti-Inflammatory Drugs

Some individuals with fibromyalgia get significant pain relief by taking prescribed or over-the-counter doses of non-steroidal anti-inflammatory drugs (NSAIDs). The most commonly used drugs in this category are Naprosyn (generic name: naproxen sodium), Feldene (generic name: piroxicam), Motrin (ibuprofen), and Relafen (generic name: nabumetone).

Some patients with fibromyalgia have also benefited from one of the more recently introduced NSAIDs, which are called COX-2 inhibitors. Celebrex (generic name: celecoxib) and Mobic (meloxicam) are medications in this category. Note that other NSAIDs in the same class of medications as Celebrex, such as Vioxx (generic name: rofecoxib) and Bextra (generic name: valdecoxib), have been withdrawn from the market by their manufacturers because of a possible risk of cardiovascular disease, particularly heart attacks. You can't get Vioxx or Bextra, but as of this writing, Celebrex and Mobic are still options.

TIP

Celebrex and Mobic have the capability to reduce pain as well as stiffness and inflammation, and when you have fibromyalgia, a drug that can attack all these problems is certainly worthy of consideration. However, individuals who are allergic to sulfa drugs (such as the antibiotic Septra) should not take Celebrex.

NSAIDs generally are taken by fibromyalgia sufferers on a daily basis to combat chronic pain, and they can be moderately effective. The primary drawback to NSAID medications is that they can cause gastrointestinal upset, which can sometimes be severe. For this reason, they should always be taken with meals, and NSAIDs should never be taken on an empty stomach. In some cases, NSAIDs can cause ulcers. Anyone who's experiencing severe abdominal pain should stop taking her NSAID medication immediately and should consult with her physician. Other side effects of NSAIDs may include rashes, rapid heartbeat, stuffy nose, blurred vision, and lightheadedness.

TIP

Some people take over-the-counter medications, such as Tums or Rolaids, along with their NSAID medication, to prevent stomach upset. Others make sure that they only take the medication with food, and that action alone is enough to alleviate the gastrointestinal distress that would occur if they took the medication on an empty stomach. Celebrex is generally less likely to cause gastrointestinal problems and is designed to be gentler on your stomach. However, some individuals who take Celebrex still develop gastrointestinal symptoms.

REMEMBER

Many physicians recommend that Celebrex and Mobic be taken with meals — even though you may not be given these instructions on your prescription bottle — as you usually would with other prescribed NSAIDs. (Doctors like to be extra careful.)

Fighting Fibromyalgia with Antidepressants

Many people with fibromyalgia take one or more antidepressant medications. These medications include

- Adapin (generic name: doxepin)
- Cymbalta (generic name: duloxetine)
- Desyrel (generic name: trazodone)
- Effexor (generic name: venlafaxine)
- Elavil (generic name: amitriptyline)
- Lexapro (generic name: citalopram)
- Pamelor (generic name: nortriptyline)
- Paxil (generic name: paroxetine)
- Prozac (generic name: fluoxetine)
- Zoloft (generic name: sertraline)

Two common antidepressant medications used by people with FMS are Elavil and Desyrel. In addition, a newer antidepressant, Cymbalta (generic name: duloxetine), approved by the FDA in 2004 to treat depression, also provides significant pain relief to many people with FMS. Cymbalta increases the levels of both serotonin and norepinephrine, important neurochemicals that can improve mood as well as decrease chronic pain. (For this reason, it is called a serotonin norepinephrine reuptake inhibitor, or SNRI; see the nearby sidebar.) This medication may cause weight loss in some individuals.

I'm not depressed! Why do I need an antidepressant?

Some patients with fibromyalgia *may* have a problem with depression. But, often, people with fibromyalgia are taking antidepressants not for depression but rather for their fibromyalgia. Research has demonstrated that low doses of some antidepressants, taken on a daily basis (or, rather, nightly because most doctors recommend the drugs be taken in the evening), can help block the pain of fibromyalgia or other chronic pain.

Sometimes, doctors prescribe two antidepressants at the same time for their patients with fibromyalgia, hoping they'll gain increased relief. For example, in one clinical study, fibromyalgia patients were given both Elavil (25 mg) and Prozac (20 mg). The result: A significant number of patients actually received twice the pain relief with this combination than they gained with either drug by itself. Although you may intuitively think that taking two drugs *would* logically give you about twice the relief as you'd receive from taking one medication, in actuality, that effect rarely happens. As a result, if and when research shows such significant pain control, this fact makes researchers stand up and pay attention. Of course, you should not take two different antidepressants unless your doctor recommends it.

Serotonin norepinephrine reuptake inhibitors: A new pain remedy

Serotonin norepinephrine reuptake inhibitors (SNRIs), particularly the drug Cymbalta (generic name: duloxetine), are a new category of antidepressants shown to be effective in treating chronic pain. Cymbalta helps the body retain two key *neurochemicals* (brain chemicals, in this case, those affecting mood) — serotonin and norepinephrine — and thus, it is not only effective at reducing depression but also has demonstrated effectiveness in reducing chronic pain, including the chronic pain of fibromyalgia. Note that another medication, Effexor (generic name: venlafaxine), is also an SNRI, but the doses of Effexor needed to reduce pain are usually high and frequently cause side effects. Cymbalta is FDA-approved to treat depression and the nerve pain of diabetics; however, it is also often prescribed off-label to treat the pain of patients with FMS.

In a study of 354 female patients with fibromyalgia (reported in the medical journal *Pain* in 2005), 29 percent of the subjects who received Cymbalta reported a 50 percent or greater decrease in their pain levels. Some patients dropped out of the study because of side effects of nausea and dry mouth. (Such side effects usually abate after several weeks.) Other studies have indicated that female patients with FMS have a significantly greater improvement than males who take Cymbalta, although the reasons for this are unknown.

Balancing the pluses and minuses of antidepressants

The good news about using antidepressants to treat fibromyalgia pain is that many antidepressants are relatively inexpensive, and most doctors will not hesitate to prescribe these medications for the treatment of chronic-pain problems. However, Cymbalta and some other antidepressants can be costly if you don't have medication coverage. In other words, you generally don't need to see a psychiatrist in order to receive a prescription for an antidepressant.

REMEMBER

However, if you or your doctor thinks that you *may* actually have a severe form of depression, you're really better off consulting with a psychiatrist. Why? Psychiatrists are the most knowledgeable physicians when it comes to antidepressants and other drugs that help people who have emotional problems.

Talking about trigger-point injections

When your pain is severe and seems to be isolated to one or several clearly defined areas, some physicians consider using treatments of trigger-point injections. These injections are usually given directly into or near the zones where the pain dominates. Often, patients with fibromyalgia suffer from the trigger points of *myofascial pain syndrome* (another pain syndrome; see Chapter 6). These trigger points (different from tender points) are painful, ropey areas that the physician can actually feel during an examination. Studies have shown that such injections are frequently helpful to patients with FMS.

Most doctors inject ropivacaine or lidocaine into the area that's the most painful. These injections can be given several times per year, and many patients with fibromyalgia gain considerable pain relief from them. The injections are usually given on an outpatient basis, and they have only minor side effects, such as slight bruising. If you experience any pain at the injection site, icing or heating the area usually provides relief. Some people may have an allergic reaction to lidocaine injections, however.

The physician who injects the medication should be a rheumatologist, anesthesiologist, or neurologist, because these types of specialists usually have the most experience with treating both fibromyalgia and pain. An inexperienced physician may be unable to identify trigger points correctly or may inject medications into the wrong areas.

WARNING!

As with all medications, antidepressants have potential side effects:

- Constipation
- Diminished *libido* (sex drive) or complete lack of libido (***Note:*** When that effect occurs, it usually goes away when the drug is out of the system, and normal libido will return.)
- Headaches or a "druggy" feeling
- Insomnia
- Upset stomach
- Weight gain or weight loss

Often (though not always), the initial side effects decrease or go away completely after the person's body becomes more accustomed to the drug.

Other Medicines Prescribed for Fibromyalgia

A variety of other categories of drugs may also be very helpful in treating the symptoms of fibromyalgia, particularly the symptom that probably bothers you the most — the pain. Doctors may prescribe anticonvulsive drugs, anti-anxiety drugs, and antihistamines for pain relief.

Analyzing anticonvulsive drugs

Some physicians prescribe anticonvulsive drugs to relieve the pain and tenderness of their FMS patients, even if those patients have never had a seizure in their lives. Anticonvulsives can calm hyperactive pain fibers and effectively reduce anxiety. The only way to know for sure whether such a drug works is to take the medication and note its effects on you.

The key side effects of these drugs are that they may be very sedating and they may also cause dry mouth and dizziness.

Anticonvulsives include such medications as Neurontin (generic name: gabapentin), Lyrica (generic name: pregabalin), Topamax (generic name: topiramate), and Lamictal (generic name: lamotrigine). This drug class is one of the most promising new therapies for fibromyalgia.

Pondering anti-anxiety medicines

Sometimes, anti-anxiety drugs can alleviate some symptoms of fibromyalgia. Anxiety makes pain worse, so decreasing anxiety can be very helpful in pain control. If the drugs work, you have relief from some symptoms of fibromyalgia, such as problems with sleeping. The drugs can also induce a level of calmness to combat the high stress that many people suffering from fibromyalgia experience.

Some anti-anxiety drugs are Valium (generic name: diazepam) and Xanax (generic name: alprazolam). Both of these are scheduled drugs because of their potential for addiction.

Some physicians may prescribe Klonopin (generic name: clonazepam). Sometimes, the drug Restoril (generic name: temazepam) is prescribed for patients with fibromyalgia. Other physicians may prescribe the antidepressants Paxil (generic name: paroxetine) or Prozac (generic name: fluoxetine) to treat anxiety.

REMEMBER

Generally, low doses of anti-anxiety drugs are used to treat fibromyalgia. However, some people with fibromyalgia need higher doses of anti-anxiety drugs because their pain is strongly influenced by high levels of anxiety. (See Chapter 16 for more information on emotional problems, such as anxiety and depression, among people with fibromyalgia.)

Anti-anxiety drugs can be highly sedating, and they may also cause nightmares. Other side effects of these medications are dizziness and lightheadedness. Of even greater concern, some anti-anxiety drugs may be habit forming, particularly Xanax (generic name: alprazolam). As a result, they have the potential to become addicting if not taken properly. (*Habit-forming* is a lower level of addiction.)

WARNING!

Don't take these drugs when you need to drive or operate equipment. Also, keep in mind the fact that, after you start taking one of these medications, you shouldn't stop them without consulting your physician. The reason: If a person who's used to taking the drug suddenly stops taking it, he may suffer from nausea/vomiting, racing heart beat, or other serious withdrawal effects.

Analyzing antihistamines

Although further research must be done, a few studies have indicated that some antihistamines have mild *analgesic* (painkilling) qualities. Histamine is a pain-promoting substance made by the body; antihistamine counteracts histamine. For example, Atarax (generic name: hydroxyzine) provides some pain relief, and it's also mildly sedating.

Researchers in Denmark found a new antihistamine, ReN 1869, which reduced inflammation and pain in laboratory mice, with no apparent ill effects. They reported on their finding in a 2002 issue of the *European Journal of Pharmacology.* It'll be years before such antihistamines can be used by humans (if they ever can). Still, such research is encouraging.

Considering pramipexole and ropinirole: Parkinson's drugs may offer pain relief

Some studies have indicated that two drugs that are technically called *dopamine receptor agonists* and that are used by patients with *Parkinson's disease* (a degenerative disease of the nervous system) may also be helpful in decreasing the chronic pain of individuals with FMS.

Mirapex (generic name: pramipexole) is a medication that works in a similar way to dopamine and, thus, reduces the pain of fibromyalgia. In one study of fibromyalgia patients reported in *Arthritis & Rheumatism* in 2005, 42 percent of patients who took Mirapex reported that their pain decreased by at least 50 percent. About half of these patients had been taking narcotics or were disabled by their pain. Common side effects were temporary anxiety and weight loss. None of the patients withdrew from the study because of side effects.

Requip (generic name: ropinirole), another drug used to treat patients with Parkinson's disease, has also been found to be effective in reducing the pain of fibromyalgia. In one study, nearly half of 30 patients taking Requip reported a 50 percent or greater reduction of their pain. Side effects included nausea, an increased risk for depression, agitation, and dizziness.

Opening Your Eyes to Sleep Remedies

If dark circles under your eyes and severe tiredness due to lack of sleep accompany your other symptoms of fibromyalgia, you're definitely not alone. Most people with fibromyalgia have severe sleep problems. If you're deprived of the restorative qualities of a good night's sleep and the opportunity for your body to rest and recuperate from the day's ordeals, this lack of sleep can greatly worsen your symptoms of pain, muscle stiffness, and fatigue.

You can choose from many ways to cope with your sleep deficit, such as using relaxation therapy or hypnosis or avoiding certain foods. (Read Chapter 14 for more information on sleep and fibromyalgia, as well as tactics for improving your sleep.) Medications can help, too.

Many medications described in this chapter, such as antidepressants, anti-anxiety drugs, muscle relaxants, and painkilling drugs, may cause drowsiness. Some NSAIDs, prescribed for muscle pain and stiffness, may also cause some individuals to feel drowsy. But sometimes, sleep-deprived people need a drug specifically designed to cope with their sleep problems.

Ambien (generic name: zolpidem) is a commonly prescribed medication for sleep difficulties. (Read more about Ambien and other sleep remedies in Chapter 14 on dealing with sleep problems.) Other sleep remedies approved by the FDA for insomniacs include Lunesta (generic name: eszoplicone) and Sonata (generic name: zaleplon). These medications have a low risk for abuse. A newer prescribed sleep remedy that is *not* a scheduled drug is Rozarem (ramelteon).

Assessing whether sleep medication is needed

Only your doctor can decide whether a specific sleep remedy should be prescribed. However, here are some indications that a sleep remedy may be necessary:

- ✓ Sleeping less than five hours per night
- ✓ Frequently waking up at night (more than two to three times)
- ✓ Severe daytime drowsiness from lack of sleep
- ✓ Impairment from lack of sleep (stumbling about, frequent instances of forgetfulness, inattentiveness), causing problems both at work and at home

Gazing at the ups and downs of sleep remedies

The most obvious benefit of a sleep remedy is that it induces or at least helps you to attain some much-needed sleep. If you're fully rested and your body has had a chance to release hormones needed by a healthy body, such as growth hormone (released during deep sleep) and others, your fibromyalgia symptoms will likely improve as well.

Although sleep remedies can be a godsend for many people, they do have some downsides. Ambien, although usually harmless, can cause continued drowsiness and diarrhea in some people.

WARNING!

As with all drugs, doctors should carefully consider potential side effects before prescribing a sleep remedy. Your doctor should also take into account other medications that you're already taking because, sometimes, drugs interact with each other, boosting or weakening the effect of each other or causing other reactions.

Pondering Future Remedies

Because so many people suffer from the symptoms of fibromyalgia, pharmaceutical companies are working very hard to develop medications that are specifically effective for people with fibromyalgia. As a result, new and better treatments should be available within the next few years or even sooner. So hang on, if you're dissatisfied with the medications that are available now. Help is on its way.

As of this writing, research appears to be surging ahead in such areas as growth hormones or dopamine receptor agonists. Some researchers have already shown that growth hormone or dopamine receptor agonists have improved the symptoms of some patients with fibromyalgia; further study is needed, however. The key problem with growth hormone is that this particular therapy is very expensive, and until the price comes down further, it can't be widely used as a therapy for fibromyalgia patients.

Researchers are also working on the development of medications that are a triple threat to FMS pain, inhibiting the reuptake of serotonin, norepinephrine, and dopamine. So far, these drugs have not been approved by the FDA and, thus, are not available to the public, but look for this type of medication in the future.

I really can't say exactly when drugs that are currently in the pipeline (that is, in clinical testing) as of this writing will actually receive FDA approval and become available to fibromyalgia patients down the road. Medications can't be prescribed for patients until they've been both thoroughly tested in clinical trials and approved by the FDA to be sold to patients in the United States. But probably within the next two to five years, FMS sufferers will have many new choices to treat the pain, fatigue, and other symptoms of fibromyalgia.

Chapter 11

Using Hands-On Therapies

In This Chapter

- Using cold or heat to beat the pain
- Getting wet and feeling better
- Checking out massage
- Finding relief magnetically
- Getting electrified with TENS
- Going to a chiropractor

When you're suffering from major pain, even the thought of a little hands-on therapy can make you cringe or shudder. Nobody likes to be touched when his body hurts, especially in those places right *where* the body's really hurting.

But sometimes, hands-on therapy can really help, whether the touching comes from cold therapy, heat therapy, massage therapy, transcranial magnetic therapy (TMS), or, in some cases, from special machines that act to stimulate and relax the tender areas.

In this chapter, I provide basic information about these hands-on techniques, including how they work, why they work, what to watch out for, and how these different options may just help you reduce the pain of your fibromyalgia syndrome (FMS).

Heating Up the Problem: Heat Therapy

Heat therapy is, hands-down, the most preferred local therapy for body aches by most FMS patients, and it may work effectively for you when you're in a lot of pain and need some relief *right now.*

Heat helps by getting your blood flowing to the painful area and by speeding up the healing process. Heat relaxes stiff muscles and improves circulation, thus easing your pain. As a result, heat that's applied to the painful area may be effective in decreasing (although probably not entirely eliminating) your underlying pain.

REMEMBER

Heat is most often best for chronic pain, such as with the aches usually experienced by people with FMS; cold seems to work better for acute pain and inflammation. So if you're experiencing chronic pain, try heat first. But if it doesn't work for you, try cold next.

Carole, who's had fibromyalgia for ten years, says that two things — hot baths and massage therapy — have really given her significant relief from her fibromyalgia symptoms.

Delivering the heat

Even something as simple as a hot bath or shower or lying down on an inexpensive heating pad (turned to the low or medium setting) may provide you with a major pain decrease.

Dry heat (such as a heating pad or a hot, dry towel) or wet heat (a hot, wet cloth or steam heat) — which is better? Sometimes, dry heat may be the best answer for you, and at other times, moist heat (using hot, wet towels or standing in a steamy shower) may ease your pain more effectively. Predicting which method — wet or dry heat — will work better for you can be hard, and, sometimes, you may need to try one and then, if it's not working, go ahead and try the other.

WARNING!

Some gel packs can be heated in the microwave oven and then applied to the skin. Be sure to carefully read the instructions on any such product that you buy. You may be the kind of person who hates reading instruction manuals — many people are — but force yourself to read the basic information anyway, and don't risk experimenting on yourself. (If you don't, you could get the pack too hot and burn yourself, or the pack could explode if left in the microwave too long!)

Avoiding overheating

Be sure that you don't overheat the painful areas of your body. *No pain, no gain* is an old saying that absolutely does *not* apply to fibromyalgia. The heat may be mildly discomforting, at most, but it shouldn't be painfully burning.

Second- or third-degree burns won't help your condition. But even if the item that you're using doesn't get to that level of heat, excessive heat can result in a serious flare-up in your fibromyalgia symptoms and your pain. Avoid it.

TIP

If you're using a heating pad, it almost certainly has a temperature control. Use it. Set it to a low or medium setting. If no temperature control is available because you're using hot towels that you may have boiled or that came straight from the dryer, test the temperature by touching it quickly. If your first response when you touch the hot towel is to spring back with an "Ouch!" then it's too hot for you.

Let the hot item cool down a little bit more before you think about applying it to your body. And then test it again with your hand before you lie on the hot towel or heating pad. After all, this therapy isn't called "burning therapy."

Chilling Out! Icing the Pain

You don't have to go live with the penguins to get some ice-cold pain relief. *Cryotherapy* (also known as "cold therapy") uses cold to dull or weaken your agitated nerve endings in the area being iced, making it harder for the pain signals to reach your brain. Cryotherapy also slows the blood flow to the affected area, decreasing inflammation and pain. However, you have to be careful. Try treating a small pain area first. Because many FMS patients are very sensitive to cold (they often find it downright painful), you must weigh the benefits as well as the drawbacks. Cold therapy may be helpful for your sore body areas but only if it is not painful!

Cryotherapy can be as close to you as your very own kitchen. Frozen water that comes from your freezer (otherwise known by its technical term, *ice*) can work very well for your personal cold therapy. Fancy ice packs and simple plastic bags filled with ice cubes can both do the job. Another option is to use a plastic package of frozen vegetables, straight from your freezer.

WARNING!

Be sure to place a clean washcloth or towel over your sore area and then place the ice over that. Avoid directly icing the painful area so you won't risk causing damage to the skin. Don't leave ice packs on for any longer than about 20 to 30 minutes at a time, or you can harm your skin (even when you use the towel). Set your timer or keep your eye on your watch, and play it safe. You don't want to add frostbite to your list of symptoms resulting from your fibromyalgia.

TIP

If you want something more advanced than a bag of frozen peas, you can make your own ice applicator very easily and inexpensively. Simply fill a paper cup with water (about three-fourths full because ice expands) and then freeze it. When you want to use cryotherapy, just peel down the sides of the top of the cup and then use the rest of the cup as your applicator — similar to the way that you use a roll-on deodorant.

Gelling the pain

You can purchase *gel packs,* which are plastic containers that are filled with a gelatinous substance. They can be frozen and applied to the painful area. Some gel packs are also enclosed in cloth. They come in many different sizes as well as a broad range of prices. You can find these gel packs in pharmacies or department stores, or buy them from companies that sell products over the Internet.

Gel packs are generally inexpensive and reusable. Some gel packs are designed for freezing only, but others may be frozen or heated in your microwave oven, so that they can be used for dual therapy. Use these packs for cold therapy or heat therapy, depending on your needs.

The pain relief from cold therapy is usually temporary, lasting several hours at most. However, when you're in severe pain from a flare-up of your fibromyalgia, even a mere few hours of relief is a worthwhile goal.

TIP If you suffer from frequent headaches, as many people with fibromyalgia do, try this simple remedy: Place an ice pack on the back of your neck for about 20 minutes. This cold can often help block the pain pathway, confusing the neurochemical pain messengers. Most important, it may relieve your headache.

Wetting Down Your Fibromyalgia Symptoms

Water can often improve your symptoms from fibromyalgia. *Hydrotherapy,* or using water exercises in a pool as a form of therapy, is an effective means to relieve fibromyalgia pain. It also often helps considerably in improving your other symptoms such as a lack of sleep. A study of 50 FMS patients reported in *Sleep Medicine* in 2006 placed patients in two groups, one receiving hydrotherapy and the other receiving conventional physical therapy. The hydrotherapy subjects did warm-ups, stretching, aerobic exercises, and relaxation. Their warm-ups included walking forward, backward, and sideways in the pool. All the patients in the hydrotherapy group increased their total sleep time by at least an hour, a significant improvement compared to the physical-therapy group.

You may also find relief from whirlpool baths or simple walking around in a pool (also called "water walking").

Because both water and warmth can make you feel better, why not soak in a hot tub or spa? This choice can be a questionable one for people with fibromyalgia because the water is often uncomfortably hot (although it should never be hotter than 104°F) and can exacerbate your symptoms. But worse than that, soaking in a hot tub (especially for an extended period) can have a dangerously sedating effect, particularly when you're taking pain medications, sleep remedies, or other drugs. Some people have actually drowned in their own hot tubs when they decided to soak alone.

WARNING!

If you use a hot tub, make sure that the temperature is set at a tolerable level before you enter the tub. It's also important to enter the tub slowly. You don't want to leap into hot water any more than you'd want to plunge your whole hand into a boiling pot on your stove. Limit the amount of time that you remain in the tub to no more than 15 minutes. Also, be sure that someone else is at home with you when you use the hot tub — preferably, *in* the tub with you.

Rubbing Out the Problem: Massage Therapy

Except when you're in excruciating pain, massage therapy is a treat! A mild massaging of your aching muscles and other tender areas of your body can be helpful, whether the massage is performed by a professional massage therapist or by your loving partner or a friend. (A professional is preferable, if you can afford it or, even better, if your health insurance covers it.)

If no one's available to provide you with a massage, you may choose to use a mechanical massager. Be sure to set such devices to the low or medium setting to start with. The high cycle may be far too vigorous for a person with fibromyalgia. And read the instructions on the device before you apply it to your body.

Sometimes, either heat or cold therapy is combined with massage therapy in an attempt to amplify the relief that's provided. For example, you may lie on a heating pad while the massage is being provided. Or you can take a hot bath at home and have your partner provide you with a gentle massage afterward.

Realizing that it's not a cure, but it can be helpful

A gentle to medium massage treatment can't cure you of your fibromyalgia, but it may ease your pain for a few hours or even a day or so. When it works, massage can stimulate the production of *endorphins,* natural pain chemicals that travel to the hurting parts of your body and provide relief — somewhat like soldiers in the cavalry, rushing in to help the besieged troops at the fort. But these endorphins only stay in the bloodstream for so long. Massage therapy clearly can be very useful for some people who have fibromyalgia, but it's a therapy that needs to be repeated on a regular basis in order to continue the benefit. Massage may be exactly what you need to get you through these challenging periods when the pain is strong but you need to keep going.

A study of the effects of massage on the painful areas of people with FMS (reported in a 1999 issue of the *European Journal of Pain*) revealed that subjects who received 15 massage sessions over ten weeks received significant pain relief. In fact, the 23 people in the treatment group who received massage therapy were able to reduce their use of painkilling medications.

However, the improvement for the fibromyalgia subjects who felt better from massage was only a temporary reprieve, and six months after the treatments ended, most of the pain had returned again.

Diana is a long-term fibromyalgia sufferer, and she's also a major massage-therapy fan. She says that massage has been such a godsend in keeping her from completely stiffening up. But not everyone feels so positively about massage and its value. Lauren, another person who's had FMS for years, says that massage therapy has helped her somewhat, but she also warns that massage is extremely short-term help. She says that she'd really need to *live* with a massage therapist in order for it to be both affordable and realistic for her. Because that's obviously not practical, she's foregoing massage therapy.

Finding a massage therapist

Interested in finding a good massage therapist, but not quite sure where to begin to look for one? You can try starting with the Yellow Pages of your local phone book, but that's usually not the best place to begin your search. Why not? Because such a cursory search can't give you the opportunity for some preliminary screening options, like the kind you'll get when you ask your doctor, friends, and others for recommendations. Also, the therapist with the biggest advertisement in the phone book isn't necessarily the best one — although he *may* be.

Asking around

Here are a few ideas to get you started in identifying a massage therapist:

- **Ask your physician if she can recommend anyone who performs massage therapy, or if she knows anyone else who may be able to recommend someone.** Also, ask your doctor's nurses if they know of anyone who performs massage therapy.
- **Ask your friends and co-workers if they can recommend a massage therapist.** Depending on your friends, this question may get you a little — or maybe a lot of — teasing.
- **Contact fitness centers in the area.** Often, members who are into exercising big time also enjoy receiving massages for their aching muscles.

TIP

Another way to locate a massage therapist in your own backyard is to contact the American Massage Therapy Association, a national organization of therapists. If you live in the United States, you can call them toll-free at 877-905-2700. If you're not a U.S. resident or simply prefer the Internet, you can go to their Web site (`www.amtamassage.org`) to search for a local massage therapist.

Screening the therapist

After you find some candidates, what next? If your state requires professional licensing, as many states do, ask the massage therapist if she's licensed. And ask to *see* the license if you do go for an appointment — just to be safe. (People who are actually licensed are very proud of that fact. They're not hesitant to show you the license, and most of them have it on display on the wall.)

Ask the following questions to the massage therapist you're considering, adding your own questions to this list of suggestions:

- **Have you treated people with fibromyalgia before?** If you get a blank look or complete silence, that's not a good sign. Move on to someone else who is at least familiar with the term.

  If the therapist says he *has* treated people with FMS before, ask him to describe the treatment that he provided. Also, about how many times did those patients receive massages? (You're looking to find out whether this therapist has had any repeat/satisfied customers who have fibromyalgia.)
- **Do you believe in very vigorous massages only?** If the answer is *yes,* that's the wrong answer for the person with fibromyalgia. Some people gain some benefit by having their bodies pummeled. You won't, and extremely vigorous massage may cause your pain and other symptoms to flare up.

- **Are you associated with a doctor, chiropractor, or other medical professional in the area?** The massage therapist may have her own business, but most have some sort of relationship, even if not a financial one, with a medical professional. If the person says that she works with patients of Dr. Smith, call Dr. Smith's office and find out whether he's ever heard of her.
- **Is your service covered by health insurance?** Maybe nobody in your area is covered, but this question is still worth asking. Also, you may be pleasantly surprised and find out that your insurance company actually will pay for a part of the therapy.

Not everyone can tolerate massage therapy, even when it's gentle. Louise, who has had FMS for several years, works part-time as a massage therapist herself, but she says that massage has actually made her fibromyalgia much worse. Louise has completely given up on this form of therapy for herself. She knows that massage therapy helps some people a great deal, but for her, it just doesn't work.

Forming a non-aggression pact with your massage therapist

Be sure to make it very clear to anyone who massages your muscles — whether that person is your partner, a friend, or a trained massage therapist or physical therapist — that he must take it slower and easier with you than he normally would with people who don't have fibromyalgia. You absolutely don't want an aggressive form of massage therapy.

The reason: When people with FMS get a very active and painful massage, that massage can be a self-defeating experience that results in a flare-up of pain. You may end up feeling much worse when you leave than you did when you came in.

If the therapist can't comply with your request for a gentle massage, ask the facility for another person to provide your massage. Or you may want to just "vote with your feet" and go someplace else.

If your therapist asks whether you want the Swedish massage or the deep-tissue massage, choose the Swedish one because it's the gentle massage option.

If the massage therapist tells you that the massage may result in a little bruising, do not proceed! Any massage that causes tissue damage is a very bad idea for a person with fibromyalgia (and not such a great idea for a person who *doesn't* have FMS).

No shoes, no shirt, service

Don't assume that you'll need to go totally naked to receive massage therapy, although if you're having a full-body massage, you may need to strip down. Your body will be draped, and only the part that the therapist is working on will be uncovered. In most cases, the uncovered area doesn't include any erogenous zones, such as women's breasts or the genitals of men or women. Instead, you usually keep on your underwear, and the areas not being massaged (such as your upper or lower torso) are covered with a sheet or a towel. If the therapist tells you that you *must* strip and you don't want to, simply refuse. You may have inadvertently stumbled into the wrong type of massage facility.

WARNING!

Never allow anyone to walk on your back. Doing so can cause serious damage as well as long-lasting pain.

Magnetically Decreasing Your Pain: Transcranial Magnetic Stimulation

Simple magnets don't provide much relief to people with fibromyalgia. But transcranial magnetic stimulation (TMS) may provide significant hands-on relief, although research is still actively ongoing and TMS is not yet officially approved by the Food and Drug Administration (FDA) for any medical disorders. TMS is an experimental therapy, and is only available now at major medical-research centers or in clinical trials. It is primarily used to treat long-standing and resistant depression, but some very preliminary research indicates that TMS may help people with fibromyalgia, too. Read on.

What it is and how it works

TMS is the use of powerful magnets targeting the brain's cortex. A surface coil is applied to the scalp, and it generates magnetic fields, which in turn create electrical currents that travel to the brain. Nerve cells that are related to mood are stimulated, which can improve mood and may decrease chronic pain. You may feel as though you're hearing a tapping noise during the treatment, which lasts about 30 minutes.

Slow-frequency and repetitive TMS has been demonstrated effective in decreasing the pain of fibromyalgia in a tiny sample of four women, published in a 2006 issue of *Pain Medicine*.

If your partner provides the massage

Suppose that you can't afford a professional massage therapist, or just don't want to for some reason. But your very own loving partner is ready and willing to give you a back rub or to massage other sore parts. Should you let her provide a much-needed massage, even if she has no training? That question is really up to you.

If you decide that the answer is *yes,* follow some simple guidelines, provided here. Also remember that an adult should perform the massaging. Don't expect your child or teenager to give you regular massages. Placing a child in such an adult role is unfair.

- **Be sure to tell your partner before any massaging starts that a little discomfort is normal when painful areas are probed.** But if it *really* hurts, it's time to immediately cease and desist with massaging that body part.
- **Tell your partner to keep the massage brief.** He'll probably tire fairly quickly anyway, but try to go for 15 to 20 minutes max.
- **Advise your partner to provide a light and nonbruising massage.** The key is "non-painful."
- **If your partner massages your body with electric devices, be cautious.** Always start on the low end of the machine's capabilities. You probably won't be able to tolerate the high levels.

The procedure may cause a mild headache and some numbness and tingling at the site where the coil was placed. However, if significant pain relief occurs, such side effects are well worth it!

Who should avoid TMS

Some individuals should definitely *avoid* TMS treatment, including people who fit the following categories:

- Those with chronic migraines
- Those who have had brain surgery
- Those with a family history of epilepsy or seizures
- Pregnant women
- People with cardiac pacemakers or other electronic devices

An Electrifying Solution: Transcutaneous Electrical Nerve Stimulation

Transcutaneous electrical nerve stimulation (TENS) is a machine-based therapy that's designed to deliver low-level electrical impulses to body areas that are in pain or spasm. The goal is to stimulate the nerve tissue to naturally release pain-fighting body chemicals. This treatment is used to help people with fibromyalgia, arthritis, and other medical conditions.

Although few clinical studies have backed up the usefulness of TENS, some people report that they gain relief from this treatment. TENS is a noninvasive form of therapy that may work as well for you as it has for others.

TENS therapy is usually not used in isolation; instead, it's combined with other pain-relieving techniques or with medications. You may also want to use periodic heat- or cold-therapy or massage along with your TENS treatments.

The working theory behind TENS

Here's the basic theory to explain why TENS may help people who experience chronic pain: When painful areas of the body are directly stimulated with regular bursts of a very mild electrical current over a short time, these hurting areas of your body are thought to respond to this electrical stimulation by releasing *endorphins* (pain-reducing chemicals in the brain).

These pain-busting chemicals, now thoroughly aroused to action by the external electrical stimulation of the TENS equipment, theoretically rush to the rescue, eventually causing a reduction in both your pain and muscle stiffness. Believers in TENS therapy also think that the stimulated area isn't the only part of the body that responds to the therapy, but that the brain itself also reacts to these periodic electrical impulses, and the end result is diminished pain.

What happens during therapy

The physical therapist — or whoever's administering the TENS therapy to you — will apply special small patches with electrodes to your skin directly on the particular areas of your body that are bothering you the most. These patches are connected by wires to a TENS machine. The machine delivers regular, periodic, and painless pulses of electricity (about 80 to 100 low-level pulses per second). Sessions typically last about an hour.

You usually need a calibration in the first treatment, during which the operator will send signals of varying intensity to you to determine when you start to feel anything. People vary in how strong a signal they need; a signal that's weak to other people may be just right or even too strong for you. The goal is for you to feel the electrical impulse but *not* feel any pain from it.

During the session, you merely lie or sit down and have your painlessly electrifying experience. Don't worry — TENS therapy is nothing like the jolt from a cattle probe or some other painful electrical device, nor is it anywhere near as unsafe. In fact, the electrical impulses emitted by TENS are completely painless. Some people fall asleep during the treatment.

Doing TENS to yourself

Some people purchase or rent portable TENS units, so that they can receive the treatment at home. Your insurance company may be willing to reimburse you for this expense, but you should be sure to check ahead of time before you spend your own money.

The insurance company may have limitations on how much money it'll reimburse you or what types of equipment it'll approve. It would be a shame if you bought your TENS unit from a particular company, not knowing that your insurance company will only pay for a TENS device from some other company.

The main benefits of having a TENS unit at home are that you won't have to drive to you doctor's office or physical therapist's office to receive treatments, and you can manage the treatment yourself in the privacy of your home. You can also arrange to have the treatments during a time that's convenient for you, rather than when you can manage to get an appointment.

The downside of using a TENS unit is that you're probably not trained in this therapy, and you'll have only the written manual that accompanies the unit to go by. If you experience any problems or discomfort, you won't know if it's normal or abnormal.

Another disadvantage is that TENS units come from many different manufacturers, and deciding which unit is really the best one for you can be difficult. Some units may be hard on the pocketbook, especially if your health-insurance company gives you the thumbs down on reimbursing you for the cost of the unit.

Bedding down in comfort

Some experts say that your choice in bedding is very important when you have FMS. Because you're prone to pain, you may need a special mattress cover like an egg crate or one made of lambs wool or a material that breathes (you don't want to become sweaty at night and make the whole problem worse) and provides extra padding at night. Most people with fibromyalgia have problems sleeping at night, so a comfortable bed is very important.

Considering Chiropractors

Many people with arthritis or fibromyalgia find small to considerable relief at the hands of a *chiropractor,* a practitioner who manipulates the bones and muscle tissues in an effort to relieve pain and stiffness. A chiropractor is not a medical doctor; instead, a chiropractor is a licensed professional who's received specialized training regarding the bones and nervous system.

Chiropractors operate in nearly all states, and many insurance companies provide at least partial medical coverage for their treatments. You may need to get approval from your insurance company before the chiropractic treatment may begin, so be sure to check first.

REMEMBER

Although most chiropractors are well aware of the need for gentleness when treating FMS patients, if you consult with a chiropractor, you may want to remind him that you need to go slow and easy before any treatment begins.

After your diagnosis of FMS has been made by the chiropractor, or she has been informed by you or your doctor that you have fibromyalgia, you should receive a plan of treatment. Massage therapy is often an integral part of the treatment plan of most chiropractors for treating many different medical problems.

Tell the chiropractor about any other medical problems that you may have in addition to your fibromyalgia, such as arthritis, heart disease, osteoporosis, and so forth. This information is important to help tailor your treatment, guiding the chiropractor to go more easily in areas of the body that may be weak.

Be sure to ask the chiropractor the following questions, to which you should add any other questions relevant in your particular case:

- **About how many treatments per week will I need?** The chiropractor should be willing to answer this question without any hesitation, although she may say "about two or three," or "about four or five," or some other approximation.
- **About how many weeks of treatment will I need?** You may have a more difficult time getting an answer to this particular question, but ask it anyway. To be fair, the chiropractor can't really know how many treatments you may need at the beginning of treatment. But he should be able to give you at least a guesstimate. Of course, because fibromyalgia is a chronic illness, treatments will usually be ongoing. More treatments are usually needed at the onset of treatment.
- **About how many treatments will it take for me to know whether the therapy is working?** This question is another tough one for the chiropractor to answer at the beginning. But ask anyway. You need to know for your own planning. For example, if the chiropractor plans to treat you for six months or longer, but you don't ask and merely assume that treatment will take a month or so, eventually you'll be dissatisfied. It's better to know upfront what may be expected down the road.
- **What can I hope to get from this treatment?** If the chiropractor promises you immediate and/or complete relief from your fibromyalgia with her treatments, watch out. Most ethical chiropractors will hope to give you significant relief and improvement in your pain problem, but they won't give you guarantees that you'll be cured.

In addition, make sure that you see the chiropractor's state license. It should be prominently displayed, along with his college degrees and other credentials that are up on the wall. If you can't find the state license on the wall, ask to see it.

Chapter 12

Considering Alternative Remedies and Treatments

In This Chapter

- Knowing whether an alternative therapy can really help you
- Using herbs and supplements
- Pinning your hopes on acupuncture
- Hoping for relief with homeopathy
- Getting Botox injections
- Trying tai chi

Millions of people rely on alternative remedies and treatments to help them with their chronic ailments, and patients with fibromyalgia syndrome (FMS) are even more frequent users of alternative therapies. A study of 13,792 patients with fibromyalgia (reported in a 2007 issue of *Arthritis & Rheumatism*) revealed that 56 percent had used some form of alternative medicine, compared to 21 percent of the 41,427 people in the control group who didn't have fibromyalgia. So, if you've tried one or more forms of alternative medicine to ease your symptoms of FMS, you're definitely not alone!

Whether alternative therapies come in the form of herbs and supplements, acupuncture, Botox injections, or another alternative solution, many people with fibromyalgia fervently hope that they'll work. Sometimes, people find that these remedies work very well — or at least *seem* to.

Other people have spent their hard-earned dollars on what turned out to be ridiculous remedies. They may have known or suspected that these remedies would never work, even when they purchased them. But they felt so bad and urgently craved some relief. When you're in major pain and you can't sleep, and a late-night infomercial is advertising some Super-Fabulous Pain Relief Stuff with Grapefruit Peel Essence, you may think, "What if it actually works? After all, the guy in the infomercial feels great!"

Bonnie is one person who's fallen for some phony cure-alls. She says that she's tried coffee enemas, and has spent thousands of dollars on supplements, all of which ended up in the trash. Bonnie says that all the purveyors of alternative remedies said that they could cure her — but they were all wrong.

Don't count out alternative remedies altogether. This chapter helps you separate alternative therapies that work — or *may* work — from snake-oil solutions that you don't want to spend your money on. When studies are available to back up a form of treatment, I briefly describe them. If a particular alternative remedy has no clinical studies so far, I discuss the treatment from a logical viewpoint.

For further information on alternative medicine, go to the Web site of the National Center for Complementary and Alternative Medicine at `http://nccam.nih.gov`. You can read more on such topics as acupuncture, dietary supplements, herbs, and other choices.

Thinking Through Alternative Remedies

How can you know if an alternative remedy — whether it's an herb or supplement, acupuncture, or another therapy not considered "mainstream" by your doctors — may help you combat your fibromyalgia symptoms?

Here are some basic questions to ask yourself about an alternative therapy (whatever it may be) before you try it:

- **Does the promoter promise that this remedy is an instant cure?** If the answer is "yes," this response is a red flag. Fibromyalgia has no quick fixes. Maybe one will be found someday, but it's not here yet.
- **Do you know anyone who has gained relief from this remedy? If so, how long has he tried it?** Often, what seems to work wonderfully for a week or two proves useless in the end. Often, however, the desire to get better can be so strong that, sometimes, people believe a new remedy will really work, and they actually feel better. This placebo effect usually wears off after a while, though.
- **Is the person promoting the remedy also selling it?** She may be a true proponent, but when she has a financial incentive, think harder before buying the remedy.
- **Have any recent studies been done on this therapy? If so, were they performed by medical doctors on at least 100 subjects?** Read the *abstract* (summary) of the study. You can read medical abstracts for free on PubMed, the National Library of Medicine's database at `www.ncbi.nih.gov/entrez`.

- **Is this therapy safe? What risks are involved?** If the person promoting the therapy says that the therapy has no risks whatsoever, be skeptical. Whatever therapy you try most likely has at least *some* risk, even if it's minimal. You need upfront knowledge of side effects and risks, even if they're unlikely to occur.
- **How much is this therapy or treatment going to cost you, and how long will it last?** The price of a remedy that may be iffy, and how lasting its effects will be, should both be key factors in your decision whether to try a therapy or forego it.
- **Would this remedy interact with other drugs that your doctor has prescribed? Also, would your doctor disapprove of it?** The best way to find out is to ask your physician. (She may surprise you, and say that the treatment's a good idea.)

Fighting Fibromyalgia Naturally with Herbs and Supplements

Can taking herbs or supplements make you feel better? When it comes to fibromyalgia, most clinical studies don't show significant effects. Keep in mind, however, that all herbs and supplements can have adverse effects on your health by interacting with other medications you take or by worsening medical problems that you already have, so always consult with your doctor first before taking any herb or supplement.

Don't forget that you can also combat FMS in more conventional ways. Be sure to read Chapter 9 on over-the-counter remedies that may help you resolve your fibromyalgia symptoms. Read Chapter 10 to find out about prescribed drugs that may help you.

Notifying your doctor about your natural choices

Studies have indicated that many people who decide to try herbal remedies or supplements never discuss that choice with their doctors. Maybe they forget to mention it when they see their physicians. Maybe they (wrongly) assume that all "natural" remedies are somehow automatically safe and, therefore, they don't need to tell the doctor about them. Or, maybe they're afraid that the doctor will tell them they should stop taking it.

Whatever the reason, it's important to overcome this qualm and inform your doctor of alternative remedies you're taking — or even *thinking* of taking. Some herbal remedies or supplements can interact significantly with other medications, boosting or diminishing their effects.

WARNING!

Don't get your medical advice from clerks working in health-food stores (no matter how knowledgeable they may sound), and don't rely solely on information provided on the label of a supplement or herb that the store is selling. Always check with your physician first before taking any alternative medication to ensure that it's safe for you.

Looking at magnesium

Everyone needs magnesium, and most people obtain this vital element in their everyday diet. However, some people are slightly (or very) deficient in magnesium, and this deficiency can lead to serious muscle pain and other symptoms. Magnesium deficiencies have also been associated with migraine headaches and other medical problems.

Some people take magnesium only (as opposed to combinations of magnesium along with other supplements). Some studies have shown that people who experience migraines and other pain syndromes may have a shortage of magnesium. Even if a person's blood-test levels of magnesium come back as "normal," that person may have a *subclinical* (slightly below-normal) level of an element. If you're subclinically deficient in magnesium, that shortage could be enough of a problem to contribute to your symptoms of fibromyalgia.

Magnesium supplements are easy to find — they're available in pharmacies, supermarkets, health-food stores, and online. Be sure to check the recommended dosage on the bottle, as well as with your physician. If you take magnesium supplements, keep in mind that magnesium is included in many over-the-counter heartburn remedies, such as Mylanta. If you have a stomachache and take such a drug, you may want to cut back on your daily dose of magnesium.

WARNING!

Avoid overdoing your magnesium intake, whether you're taking a magnesium combination or supplement. Too much magnesium can lead to a shortage of potassium or other minerals that you need. You don't want to unnecessarily create new medical problems while you're trying to resolve your fibromyalgia symptoms. Be sure to take *only* the dose that your doctor advises.

You may also find that magnesium causes looser stools or may bring on actual diarrhea. Of course, if you have a problem with chronic constipation that accompanies your fibromyalgia, as with some people who have irritable bowel syndrome, then magnesium may seem like a dream drug to you. It may ease your muscle pain, and also make it possible to have a normal bowel movement. If you're in that situation, what could be better?

Evaluating valerian

Valerian is an herbal remedy that some people take to alleviate their insomnia. (Read more about valerian and its potential impact on overcoming sleep difficulties in Chapter 14.) Valerian may act as a natural anti-anxiety drug as well. Some people take valerian for headaches.

According to the National Center for Complementary and Alternative Medicine (NCCAM), there is insufficient evidence to know if valerian really works; however, it is generally safe to use for four to six weeks.

WARNING!

This herb may cause stomachaches, headaches, dizziness, or fatigue. If you decide to take valerian for insomnia or anxiety (or both), follow the directions on the bottle. Try this herbal remedy for the first time in the evening or at another time when you won't need to drive a car, operate equipment, or do anything else that requires alertness — just in case valerian makes you sleepy.

You can find valerian in many pharmacies and supermarkets, as well as in health-food stores or online.

Watching out for dangerous remedies

Some natural remedies can be extremely dangerous, particularly some drugs that purport to help you lose weight but that are primarily comprised of highly stimulating drugs (such as ephedra, also known as ma huang). The effects of such drugs are similar to the action of an excessive level of the hormone adrenaline. These drugs may act like a nonprescription amphetamine drug, speeding up your metabolism to dangerous or even fatal levels.

In 2004, the Food and Drug Administration (FDA) banned the sale of any supplements containing ephedrine alkaloids, which are found in plants such as ephedra, Sida cordifolia, and *Pinellia.* However, prescribed drugs containing chemically synthesized ephedrine — including drugs used for the treatment of allergic reactions, asthma, or bronchitis — are not included in this ban.

Other supplements can cause adverse effects and should be avoided by some patients altogether. For example, *Ginkgo biloba* thins the blood, and people who also take blood thinners, such as Coumadin (generic name: warfarin), should not take this substance. *Gingko biloba* should *never* be taken by anyone before having surgery or a medical procedure.

Of course, women who are pregnant or think they may be pregnant should not take *any* supplements without first checking with their obstetrician. Many drugs that are generally safe, including over-the-counter remedies and supplements, can be dangerous to a developing fetus.

Getting some help that your taxes paid for

The FDA offers many helpful tips on dietary supplements, and basics to consider before taking these drugs, in their online publication, "Tips for the Savvy Supplement User: Making Informed Decisions and Evaluating Information." You can read this publication online at `http://vm.cfsan.fda.gov/~dms/ds-savvy.html`. You can also get information on specific dietary supplements at the Web site of the Office of Dietary Supplements at `http://ods.od.nih.gov/Health_Information/Information_About_Individual_Dietary_Supplements.aspx`.

If you note any negative effect that may have been caused by a supplement, call MedWatch, a toll-free service offered by the FDA, at 800-332-1088. Or you can contact the FDA online at `www.fda.gov/medwatch/how.htm`.

Pinning Down a Solution: Acupuncture

Some people with fibromyalgia announce feeling considerable relief after undergoing *acupuncture,* the careful insertion of special pins at specific points of the body by a trained practitioner. Others, however, have said that acupuncture had no effect on them, and some have reported that the experience made them feel worse.

Several key clinical studies on acupuncture have shown that acupuncture is effective against the pain of fibromyalgia. For example, in a study on fibromyalgia patients reported in 2006 in *Mayo Clinic Proceedings,* the researchers placed 25 of the patients in the acupuncture group and 25 in the control group receiving simulated acupuncture. The researchers found that the symptoms of fatigue, anxiety, and pain were significantly reduced in the acupuncture group compared to the control group. It's worth noting that some studies find that patients don't obtain significant relief from their FMS symptoms with acupuncture.

According to the Centers for Disease Control and Prevention (CDC), about 2 million people per year in the United States use acupuncture as a therapy.

Acupuncture therapy may or may not be covered by your health insurance, so check ahead of time to find out. If your health-insurance company *does* cover acupuncture treatments, keep in mind that your acupuncture sessions are far more likely to be covered when the person performing the acupuncture is a medical doctor, osteopathic physician, or nurse practitioner.

Understanding acupuncture

The Chinese have explanations about acupuncture that are fairly complicated and may make little sense to the Western mind. So here I stick to one possible explanation of acupuncture that may be feasible and more understandable to the average American. That explanation is that, if and when acupuncture works, the pins that are inserted in certain identified points may stimulate the production of *endorphins* (pain-fighting brain chemicals). When endorphins go up, pain goes down.

Because your pain actually preceded the acupuncture treatment, why weren't those endorphins already working beforehand? Didn't your body know that it was hurting and shouldn't it have marshaled your endorphins to get to work? No one knows why pain sometimes seems to get stuck in the "on" mode. But acupuncture may give your system that extra little jolt that's enough to stimulate the endorphins to rush to the hurting area.

Acupuncture is only a temporary fix at best. But then, few remedies that are associated with fibromyalgia are long-term solutions.

Finding an acupuncturist

You can ask your physician or your friends to recommend an acupuncturist, but, sometimes, they may disapprove of your plan. Even if they feel neutral or okay about it, they may not know of an acupuncture practitioner. Another alternative is to check the Yellow Pages of the phone book under "acupuncture" and look for ads there. Are any of the practitioners medical doctors? Start with them.

If you're also considering an acupuncturist who's not a medical doctor or an osteopathic physician, make sure that any individual you're considering is licensed by the state. Check with the state department of professional regulation, usually based in the state capital. Then be sure that you at least first talk to that person on the phone before going for an appointment.

WARNING!

Although many non-medical acupuncture practitioners are honest people who know what they're doing, some may regard acupuncture as an easy way to make a few bucks. You should avoid such people! People trying to get rich quick may also be very careless — in order to save money, they may reuse the acupuncture needles. Reusing needles is an absolute no-no in acupuncture therapy, because it places you at risk for contracting hepatitis or the HIV virus that leads to AIDS, as well as far too many other infectious diseases to mention. The probability that someone would take this risk seems low, but you need to consider worst-case scenarios and protect yourself as much as possible.

No needling me!

Acupressure is a form of therapy that uses direct pressure in the same areas as acupuncture, but it doesn't penetrate the skin like the pins used in acupuncture do. Instead, noninvasive (and non-painful), firm pressure is applied. For areas that you can't easily reach, such as your middle or lower back, some people suggest that your acupressurize yourself by lying on top of a tennis ball and moving around on it.

I'm not saying that the *only* good acupuncturist is a person with a medical degree. I'm just saying that you should put on your best skeptical thinking cap and your good listening ears, and ask plenty of questions before signing up for acupuncture treatments with someone who isn't a doctor. (Actually, you should also ask plenty of questions even if the acupuncture practitioner *is* a medical doctor.)

Some questions to consider asking an acupuncturist — whether the person is a doctor or not — are

- **How long have you been performing acupuncture?** More than a year would be desirable.
- **Are you affiliated with a medical doctor or a chiropractor?** "Yes" is better than "no" because it means that someone is at least periodically checking on the acupuncturist. You should also verify with the doctor or chiropractor that she does, in fact, have a business relationship with the acupuncturist. Don't just take the acupuncturist's word for it.
- **How many sessions will it take for me to feel better, if acupuncture works for me?** If the acupuncturist says daily for weeks, that's too many. At most, several times a week at the start of therapy should be sufficient to start to gain relief. Later, weekly sessions may be sufficient.
- **Do you guarantee that this procedure will make me feel better?** If the person says "yes," leave. No competent person will issue blanket guarantees.

To get a listing of medical doctors and osteopathic physicians in your area who perform acupuncture on patients, contact the American Academy of Medical Acupuncture at 323-937-5514 or search its Web site at `www.medicalacupuncture.org`.

Homing In on Homeopathy

Homeopathy is based on a 19th-century belief that minute amounts of herbs can stimulate a healthy reaction in the body. Often, homeopaths rely upon a mixture of a variety of herbal remedies to treat various chronic medical problems.

In 2001, the National Institutes of Health (NIH) awarded a grant to study the effectiveness of homeopathy to the Society for the Establishment of Research in Classical Homeopathy (SERCH) in Phoenix, Arizona. They conducted a two-year study to determine what type of individuals respond best to homeopathy. In this study, published in 2004 in *Rheumatology,* the researchers described some of their findings, based on treating 53 FMS patients with individually chosen homeopathic remedies versus those given a placebo. The researchers found that the patients receiving the homeopathic remedies experienced significantly greater improvements in pain and the number of tender points, as well as in their quality of life and overall health.

Would homeopathy work for you? Possibly. But in my opinion, it's best if you try other treatments first — beginning with mainstream medical treatments and medications, followed by massage, then acupuncture and/or herbal remedies and supplements, and then Botox injections. If you've tried all these other treatments (in the order I mention them), and you're still not getting relief, then you may want to try homeopathic remedies.

Many people purport to be homeopaths, but do some basic checking. Does your state require the licensing of homeopaths? If so, check with the licensing bureau or the state health department for a list of licensed individuals in your area. You may also check the Yellow Pages of your phone book and contact individuals directly. Ask them:

- ✓ **How long have you been in business?** It should be at least three to five years, to show a track record.
- ✓ **Are you state-licensed?** Check with your state health department to see if licensing is required, and only ask this question if it is.
- ✓ **Do you treat fibromyalgia?** If the person says, "What's that?", move on to the next candidate.

Beating Fibromyalgia with Botox Injections

One of the newer and somewhat controversial remedies that doctors sometimes use to treat people with fibromyalgia is the injection of Botox. *Botox* is a form of the *botulinum* toxin, which is a kind of a poison that's created by a specific bacterium, *Clostridium botulinum.* At least seven or eight different forms of Botox are used to treat a wide array of medical problems.

The doses of Botox that are used are considered to be small enough to avoid harming the patient, but, at the same time, they're also large enough to provide noticeable results with a problem of the nervous system or the musculoskeletal system.

Physicians use Botox to treat many different types of medical problems, such as tremors, tics, stroke, cerebral palsy, multiple sclerosis, chronic low-back or neck pain, chronic headaches, and a wide variety of other medical conditions. Some plastic surgeons also use Botox to cosmetically (and temporarily) rid people of their facial wrinkles.

Physicians who are open to using acupuncture, as well as other alternative treatments, may also be more open to using Botox therapy. Doctors who are pain-management experts and neurologists are probably more likely to consider using Botox therapy, although there's no uniformity on which particular specialty of doctors use Botox on their patients and which don't.

Doctors who treat patients with Botox injections should have previous experience with using this therapy, particularly when using Botox with their patients who have fibromyalgia and who are very pain sensitive. Don't let someone practice on you! In addition, the physician should also be someone whom you can fully trust with using this relatively new form of therapy on you.

In the hands of an inexperienced and incompetent practitioner who may inject too high a dose or make other medical errors, Botox treatments can theoretically cause a temporary paralysis or even result in more severe harm to some patients. This risk is yet another reason to make sure that you receive your Botox treatments only from a doctor knowledgeable and experienced in the procedure.

Botox and fibromyalgia

Botox treatments for people with fibromyalgia are a relatively new form of therapy. But Botox use may explode in the next few years, particularly if both clinical research and patients' word of mouth indicate that Botox can provide the pain relief that patients so desperately want and need. In fact, it could *really* take off if the prices come down.

Joseph Kandel, MD, a neurologist and the medical director of Neuroscience & Spine Associates in Naples, Florida, has treated numerous fibromyalgia

A healthful bacteria

Most people spend a lot of time trying to *avoid* bacteria, carefully washing their hands with antibacterial soap, taking daily baths or showers, and trying to keep their bodies and their clothes as clean as they can. For the most part, bacteria are seen as being bad and something to avoid. Botox is created by bacteria, so the idea of injecting it into your system may make you feel a little squeamish. It may almost sound like injecting dirt into your body.

Yet, when you really think about it, not all bacteria are bad. Here's one simple example: Bacteria in your stomach enable you to digest your food more easily by helping to break it down. When you take antibiotics to combat an infection that you have (such as a strep throat or a urinary tract infection), those bacteria may be killed, or at least weakened, and thus, you get diarrhea and can't digest your food as well.

You may also develop a yeast infection while you're taking antibiotics because the bacteria that were killed by the antibiotic were also the ones that had previously kept the yeast at bay. They're gone, so the yeast can proliferate. So, it's not exactly true that the only good bacteria are dead bacteria.

patients with Botox treatments. Dr. Kandel says that Botox injections can be quite successful in treating the muscle changes, muscle spasms, and the general spasticity that many patients with fibromyalgia experience.

Dr. Kandel says that the relief that's provided by a Botox injection may take 7 to 21 days to start working; however, many patients get some pain relief within a few days because of the acupuncture effect of the needle. When it starts working, the pain relief from Botox injections may last anywhere from a few weeks to a few months, depending on the individual patient. During that temporary period, patients may experience at least a partial reprieve from their severe pain, allowing them to exercise and increase range of motion and muscle function. These actions can then help patients to prevent, or at least delay, a further flare-up in problem areas.

Using Botox in pain management is a relatively new application. The use of Botox in fibromyalgia has not been sufficiently studied in clinical tests to determine whether it's a useful therapy. Doctors who do favor Botox say that it works for most, but not all, of their patients. So don't expect any guarantees if you sign up for Botox injections. (For that matter, don't expect guarantees with any other medical procedures that you receive, either.)

As of this writing, the FDA hasn't approved Botox injections to treat chronic pain from fibromyalgia or any other chronic-pain condition. This approval may come in the near future, but it's not here yet. Despite this fact, doctors may still legally administer the injections.

How much Botox costs and whether insurance pays

If you're currently considering Botox therapy, keep in mind that this form of therapy is generally not a low-cost option, and if you have a shortage of dollars, you may not even be able to afford it. In general, Botox is more like the upscale, probably-not-covered-by-your-health-insurance form of treatment. Always check first by simply calling and asking your insurance company if Botox treatments are covered. If and when the FDA approves Botox as a therapy for chronic pain, more health-insurance providers will likely cover such treatments.

Most patients need to receive at least two vials of Botox to gain a sufficient amount of the substance to obtain relief from their chronic pain, and one vial costs about $600. As a result, in considering all the costs involved, a Botox procedure can cost at least $1,200 — and the price can go much higher than that.

However, proponents say that when Botox injections work to resolve symptoms, patients won't need lots of doctor visits, and they can also avoid taking many doses of pain medications and, thus, avoid enduring their side effects. Looking at it from that point of view, Botox injections may be cost-effective treatments for some fibromyalgia patients.

Taking On Tai Chi

The gentle art of the basic Chinese exercise movements of tai chi are usually not overly difficult to master, and generally these movements can also be a very good form of exercise for people who have fibromyalgia or other chronic-pain problems. According to the CDC, about 5 million adults in the United States have tried tai chi and 2.6 million have used it in the past year.

The basic exercises of tai chi are meant to resemble natural animal movements, such as movements that may be made by a crane, a tiger, a snake, or other animals. For example, one simple tai chi movement involves standing on one leg as a crane would.

Tai chi helps patients with FMS in two basic ways: The exercises are relatively easy to perform for people with muscle problems who find it difficult to perform more arduous exercises. Also, the exercises can help with relaxation, in a meditative sort of way.

Nerving yourself for neurotherapies in the future

A number of new treatment techniques are emerging that change the way the brain responds to pain without medications. They are called *neurotherapies,* and research is showing them as promising. The idea behind neurotherapies is that abnormal brain activity is one of the fundamental issues behind pain and sleep problems in FMS. Theoretically, if that abnormal function can be corrected, symptom improvement should follow.

For example, *neurofeedback* is a treatment option that enables users to consciously modify their electroencephalographic (EEG) brainwave patterns. Research has shown that patients with fibromyalgia have abnormal brainwave patterns, and the more severe their pain, the more abnormal the EEG pattern problem. The idea is that, when abnormal patterns are identified, subjects can use neurofeedback to modify them in a positive way, leading to improvements in their fibromyalgia symptoms.

Neurofeedback, a technique pioneered by NASA, is different from biofeedback (described in Chapter 13). With biofeedback, users concentrate on lowering their blood pressure, pulse, and body temperature to achieve a relaxed state. In contrast, with neurofeedback, users try to change their actual brain waves, with expert assistance.

Physicians and other experts who support neurofeedback as a treatment for fibromyalgia and other chronic pain problems say it can be highly effective. The International Society for Neurofeedback & Research (`www.isnr.org`) is an organization promoting education and research for neurofeedback. A section of its Web site is dedicated to information for patients and families.

Neuromodulation is another high-tech treatment option for FMS patients, and one that does *not* rely upon feedback, as do neurofeedback and biofeedback. Instead, tiny electrical signals non-invasively target and correct abnormal brain activity. During neuromodulation therapy in a doctor's office, the patient rests in a comfortable chair. A few sensors are placed on the scalp near areas of the brain that are functioning abnormally. The sensors rest on the scalp and nothing pierces the skin, so there is no pain or discomfort. When the sensors are in place, patients close their eyes and relax. A trained clinician uses special neuromodulation equipment to monitor the patient's EEG and deliver the targeted neuromodulation signal. The process lasts about 15 minutes. Usually a few weeks of therapy with visits twice a week are needed.

Tai chi movements are also considered low-impact exercises, so they generally involve very little risk for the person who's practicing them. In fact, tai chi exercises are even recommended for elderly and sick people who are living in nursing homes — so how hard can they be for the rest of us? You may also find that regular practicing of the basic tai chi exercises may considerably ease your pain and fatigue.

How do you master tai chi? You can often take classes on tai chi movements at a community center or at your fitness club; check your local newspapers for mentions of classes. You may also want to supplement your knowledge with *T'ai Chi For Dummies,* by Therese Iknoian (Wiley), a helpful book that can show you all the ropes.

Repelling Magnet Therapy

Some people believe that using magnetized necklaces, bracelets, earrings, or even magnetic bed mattresses — as well as magnets in many other forms — can somehow decrease their pain. Sadly, a review of the existing evidence on magnet therapy indicates there is little evidence that static magnets provide significant pain relief for people with fibromyalgia or other diseases with chronic pain. It would be nice if they did, but the truth is, they simply don't work. However, read about transcranial magnetic therapy (TMS) in Chapter 11. This emerging therapy may actually help patients with FMS.

Be a skeptical reader when you come across ads or even articles about non-traditional therapies, particularly when you read about claims for "magnet therapy." Despite the dramatic ad copy, complete with testimonials, and despite rhetoric that sounds really scientific (although it's usually written in such a way that few people could make sense out of it), keep in mind that magnet therapy is a no-sale when it comes to pain relief for fibromyalgia.

If you use magnets to help your pain, fatigue, and other symptoms of fibromyalgia and find that you *are* feeling better, you're most likely experiencing the *placebo effect.* In other words, you intensely hoped and believed that the therapy would work for you, and so, for a short time, your fervent desire for symptomatic relief seemed to make magnet therapy improve your condition.

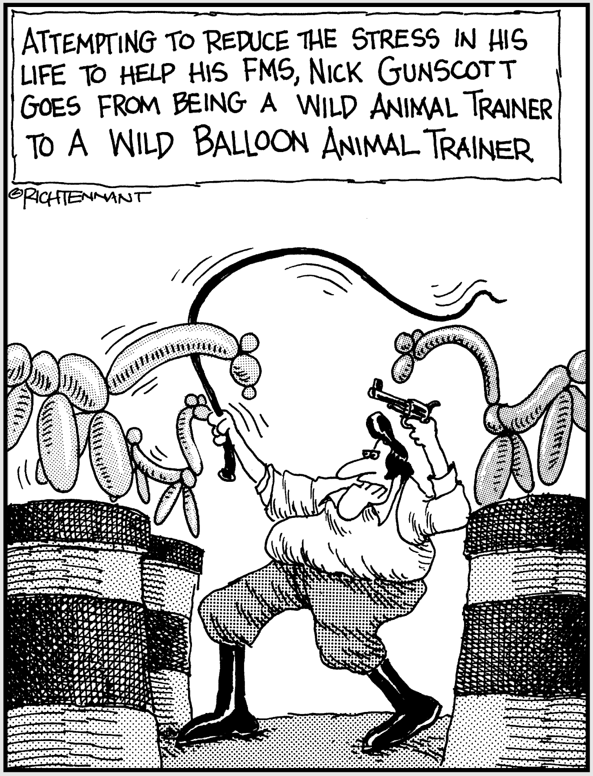
After a while, however, your mind and your pain will both overcome your wishful thinking, and you'll be right back to where you started: hurting again (minus the money you spent for all the magnetized paraphernalia).

Will magnet therapy hurt you in any way at all? Probably not. No evidence suggests that using magnets will be harmful to you — *unless* you decide to substitute magnet therapy for your medication or for other treatments that can provide you with real pain improvement.

Part IV

Modifying Your Lifestyle: Small Changes, Big Results

The 5th Wave By Rich Tennant



In this part . . .

Many people want to get rid of their pain and the other symptoms related to fibromyalgia even more than they can by simply taking medications. They want to be proactive. I agree! I recommend plenty of good lifestyle changes for patients with fibromyalgia, and I include them all in Part IV. For example, most people with fibromyalgia are hyperstressed, much more so than the average person without fibromyalgia. Reduce the stress, and you ease your symptoms, which is why I devote Chapter 13 to "depressurizing" yourself.

Increasing your amount of quality sleep time is another good lifestyle change. Many people with fibromyalgia are insomniacs or have other sleep problems, which worsens their symptoms. I address these issues in Chapter 14. I also cover the importance of exercising (yes, I *do* have to discuss this, and yes it helps), paying attention to weight issues, and avoiding foods that can trigger symptoms. You get all this in one chapter: Chapter 15. Then I discuss your emotions, which are often run pretty ragged from the pain, fatigue, and other symptoms. So I tell you what to do about those emotional troughs in Chapter 16.

Chapter 13

Depressurizing Yourself: Controlling the Stress-Eyed Monster

In This Chapter

- Knowing when you're stressed out
- Relaxing with relaxation therapy
- Using biofeedback therapy to beat stress
- Trying out hypnotherapy
- Using meditation, yoga, or prayer to take your troubles off your mind

Did you ever think that you'd need help with relaxing? Can you simply just let go and relax yourself at will — take a vacation, go see a movie, do something else that you enjoy so that you make the stress evaporate like the dew before the morning sun? It'd be wonderful if unwinding from life's stresses were that easy. But often, it's not.

Most people really don't know how to relax. They may *think* that they know how, but often, the means that they choose to relax themselves can be useless or even harmful.

If you think that I'm exaggerating, let me give you a few common examples of some of the major means that people use to "relax": drinking alcohol, gorging on chocolate cake (or chocolate anything), going to visit the in-laws. (Just kidding about that last one, which is actually a stress creator for many people!)

In this chapter, I explain several effective ways that you can relax by using various stress-busting techniques. When you use these techniques to de-stress, you also help to diminish your fibromyalgia syndrome (FMS) symptoms — because stress and fibromyalgia *are* related.

The stress-pain connection in fibromyalgia

Studies indicate that people with fibromyalgia are much more prone to suffering from stress than other people are, and that this increased vulnerability to stress worsens their fibromyalgia-related pain. One study, reported in a 2001 issue of the *Annals of Behavioral Medicine,* asked 101 women, including women with fibromyalgia and women with severe knee pain from osteoarthritis, about their stress. The researchers found that the women with FMS reported much greater levels of stress than the women with severe osteoarthritis.

In a related study, researchers purposely *caused* the women with fibromyalgia and those with osteoarthritis to experience stress by having them discuss stressful events. The researchers found that the women with FMS experienced increased pain with stress, but the women who had osteoarthritis were not similarly affected. Stress doesn't *cause* pain, but for women with fibromyalgia, it clearly can make it much worse.

Knowing When You're Too Stressed

Maybe you don't think that you're really all that stressed out, or at least no more than most of the other people you know at work or at home. But, sometimes, when people feel the same bad way for a long time, they don't even realize that they could feel better — sometimes, much better. This skewed perspective is certainly true for overly stressed people. You may have forgotten what feeling plain-old normal is like. How do you know?

Reading through the following list can help you determine just how stressed you are. This list isn't really a test, where you answer true or false, and then I tell you exactly what to do based on your answers. But it should get you thinking about how much stress you really have in your life.

- **I frequently berate the driving of other people when I drive. They all drive like total morons.** If you spend most of your driving time ridiculing the driving of others, and screaming and yelling at these people who can't hear you, you're probably stressed out. Sure, some of the drivers are probably annoying or even incompetent. But most of them are, at least, average. Maybe the real problem is your own underlying stress, which you're taking out on others who can't argue back.
- **Nearly every morning when I wake up, I'm worried about whether I'll be able to get everything done.** If your first thought upon waking up in the morning is to worry about getting all your many tasks done, you're not hitting the day running. You're hitting the day crashing and burning. Everyone worries sometimes. But you need to take a moment to chill out, including in the a.m.

- **I feel like everyone is demanding too much of me, and I'm being torn apart.** You may feel like your partner wants things from you, your family members are demanding other things, and your boss wants something else. You feel like the rope in a game of emotional tug-of-war. That's stress.
- **If my boss asks me to do just one more thing, I think I'll explode.** You may think that you have too much to do as it is, but while you're trying to do what you're supposed to do, your boss keeps loading you down with even more work. It's maddening! If you feel terribly overloaded and your boss is unsympathetic, take a deep breath and work on relaxation. Therapy may also help you deal with your anger, even when it's well-placed anger.
- **My family members don't care about my problems and they never offer to help.** If you don't think that your family is caring and supportive, you may have a problem with stress. This is true whether you're right about your uncaring family or wrong, and they really *do* care. (Perception can cloud out reality.)

  A caring family can go a long way to reduce stress. However, for some people, a caring and helpful family can be a stress inducer — if you're worried that your child is doing too much for you or if you're an overachiever and you can't stand it that others are doing things for you that you think you should be doing yourself.
- **As soon as I get home, I make a beeline for the liquor cabinet or a six-pack in the fridge.** If you feel so overwhelmed by work and/or family problems that you head for some alcoholic refreshment at the slightest provocation, you need to be concerned about your stress levels. Many people think that alcohol is the answer for stress relief, but if you're emotionally or physically dependent on it, it isn't. Work on de-stressing your life, using various healthy techniques, instead. And get some help for the alcohol dependency.
- **On a scale of 1 to 10, with 10 being best, my life is a –5.** This one is a little silly, asking if your life could be rated in the negative numbers on a scale of 1 to 10. However, if you nodded your head when you read this, you're experiencing entirely too much stress in your life.
- **I can't remember when I've been to a nonbusiness dinner or done anything that's fun.** Doing things just for fun is a normal part of life. If you can't remember the last night you had a nonbusiness dinner, went to the movie, or just plain did something fun, then face it: You're saddling yourself with too much stress. Don't have any time for fun? You need to *make* and *take* the time. Doing so pays off in reduced symptoms of stress and fibromyalgia.
- **I've been averaging about five hours of sleep a night.** Sleep problems are a major factor for many people with fibromyalgia. If you get less than eight hours of sleep a night, you need to work on that problem. A good night's sleep can help you de-stress and reduce your symptoms. (Read Chapter 14 for more information on sleep and fibromyalgia.)

- **Sometimes, I worry that the boss will fire me. Sometimes, I worry that he won't, and I'll have to do this job for the rest of my life.** If you constantly worry about getting fired, you're under some stress. You may also be suffering from problems with anxiety and depression as well. If you really hate your job this much, isn't it time to just look for another one? Feeling trapped in a job can increase your stress levels tremendously.

Chilling Out with Relaxation Therapy

Relaxation therapy is a strategy that uses steps to achieve an overall calming of both the body and the mind. In general, the person consciously concentrates on relaxing one part of the body, or one set of muscles, at a time until the entire body is in a state of relaxation. The great thing about relaxation therapy is that you can practice it on your own at home as often as you want.

Here's how it works: Close the blinds or pull down the shades (if darkness helps you relax, as it does for many people). Then lie down and begin the therapy.

You can really start by relaxing any part of your body, as long as you concentrate, focus, and work to *completely* relax that part of your body. For example, you may choose to start at your feet.

In this case, you start by imagining your feet becoming increasingly relaxed, loose, and tension-free. You breathe deeply and tell yourself, in your mind, that your feet are becoming heavy and too hard to hold up. Then you imagine this relaxed feeling slowly moving its way up your body to the knees and then to the upper legs. Keep telling yourself that each part of the body is heavy and needs (and *wants*) to rest.

REMEMBER

Take your time. You can't rush through relaxation therapy. Don't move on to another part of your body until the part that you're concentrating on feels completely relaxed.

The relaxation mode continues up through the trunk of your body and out into your arms. You may choose to end with your head and your very, very tired eyes that just want to close. Or you may want to close your eyes at the very beginning of your relaxation session. Either way can work.

You may notice that relaxation therapy uses some of the basic techniques that are also used in hypnotherapy; however, with relaxation therapy, relaxation is the goal. With hypnotherapy, relaxation is merely the path to get to the goal, which is to adopt suggestions that are given to you while you're under hypnosis.

Some people accompany their relaxation “self-talk” with thinking about a pleasant place where they feel relaxed. Some people imagine resting in a quiet forest; others may equate relaxation with thinking about the crashing of the ocean’s waves or another scene. You’re bounded only by your own imagination.

If you think that relaxation therapy sounds like nonsense, try making a deal with yourself. You want to find a way to feel more relaxed, with less fatigue, stiffness, and pain, right? So why not give relaxation therapy at least one or two tries? What have you got to lose? If it doesn’t work, you haven’t done yourself any harm or even wasted any money. And if it does work, you’ve gained a new strategy to cope with your stress and, perhaps, lessen your FMS pain.

TIP

You can purchase a relaxation audiotape to help you discover everything you’d ever need to know about relaxation therapy. Some stores even let you listen to relaxation audiotapes before you decide to buy one. Listen for a voice you find appealing and soothing. Avoid tapes that offer *subliminal messages* (messages heard only unconsciously); they may work, but the goal is to figure out how to achieve relaxation on your own, when you don’t have the tape available.

Stress-Busting with Biofeedback Therapy

When most people become upset or angry, their bodies react with raised blood pressure and pulse and with changes in skin temperature as well. They may remain angry or upset for a long time, which worsens their fibromyalgia symptoms of pain, fatigue, sleep difficulties, and so on.

You can work on what’s bothering you with *talk therapy,* by discussing it with a therapist. Another option is to master the art of controlling and changing your own body responses. It’s hard to stay upset when your blood pressure and pulse drop, your breathing steadies, and your body temperature stabilizes.

Can you really control your body changes, such as lowering your blood pressure, dropping your skin temperature, and making other physical changes? Supporters of *biofeedback* (a therapy that works to enable the user to change his body responses through concentration and observation of physical changes on a computer screen) think that *yes,* you can. And they also believe that biofeedback training can enable you to become more focused and more relaxed.

If relaxation therapy can help with heartburn, it can help with fibromyalgia

In 1994, researchers reported on the results of training people who suffer from severe chronic heartburn in relaxation therapy in *Gastroenterology,* a journal for physicians specializing in digestive diseases. Chronic heartburn? What's that got to do with fibromyalgia? Just bear with me for a moment.

The researchers had inserted special instruments in the stomachs of the subjects, so that they could actually measure each person's stomach acidity when the experiment began, and then again when it ended. Then they trained subjects in one group to perform relaxation therapy, while the other group watched a movie. Both groups were given the same heartburn-inducing meals. (Pepperoni pizza with extra cheese and cola to drink.)

So what happened? The relaxation-therapy group experienced a significant reduction in the level of acidity in their stomachs, and they also felt much better. The other group, which didn't receive the relaxation training, suffered from significantly higher levels of stomach acidity, and they also experienced heartburn.

The researchers hypothesized that maybe the deep breathing that was part of the relaxation therapy helped people with heartburn feel better. Or maybe the relaxation itself somehow reduced the production of acid.

The point, and the relationship to fibromyalgia, is this: Relaxation therapy had a pronounced effect in this study, such that people somehow unknowingly reduced their stomach acid by practicing relaxation therapy. So, isn't it also possible that relaxation therapy may help reduce some of your troubling symptoms of fibromyalgia, such as pain, morning stiffness, and sleep problems? Certainly, relaxation therapy seems to be well worth a try.

Understanding what happens

Different biofeedback practitioners use different methods, but in general, the patient sits in a chair and is connected to a series of monitors. One monitor takes the skin temperature of the hand or arm. Another monitor, often placed on a finger, takes the pulse. Other monitors may also be used to take various body measurements, such as your blood pressure.

The individual views a representation (often a line graph) of temperature or pulse on a monitor, and is told to relax. As the person relaxes, she can see the measures dropping down. As she relaxes further, the line also drops as well. If the person gets agitated, the line starts to climb up.

When it works, biofeedback enables a person to learn to decrease these various measures of stress. By doing so, that person can achieve a better state of relaxation, which she can duplicate when she's not hooked up to monitors and machines.

That's the theory, anyway. It doesn't always work, particularly with Type A achievers who are more likely to see the graph take a downturn and automatically become excited, causing stress levels to rise. For some people, equating relaxation with success is very difficult.

Some studies of the results of biofeedback have indicated that patients with fibromyalgia have decreased their pain, fatigue, and morning stiffness and also improved their sleep.

Perhaps one reason why biofeedback may work for people with fibromyalgia is that studies of people with FMS have indicated that they have temperature differences as well as differences in the blood flow, compared to people who don't have fibromyalgia. If the problem is body responses, and you can discover how to change your physical responses, you may also be able to master your fibromyalgia symptoms. This ability to control your physical responses doesn't mean that you can cure yourself of all pain and fatigue forever. But if biofeedback works for you, it may give you an edge, and a way to improve how you feel.

Weighing the pros and cons of biofeedback therapy

As you may expect, biofeedback therapy has both benefits and liabilities. Let me start with the "bad" news:

- **Your health-insurance company may not provide coverage, so the sessions can be pricey.**
- **Identifying a trained professional who has the equipment and who is competent to provide the therapy may be difficult.**
- **The therapy takes time.** Biofeedback improvements may not occur in the first few sessions, and it may take longer than you'd like before you see any results — not a good thing if you're paying out of pocket for these treatments.

The major pro is that if biofeedback therapy works, you'll feel better. Experts also believe that you can generalize the results of biofeedback to your daily life. That is, after you've mastered the technique, you no longer need to be hooked up to a machine that measures your blood pressure, pulse, and so forth. Instead, when you feel yourself starting to stress out, you can (at least, theoretically) call upon the capabilities that you've gained through the biofeedback training. In one study, patients were still successful at using what they'd learned even six months after biofeedback therapy had completely ended. They hadn't forgotten the techniques, even though they were no longer receiving the treatments.

A reminder: Rest!

Taking time out for some rest and relaxation is not a bad thing, although you may think that it is in our hyperactive society where the cultural concentration is centered on working harder and faster. Your body and your mind need diversions. At least once every few days, do something fun or take some time to do nothing at all. Doing nothing involves activities like listening to gentle music, or watching birds outside your window, or taking a bubble bath. Include this kind of downtime in your schedule because it's good for your body and for your soul.

Don't watch television to relax, and if you do watch TV, stop watching it at least 30 minutes before you want to go to bed. Watching TV (or searching the Internet on your computer) causes the electrical activity of the brain to increase, and makes relaxation and sleep more difficult to achieve.

Finding biofeedback providers

In general, psychologists and therapists are the primary people who provide biofeedback therapy to the stressed-out individuals who need it. They have the equipment, and they have the training to know how to use it correctly and to help you mobilize your abilities. You can ask your physician and others you know if they can recommend anyone with training in biofeedback therapy. If you live near a university or major hospital, you can call the public-relations staff to find out if they know of any biofeedback practitioners.

Mesmerizing the Pain: Hypnotherapy

Look deeply into my eyes! You're getting sleepy, very sleepy. Most people think of hypnotherapy in terms of a rather scary-looking person who somehow makes them fall into his "power" and then induces them to lose weight or rid themselves of other bad habits. Or they may perceive hypnosis as something fake and useless — a carnival trick — and nothing more.

Although, sadly, plenty of charlatans *are* out there in the business, claiming to offer hypnosis services but selling only lies, many other people in the business actually do provide a genuine service. Hypnosis (done correctly) really can help some people gain better control over their lives, helping them to become more calm (and not zombified!), lose weight, stop smoking, or alter their other bad habits.

Hypnosis has other possible applications as well, and one practical possibility (if it works) is to assist you with getting to sleep or gaining some control over your pain. Hypnosis has been used successfully to calm people who need painful medical or dental procedures, and even to help cancer patients who need to control their pain. Hypnosis can be very helpful with pain management for many conditions, including fibromyalgia.

In fact, hypnotherapy has been shown to work for some patients with fibromyalgia. For example, in a study of patients with fibromyalgia treated with hypnotherapy or physical therapy (reported in a 1991 issue of the *Journal of Rheumatology*), researchers found that the patients who received 12 weeks of hypnotherapy reported better sleep, less fatigue, and less pain than the subjects who'd received physical therapy. The benefits were sustained for six months after the end of the hypnotherapy.

Considering what hypnosis is and isn't

Hypnosis is an altered state of consciousness. It isn't a state of sleep, but it isn't exactly a state of being awake, either. Contrary to any myths that you may have heard about hypnosis, it's not some magic trick that's performed on you to make you do stupid things (like barking like a dog) that you aren't aware of. In addition, a hypnotist can't compel you to do anything that you'd consider objectionable or dangerous. A hypnotist may, however, be able to help you marshal your inner resources to figure out how to relax, as well as lose weight, quit smoking, and conquer other bad habits.

Knowing exactly what goes on during hypnotherapy

Hypnosis creates a passive, relaxed state. During that state, the person being hypnotized is receptive to suggestions that can benefit her needs or goals. During a hypnotherapy session, the hypnotist has the patient sit back or lie down. Often, the individual closes her eyes. The hypnotist uses some relaxation-therapy techniques, such as telling the person that her feet are very tired, then her knees, and so on. The hypnotist may tell the person that on the count of ten, she will be extremely relaxed.

The hypnotist may then tell the person that she can't open her eyes, and then tell the person to *try* to open her eyes, even though she can't. If the person struggles to open her eyes, but fails, she's in a hypnotic trance. If her eyes fly open, she isn't, and more effort needs to be done to achieve a light trance.

In most cases, the hypnotist tailors the session to the problem to be addressed. For example, if stress reduction is the goal, the hypnotist may tell the person to imagine a place where she felt really calm, happy, and serene. The hypnotist may tell her to think about how she felt, what the scene appeared like, what sounds she heard, and so forth. The person may be told that she's in this place, and she's very happy. She may be told that when she's feeling very stressed out, she should think about this place, and she'll begin to feel calmer and more relaxed.

Locating a hypnotherapist

You may want to ask your physician if she can recommend a hypnotist — keeping in mind that many doctors consider hypnosis a dubious procedure, at best. You can also locate therapists who've been trained and certified in hypnotherapy through your state or local psychological and psychiatric associations. (If your doctor has a negative opinion of hypnosis, you don't have to let that prevent you from finding a qualified hypnotherapist.)

Mastering self-hypnosis

Maybe you'd prefer to take charge and figure out how to perform hypnosis on yourself. But how on earth can you first put yourself under, and then, at the same time, give yourself hypnotic suggestions? It may sound impossible, but experts say that self-hypnosis is doable.

One possibility is to use a tape recording of your voice with the suggestions that you want to reinforce in your mind. Another possibility is to sort of "pre-program" your mind with the ideas and concepts that you want to concentrate upon, such as imagining your body as healthy, strong, and with little or no pain. Use your relaxation therapy techniques to achieve a state of relaxation, and then introduce the positive goals that you want to achieve.

TIP

For more information on self-hypnosis, you may want to read *Healing Yourself with Self-Hypnosis,* by Frank Caprio, MD, and Joseph Berger. You can also read a description of self-hypnosis online at `http://mentalhelp.net/psyhelp/chap14/chap14w.htm`.

Meditating, Doing Yoga, and Praying

Shutting out the world outside and just concentrating on your own inner self, thinking about a higher power, or thinking about nothing at all can help you to calm your body down and ease your mind away from the things that bother you so much. It may help you cut back on your painful symptoms of fibromyalgia as well.

Meditation

One of the many forms of meditation may work for you. One study indicated that women with fibromyalgia who practiced daily meditation — about an hour a day for six days a week, over an eight-week period — reported lower levels of pain, better sleep, and lower levels of depression than when they'd begun the study.

Psychologists and other experts can teach methods of meditation, and many communities have free or low-cost classes to provide training on how to meditate. Experts say that meditation is not, however, a quick-fix answer, and the techniques must be learned and practiced for at least a few months before significant results can be noticed.

TIP

If you're interested in finding out more about meditation, check out *Meditation For Dummies,* 2nd Edition, by Stephen Bodian (Wiley). It comes with a CD of guided meditation exercises that you can follow along with if the idea of sitting silently for more than a couple minutes makes you stir-crazy.

Yoga

Twisting your body around like a pretzel? Sounds more like a stress-inducing plan instead of something that can cause a state of calmness. So how on earth can yoga help you? Well, first of all, erase from your mind the idea that you must contort your body into impossible (and painful) positions, because that's a stereotypical view of yoga. True, yoga does have some very tough positions, but those are for advanced students, not beginners. As with most new forms of exercise, you start slowly and build your way up. When you have fibromyalgia, this building-block policy is particularly important to avoid more strain and pain.

If you want to discover much more information on the basics of yoga — and just about everything else you need to know about this subject — be sure to read *Yoga For Dummies,* by Georg Feuerstein, PhD, and Larry Payne, PhD (Wiley).

Prayer

Some people with FMS report that praying helps them feel much better. Prayer may act much in the same way as meditation and yoga do, instilling calmness and an acceptance that you're really not in control, that you can't be expected to be accountable for everything, and that you don't need to frantically rush about trying to solve difficult problems right away. Instead, you give yourself a break and — at least temporarily — leave the resolutions of your pain and your problems to the cosmos.

Many churches have *prayer circles,* in which you can ask other people to pray for you. You can even find prayer circles on the Internet. In some studies, doctors have found that being prayed for can improve an individual's ability to survive a heart attack or dangerous surgeries. So, why shouldn't they work for fibromyalgia?

Chapter 14

Sweet Dreams! Combating Sleep Disorders

In This Chapter

- Understanding sleep and its importance for people with fibromyalgia
- Knowing about sleep stages and their relevance to fibromyalgia syndrome
- Discovering common sleep disorders for those with fibromyalgia
- Considering lifestyle changes that enhance sleep
- Treating sleep disorders with medications and alternative remedies

Juanita's fibromyalgia pain occurs every day, and it's very severe — so bad that she can't work most days and is considering filing for disability benefits. Bob's pain is intermittent; some days are overwhelming, and other days he can pretty much ignore the pain and the fatigue. Darlene feels achy and exhausted nearly every day, but she somehow manages to take care of the kids and work part-time.

All three have been diagnosed with fibromyalgia syndrome (FMS), although the severity of their disease and how they cope with it are very different for each person. They all share one common denominator, though: Juanita, Bob, and Darlene have serious sleep problems, each averaging only about four to six hours of sleep nearly every night.

The majority of people with fibromyalgia (at least 55 percent) have sleep difficulties, whether they have trouble getting to sleep in the first place or frequently wake up after falling asleep. (Some people have both problems.)

Of course, solving sleep disorders doesn't automatically cure your fibromyalgia. But in many cases, a good night's sleep can considerably ease the pain and the fatigue of your illness. Because pain and fatigue are usually the most troubling symptoms for people with fibromyalgia, resolving sleep problems is clearly very important.

In this chapter, I cover why a good night's sleep is so important for people with fibromyalgia, including spending sufficient quality time in each sleep stage. I also cover the key types of sleep problems that people with FMS experience and offer practical advice on how to achieve the sleep time you need through lifestyle changes, medications, and other immediately doable options.

What Is Sleep?

Sleep is a biological process of altered consciousness that all humans must undergo on a regular basis in order to replenish their bodies in physical, biochemical, and psychological ways.

I don't want you to feel like you're in Biology 101, but you do need to have a basic grasp of what exactly sleep is and how it affects your body. Sure, you probably think that you *know* what sleep is. It's that process that occurs sometime between going to bed and waking up again. (Or, if you have fibromyalgia, it's that annoying process of trying to rest and waking up with pain and frustration several times each night.) But did you know that sleep has important levels that people need to experience? And did you also know that sleep has necessary biochemical and psychological purposes? Sleep enables the body to repair damaged tissue and also provides the opportunity for dreaming, which scientists have proven is a necessary process for physical and mental health.

Contrary to popular belief, your body doesn't automatically shut down to the point of being just short of switching to the "Off" position when you go to sleep. Some processes slow down, but others speed up. Some important hormones, such as cortisol, growth hormone, and prolactin, are secreted when you sleep or shortly before you wake up. If you don't sleep enough, the production of these hormones can be thrown off, which may increase the probability of pain for fibromyalgia sufferers. Your brain continues to be extremely active in sleep, orchestrating all these processes for you.

Your body also operates with an underlying *circadian rhythm,* like an internal clock for when you're asleep and when you're wide awake. Unfortunately, bad sleep patterns can become engrained sometimes. Don't worry: You can break them, and in this chapter I discuss ways to achieve good sleep habits.

Understanding the Importance of Sleep Stages

People need to experience enough sleep, in terms of the number of hours that they sleep (usually seven to eight hours per night), and they also need to experience all the different stages of sleep, ranging from light sleep to deep sleep. Some researchers believe that people with fibromyalgia don’t spend enough time in the very deep sleep levels. A lack of quality deep sleep may inhibit an adequate production of important protective hormones that are normally made while we sleep, such as growth hormones and *prolactin.* Prolactin is the same hormone that’s released by nursing mothers (although sleep releases much less of it), but scientists aren’t sure exactly what function prolactin fulfills in nonlactating people.

In 2001, researchers reported on their study of the nighttime hormone levels of women with and without fibromyalgia in the *Journal of Clinical Endocrinology & Metabolism.* They found that women with fibromyalgia (who agreed to take no medication during the study) had significantly lower levels of both nocturnal growth hormone and prolactin. This result provides even more proof that fibromyalgia is real! It also serves as another indicator that people with fibromyalgia should pay special attention to resolving their sleep problems.

Note: Men also release prolactin during deep sleep stages, but less than women.

When people with fibromyalgia sleep even less than they usually do, they hurt more. Sleep expert William C. Dement, MD, PhD, and Christopher Vaughan say in their book, *The Promise of Sleep,* that in experiments in which people with fibromyalgia are purposely deprived of sleep, their pain is significantly greater.

Here are the three basic types of sleep, according to sleep experts:

- Light sleep (Stages 1 and 2)
- Deep sleep (Stages 3 and 4)
- Rapid eye movement (REM) sleep

Light sleep

Stage 1 is the lightest stage of sleep, and it’s also the doorway to eventual dreamland. If you’re awakened from Stage 1 sleep, you may deny that you were sleeping at all and may say that you were simply “resting your eyes.” In this stage, virtually any little thing — a minor sound or a light touch — can easily awaken you. In Stage 2, another stage of light sleep, you can still be awakened easily, but you’ll know that you were asleep if you’re awakened.

Light sleep is important because of its relaxation qualities and also because it’s part of the stepwise process that leads to deep sleep and to the rapid eye movement (REM) stage of sleep. You can’t get to the deeper stages of sleep unless you go through the first two stages of light sleep.

Deep sleep

When you're in the deep and deeper levels of Stage 3 and Stage 4 sleep, your body is completely relaxed and people have difficulty waking you up. Stage 4 is also known as *slow-wave sleep* because of the characteristic brain wave patterns of this stage.

During deep sleep, your heart slows down and your breathing becomes regular and relaxed. Your body also releases a small amount of growth hormone, which helps rebuild damaged tissue. Other hormones are also released, such as prolactin and melatonin.

If you don't have enough sleep and, consequently, don't spend enough time in deep sleep, the biochemical processes that are supposed to occur are aborted or may not happen at all. This is probably a key reason why the pain is worse for an FMS sufferer who's slept very little.

If you have trouble sleeping, one tactic that may help is simulating the breathing of a very deep sleep. Doing so may induce your tired body to slip into a sleep state. Try this: Lie down in a comfortable and quiet place. Take in a deep breath and let it out very slowly. Repeat several times. Concentrate only on your breathing and on nothing else. Don't worry about falling asleep, about your fibromyalgia, or work or family problems. Just breathe. Breathing is all that matters.

REM sleep

The REM stage of sleep is the time when dreams occur. This stage is called *rapid eye movement* because scientists have studied the brain waves of people who are dreaming and have noted that sleepers actually move their eyes back and forth under their eyelids at that time, almost as if they were watching a movie.

The body may release *cortisol* in this stage (although cortisol can be released anytime during sleep). Cortisol is a hormone released by the adrenal glands. It controls blood pressure, blood sugar, and other key body functions. Some people with FMS may have overly low levels of cortisol in the daytime, leading to excessive fatigue, and overly high levels at night (causing insomnia). Cortisol production peaks early in the morning, shortly before you awake.

Identifying Key Sleep Problems

Everyone has trouble sleeping once in awhile, but suffering from a chronic sleep deficit is a sign of trouble, especially if you have fibromyalgia. For people with FMS, this simple equation is very important: Less sleep = more pain.

In general, people with FMS may have one or all of the following sleep difficulties:

- Difficulty falling asleep
- Frequent awakenings
- Lack of deep, restorative sleep

It's 2 a.m. and I'm still awake: Difficulty falling asleep

You've been trying as hard as you can to get yourself to sleep, but your brain just won't cooperate! Instead, it keeps wanting you to think about that problem with the report you were working on today, the bully at school who's harassing your child, and so many other problems. "Sleep now!" you order yourself — except your body won't cooperate. As you get angrier and more frustrated, the probability of falling asleep soon decreases.

The answer in this situation: Get up, get a drink of water, walk around, and then lie down when you feel like it. Don't be mad at yourself for not falling asleep and don't blame your boss, the nasty kid at school, or anyone else. Be philosophical: These things happen. If insomnia occurs night after night, however, it'll start wearing on your brain and your body, and your fibromyalgia may get worse. Read this chapter carefully and follow my advice.

Too many wake-up calls: You're constantly waking

Another problem many people have is that they fall asleep okay, but they keep waking up. Someone flushes the toilet, and they wake up. They hear a bird chirp, and the sound acts as an untimely wake-up call. It almost seems like a leaf could fall off a tree and wake them up. If you have this problem, you're clearly not getting enough deep sleep.

What can help? A white-noise generator that makes a kind of *sshhhh* sound can help you tune out that noisy world and fall deeply asleep. Soft music on the radio may help lull you to sleep. Some people can benefit from deep-breathing exercises, meditation, or relaxation therapy. (Read Chapter 13 for more information on these techniques.)

Be sure to use the most comfortable mattress that you can find. Sometimes waterbeds are a great solution to help you relax and fall deeply asleep. Some people like cotton flannel sheets because they're cool in the summer and warm in the winter. Check other aspects of your environment as well. For

Dream on

Whether dreams have important messages to sleepers is an issue that's been debated for millennia. Some people believe that dreams are like garbage from the brain, akin to the waste material excreted after food is processed by the digestive system. Others believe that dreams hold very important meanings for the dreamer and should be pursued.

I don't know which point of view is right about the significance of dreaming, but I do know that having dreams is important. In experiments in which people were deprived of dreaming (by being wakened when a REM stage was detected), the subjects became very irritable and angry. People with fibromyalgia, like everyone else, need to dream.

example, is the room too hot or too cold, even if only slightly? If you're uncomfortable, do something to fix the situation and see if that helps you relax.

Not enough downtime in deep sleep

Even when you finally fall asleep, you may spend the night tossing and turning in the early sleep stages, and experience an insufficient time in the kind of deep, restorative sleep that your body truly needs. In fact, studies indicate that some people with fibromyalgia suffer from a lack of time in deep sleep.

The more you relax (which I know is often not easy!), the more likely you are to achieve a deep, restorative sleep state. Research has shown that, for some people, tricyclic antidepressants, such as Elavil, may help to prolong sleep stages 3 and 4. If tricyclic antidepressants don't work, Prozac (generic name: fluoxetine), another type of antidepressant, helps some people. (For more on these medications, check out "Taking prescriptions for sleepyland," later in this chapter.)

Analyzing Your Sleep: A Self-Test

Answer "true" or "false" to the following eight questions to determine if you or someone you care about may have a sleep problem. And be honest! Nobody but you needs to know your answers.

1. **On most nights, falling asleep takes me an hour or more.**
2. **After I fall asleep, I sleep at least seven or eight hours. If I wake up, I fall back to sleep again easily.**

3. **I rely on at least several drinks of beer, wine, or another form of alcohol before bed.**
4. **I consider myself a light sleeper.**
5. **My partner says that I snore.**
6. **When I wake up in the morning, I feel refreshed.**
7. **I take naps on the weekend.**
8. **I like watching scary or exciting TV programs before bed.**

What do your answers mean? Let's take them one by one.

If you answered "true" to question 1, you have plenty of company — and you also have a sleep problem.

Lisa was diagnosed with fibromyalgia about a year ago, and she says that on most nights, she just lies in bed and can't sleep. The hours pass from 11 p.m. to 2 a.m., but she feels almost more wide awake than she did at noon. She wonders what's wrong with her. Part of Lisa's problem may be that she's just trying too hard to fall asleep. Ironically, the harder she tries, the angrier and more frustrated she gets and the less likely she is to fall asleep. Ease up, Lisa! She (and maybe you) needs to try some of the sleep remedies provided later in this chapter.

If you answered "true" to question 2, good for you! Keep up the good work. Maybe you have some good sleep tips that you can share with your fellow fibromyalgia sufferers.

If you answered "true" to question 3, you need to break this habit as soon as possible. One glass of beer or wine may be a good way to get to sleep for some people. But having more than one glass of beer or wine, as well as drinking any other forms of alcohol, is definitely not a smart choice. You're far more likely to wake up, dehydrated and headachy, around 1 or 2 a.m. with a bad case of insomnia.

If you answered "true" to question 4, you may be a person who isn't getting enough sleep. Do you ever feel truly rested in the morning? If not, you need to try my sleep suggestions later in this chapter.

Lack of exercise can impede sleep

Maybe you haven't been exercising much (or at all) because of your pain and fatigue. But if you can manage some light exercise, such as a short walk an hour or two before bedtime, this activity could help you get to sleep easier. Be sure to read Chapter 15 for more information on how exercising can improve your FMS symptoms.

Did you answer “true” to question 5? If so, you may have sleep apnea. Sleep apnea is a dangerous condition by itself. It’s also bad because the lack of sleep that this condition induces can also increase the pain of fibromyalgia. Talk to your doctor about resolving this problem.

If you answered “true” to question 6, and you wake up in the morning feeling refreshed, that’s great! Sounds like you’re doing the right thing. Whatever it is, keep doing it.

If your answer to question 7 was “true,” I have to tell you that taking naps on the weekend is a no-no for the person with fibromyalgia — unless a daily siesta is your status quo. If you make naps a weekend-only habit, you may disrupt your sleep cycle. Whenever possible, maintain the same sleep hours (within an hour or two) on weeknights and weekends. You should get up at about the same time every day and go to bed at about the same time every night. This habit is especially important for people with sleep problems — with or without fibromyalgia.

If you answered “true” to question 8, and you become excited or upset by scary or violent movies, but you don’t want to give them up, avoid watching them before bedtime. Watch a DVD of *Saw III* on Saturday afternoon instead of late at night.

REMEMBER

Most people don’t get enough refreshing sleep, and people with fibromyalgia aren’t alone in being sleep deprived. According to a survey performed by the National Sleep Foundation in 2000, two-thirds of 1,000 people reported having trouble sleeping at least a few times a week. In fact, sometimes the sleep deprivation is voluntary. Nearly half (45 percent) said that they’d sacrifice more sleep if they could get more done. Yet sleep deprivation leads to car crashes, mistakes at work, and yelling at your kids. A good night’s sleep is important for everyone, and it’s especially vital for people with FMS.

Understanding sleep apnea

Infrequently, *sleep apnea* is the cause of fatigue or daytime sleepiness. Sleep apnea is a medical problem that causes people (especially people who are overweight) to actually stop breathing while they’re asleep. Although each apnea episode lasts for only a short period, and the breathing eventually gets jump-started again by the brain, people can suffer from dozens of these episodes each hour. These lapses of breathing, when added together, can be dangerous for people. In some cases, they can cause heart or lung problems and even be fatal. If your spouse commonly complains that your snoring can be heard in other rooms of the house, or you constantly wake up with choking and coughing, you may have an allergy or a problem with sleep apnea. See your doctor to find out, and if you have this problem, get treatment for it.

Adjusting Your Lifestyle to Cope with the Problem

Medications can help you fall asleep and sleep peacefully through the night (I discuss drugs in the next section, “Slipping into Slumber Using Medications and Other Remedies”). But you can also make simple changes in your life that will often help carry you off into the wonderful world of sleep. The following are some good lifestyle options:

- Pay attention to what you eat and drink at dinnertime and afterward.
- Discover how to relax. (Read more about relaxation therapy in Chapter 13.)
- Accept that your bed is for sleeping only. (Okay, it’s for sex, too. But that’s it!) Do your working, reading, and TV watching elsewhere.
- Encourage a snoring partner to get help. If he refuses to get help, consider using earplugs or a white-noise machine to help cancel out the noise.

Consuming soporific suppers

If you suffer from insomnia, avoid eating a fashionably late dinner; stop eating at least three hours before bed. Also, be sure to take other basic steps that can facilitate sleep. For example, avoid all caffeine (coffee, tea, cola drinks, and chocolate) starting six to seven hours before bedtime, so your system won’t be overstimulated when it’s time to fall asleep. Consider eating foods that are known to be rich in natural *tryptophan,* a chemical that induces sleep. Turkey’s packed with it. Milk also has this substance, although in lower quantities than turkey has.

TIP

Eating a few pieces of turkey or a turkey sandwich, combined with a glass of milk, an hour before you want to go to sleep may relax you enough to help you nod off without (or with less) difficulty. Of course, be sure not to overeat, which can defeat your purpose because you may get a stomachache and find it even more difficult to fall asleep. And be sure *not* to rationalize to yourself that a slice of pizza or a dish of ice cream before bed will help you relax and fall asleep. It won’t!

Relaxing

Falling asleep is nearly impossible when your body is tense from the day’s battles and problems. But you can discover how to relax, whether through deep breathing (relaxation therapy (see Chapter 13), or special relaxing exercises, such as Chinese tai chi (see Chapter 12). The point is, relaxation isn't bad; it's absolutely necessary. Yet in our achievement-oriented society, where many people think every nanosecond must be a productive one, relaxation may be a tough concept to accept as being good.

Think of it this way: Even machines need some downtime. Your body is a wonderful and unique kind of biological machine, and it definitely needs some time off from intensive efforts. And it needs that time off every day. It needs restorative sleep. And besides, good sleep can enable *more* productivity the next day. Don't deny yourself this important need.

Using your bed for sleeping (and sex)

Your bed is for sleeping. This statement may sound obvious, but too many people don't grasp this simple point. Your bed really isn't a good place to read books, grade papers, or perform other nonrestful activities. With the exception of sexual activities (which are also good for your body and may help you sleep deeply), do nothing in your bed except sleep. Perform your other activities elsewhere.

Quieting a snoring partner

What if you're not the one who's snoring, but your partner is? Encourage her to get help. Your partner may have sleep apnea, a sinus infection, or some other medical problem. The snoring is also disrupting your sleep! Resolving this snoring problem can help you both.

Slipping into Slumber Using Medications and Other Remedies

Sometimes, you try lifestyle changes, limit your heavy meals, and follow my other good suggestions in this chapter and this book, but you're still not registering enough Zs. You may need to try a sleep medication. Over-the-counter medicines, alternative remedies, and prescribed medicines are all available today and just may help you.

Buying nonprescription medicines

You can purchase over-the-counter sleep remedies at your pharmacy or even your supermarket. Most of these drugs have the same ingredients as *antihistamines* (cold and allergy medicines). They may make you a little drowsy, but generally, they have a limited effectiveness at inducing sleep. In most cases, when they do induce sleep, these medications fail to deliver significant restorative sleep to their users. They can cause constipation, dry mouth, and other side effects. They may also cause *rebound insomnia,* which means that these medicines actually cause you to have insomnia if you stop taking the medicine. If you have insomnia, you need a sleep remedy, not an allergy drug.

If you do decide to use an over-the-counter sleep remedy, be sure to read the instructions on the package and any inserts first. You don't want to risk having the drug interact with other medications you may be taking for fibromyalgia or other illnesses. If possible, ask your doctor if he recommends this medicine or considers it safe. You can also call the doctor's office and ask the nurse to ask the physician for you.

Using helpful alternative remedies

Alternative remedies to the standard over-the-counter medications are effective in helping some people get to sleep. Some key alternative remedies are valerian, kava kava, and melatonin.

REMEMBER

Be sure to let your doctor know that you plan to take or are already taking herbal medicines or other supplements. These alternative remedies can interact with other medicines you're taking.

Valerian

Clinical studies in the United States, the United Kingdom, and Germany on the use of valerian as a mild sedative have proven that this herbal root does help some people with their insomnia. Studies also indicate that valerian doesn't appear to affect sleep stages negatively or to impede the concentration or reactions of users on the day after they use it.

WARNING!

According to the American Society of Anesthesiologists, valerian may boost the effects of some antiseizure medicines. If you take an antiseizure medicine, be sure to ask your doctor if you can safely take valerian. Better yet, try a different remedy.

Kava kava

What about the herbal remedy kava kava? People have used this herb (also known as *Piper methysticum*) for problems of insomnia, stress, anxiety, and premenstrual syndrome. In a study reported in *Phytotherapy Research* in 2001, researchers treated subjects who suffered from stress-induced insomnia with kava kava for several weeks and then treated them with valerian. The researchers found that both herbs were effective. The most frequent side effect found with valerian was vivid dreams, experienced by 16 percent of the subjects. The most frequent side effect experienced with kava kava was dizziness, experienced by 12 percent of the subjects.

WARNING!

In late 2001, the Food and Drug Administration (FDA) issued a warning that some people in Europe who've used kava kava have experienced severe *liver toxicity* (damage to the liver, a crucial organ that you can't live without), suffering from such problems as hepatitis, cirrhosis, and even liver failure. In addition, the FDA also received reports on Americans experiencing liver problems with taking kava kava.

Melatonin

The hormone melatonin has proven effective at helping some people get to sleep, and studies indicate that melatonin may be especially helpful for travelers who are plagued with problems of jetlag. The drug appears to reset the natural body rhythm of the user. Your body actually produces melatonin naturally (it's produced by the pineal gland in your brain). But you may need an extra boost from nature from time to time, and taking supplemental melatonin may help you. Keep in mind, however, that melatonin has been reported to cause headaches, stomachaches, strange dreams, and even depression in some people.

Taking prescriptions for sleepyland

Are prescribed medications for sleep safe? In most cases, yes — although you should pay attention to your doctor's warnings about side effects, the dose you should take, and any other warnings your doctor gives you. Also ask your pharmacist about any side effects or potential interactions with other medications you're taking.

The key medications that are prescribed to help people sleep are

- Prescribed sleep remedies
- Antidepressant medications
- Anti-anxiety drugs
- Fibromyalgia medications that also induce sleep

Melatonin may help with pain and depression, too

Some studies have shown that taking melatonin, an over-the-counter supplement, may not only normalize the sleep cycle of people with fibromyalgia, but also decrease their pain and depression. Melatonin may reduce the anxiety caused by sleeplessness and it also has sedative effects, which help to reestablish the circadian sleep cycle. Melatonin may also normalize neurotransmitters and, thus, reduce pain. Some studies have shown efficacy with a dosage of 3 mg of melatonin. As with any medication, talk to your doctor first before trying melatonin.

Prescribed sleep remedies

Approved by the FDA in 1992, Ambien (generic name: zolpidem) was the first prescribed drug created specifically for insomniacs in the United States. Since then, other drugs have become available for insomniacs, including Lunesta (generic name: eszoplicone) and Sonata (generic name: zaleplon). These medications are classified as Schedule IV drugs under the Controlled Substances Act, which means that they have a low risk for abuse compared to other scheduled drugs, such as most narcotics, which are Schedule II drugs. (Read more about scheduled drugs in Chapter 10.) A newer prescribed sleep remedy that is *not* a scheduled drug is Rozarem (ramelton), a medication that works in about an hour — if it works.

These sleep remedies may increase depression and memory problems, and sleepiness may be prolonged in some people.

WARNING!

Don't take sedating medications during daylight hours unless you can stay home. Don't even think about driving a car or operating any type of equipment beyond perhaps turning on your computer.

Antidepressants

Doctors frequently prescribe antidepressant medications for people with fibromyalgia. These drugs are not usually prescribed in a high enough dose to treat someone with depression; instead, doctors order them at a lower dose to help induce sleep and also to ease pain from fibromyalgia or other medical problems.

Drugs, such as Elavil (generic name: amitriptyline) and Desyrel (generic name: trazodone) make most people tired, and they fall asleep. The downside is that these drugs may also cause weight gain and a "druggy" feeling the next day in some people. Dry eyes and mouth are other side effects that can occur.

Prozac (generic name: fluoxetine) may help some people achieve a deeper sleep if other antidepressants don't work well. One rather unfortunate side effect is that Prozac may inhibit orgasm in some people.

Anti-anxiety drugs

Sometimes people with serious sleep problems are prescribed anti-anxiety drugs, also known as *benzodiazepines.* When the problem is insomnia, some anti-anxiety drugs may be helpful, including Restoril (generic name: temazepam), ProSom (generic name: estazolam), and Halcion (generic name: triazolam). As with specific sleep remedies, these medications are Schedule IV drugs; thus, they have some risk to be habit-forming. Pregnant women should avoid them, as should patients with sleep apnea or impaired respiration or anyone with glaucoma. Don't take these medications with sedating supplements, such as chamomile, melatonin, kava kava, or valerian.

Other sleep-inducing medications

Some pain medications that doctors prescribe for people with fibromyalgia also induce sedation, so doctors may feel that they're conquering two problems with one drug. (Read more on medications in Chapter 10.) Flexeril (generic name: cyclobenzaprine) is a muscle relaxant that makes many users feel drowsy. Ultram (generic name: tramadol) is another effective pain medication that also has sedating effects.

Most patients take these drugs at night because of their sedative effects, even when the medications are taken primarily to control pain. If they're taken during the day, patients must usually refrain from performing tasks that require high alertness.

Chapter 15

Exercising, Losing Weight, and Avoiding Trigger Foods and Drinks

In This Chapter

- Exercising and how it can improve how you feel
- Working on weight loss to decrease pain
- Staying away from foods that may worsen your pain

You've heard it all before: You should exercise, lose weight, and do all that boring and hard stuff that most doctors constantly urge so many patients to do. But the reality is, they're right!

Exercising and losing weight (if you're overweight) really *can* help you feel better by decreasing your fibromyalgia pain, fatigue, and muscle stiffness. And here's a little secret: You don't have to exercise to the point of exhaustion, nor do you have to lose great amounts of weight to feel better.

This chapter talks about several important lifestyle changes that you can make to gain more control over your fibromyalgia syndrome (FMS) symptoms. First, I cover the benefits of exercising. I also include some basic do's and don'ts on exercising and provide four simple exercises to try. Next, I cover weight loss, providing a chart to determine for yourself whether you need to lose weight. I also cover popular prescribed diet drugs and their basic pros and cons. Finally, I cover dietary *hyperstimulants,* a made-up word for food substances that some experts believe can aggravate your FMS symptoms. You may find that avoiding these substances will help improve your condition.

Exercising to Relieve Fibromyalgia Pain

Most people associate painkilling with a variety of over-the-counter or prescribed medications. But drugs aren't the only means to improving your fibromyalgia symptoms. Getting physical by starting a plan of exercising can work well, too, although exercising may seem like a sort of strange way to gain pain relief. Gentle, low-stress, paced exercising can make you feel better, loosening muscles and greasing your stiff joints and possibly acting as a preventive measure to ease your pain down the road.

Some studies have indicated that people with fibromyalgia have a fitness level that's significantly lower than levels found among people who don't have fibromyalgia. (Not that amazing when you think about it — people with FMS generally feel pretty bad, so are less likely to be physically fit.) Regular exercise may help people with FMS to close that gap, although not in a few days or even in a few weeks. Be patient and persistent, and you'll get there.

Here are a few tips to keep in mind as you gear up to exercise:

- **Create a basic fitness program that suits your needs.** Realize also that if you were more athletic in the past, as many people with fibromyalgia report that they were, that was *then.* Make a plan that works for you *now.*
- **Set a realistic goal.** Whether exercise goals are set by a physician, a physical therapist, a personal trainer, or anyone else (including you), the goals for a person with fibromyalgia shouldn't be the same as for a person who doesn't have fibromyalgia, because people with FMS have a lower pain tolerance and tire faster than others. Too much exercise, too fast, can accelerate the pain. Physical expectations need to be scaled down considerably for the person who has FMS.

  Watch out what type of exercises you perform. Research has shown that static exercise (like weight lifting) compared to dynamic exercise (like running) can cause significantly increased pain for people with FMS, although the cause is unknown. Walking and swimming are better exercise choices for people with FMS than weight lifting.
- **Consult your physician before you start a new exercise program.** Your doctor may want to check out your overall fitness level with a treadmill test or other screening measures. She may also listen to your plan, nod wisely, and then give you the thumbs up, wishing you well.
- **Start slowly and steadily build your way up.** Start with five minutes a day, several times a week (except for walking, which can be for longer periods). Then every four or five days or so, add a minute of exercise. Keep adding minutes, until you're up at a half-hour for three to four days per week. You can also increase the speed at which you perform your exercises, gauging how fast to go by your own comfort level.

  Note: When it comes to walking, many people with FMS should be able to follow the walking program in the "Walking off the pain and strain of fibromyalgia" section later in this chapter, walking up to 60 minutes after 12 weeks. However, even daily walks that last only minutes are helpful. Walking is a moderate, steady type of exercise; you can walk for a longer period than you can perform reps of strenuous exercises.

- **Keep it simple.** Consider the simple exercises offered in this chapter, which can help you build up strength and cut back your pain level without breaking your bank on expensive gym memberships.
- **Don't overdo it!** Now isn't the time to adopt "No pain, no gain!" as your motto. It simply doesn't work for people with fibromyalgia. A little discomfort is okay and sweating is good. But actual pain? Forget it.

Prepare for exercising by drinking plenty of fluids and making sure that you dress comfortably and appropriately. Skip the spandex pants and tight T-shirts. Wear something loose fitting. Wear good, comfortable walking shoes. Don't worry about the fashion police. Assume that they've taken the day off.

Exploring Pain-Relieving Exercises

An effective exercise designed to alleviate pain over time is simple to perform and doesn't take a lot of time, and yet it adequately manipulates the targeted muscle groups. Here are a few ideas for you to try.

Walking off the pain and strain of fibromyalgia

Walking is an excellent and easy exercise for most people, and it's one that most people can perform nearly every day. It doesn't cost anything, and you decide when the time is right and where you want to walk.

However, when you feel really bad, even walking can be hard to do, and it may cause you some pain. So you shouldn't strive for long distances — at least when you first start your walking program. And don't strain yourself to keep up with others who may be in much more of a rush than you are. Pace yourself. Walk briskly, but don't push too hard. You know how fast is fast enough for you.

Table 15-1 shows a walking program for you to try, developed by the National Heart Lung and Blood Institute. It allows you to build up slowly. Use the program as is, or adapt it to your needs. During the warmup portion, walk at a comfortable pace and work up to a brisk pace for the exercise portion. When you're ready for the cool-down, begin walking at a slower pace to get your heart rate back down.

Table 15-1 A Sample Walking Program

Week Number	*Warmup*	*Exercising*	*Cool-Down*	*Total Time*
1	5 minutes	5 minutes	5 minutes	15 minutes
2	5 minutes	7 minutes	5 minutes	17 minutes
3	5 minutes	9 minutes	5 minutes	19 minutes
4	5 minutes	11 minutes	5 minutes	21 minutes
5	5 minutes	13 minutes	5 minutes	23 minutes
6	5 minutes	15 minutes	5 minutes	25 minutes
7	5 minutes	18 minutes	5 minutes	28 minutes
8	5 minutes	20 minutes	5 minutes	30 minutes
9	5 minutes	23 minutes	5 minutes	33 minutes
10	5 minutes	26 minutes	5 minutes	36 minutes
11	5 minutes	28 minutes	5 minutes	38 minutes
12	5 minutes	30 minutes	5 minutes	40 minutes

Source: Derived from the National Heart Lung and Blood Institute (`www.nhlbi.nih.gov/hbp/prevent/p_active/walk.htm`*).*

After you complete Week 12, gradually increase your brisk walking time to 60 minutes, 3 or 4 times a week.

TIP

Make walking enjoyable by walking with a friend or your dog. Play your favorite music while you do the exercises in this chapter or other exercises that you and your doctor have identified as helpful. Headphones allow you to keep the music to yourself. Go for upbeat, energetic music — whether pop, hip-hop, show tunes, whatever.

TIP

After you've become used to walking, you'll probably actually miss your daily walk if you have to forego it due to bad weather or some other circumstance. (No kidding! You'll start to look forward to your daily workouts.) So, you may want a plan for walking indoors when the need arises. If bad weather or long work hours prevent you from walking outside, drive to the nearest shopping mall and walk several laps around the mall.

Incorporate more walking into other parts of your daily life. For example, when you go shopping at the supermarket or elsewhere, don't consider it a major victory when you can park close to the entrance. Instead, park farther away and walk a little farther than usual. A side benefit of parking farther away is that you won't have other drivers lined up and eager to take your very close spot. When you're out in left field, you can take your time to reach your car, find your car keys, and get yourself comfortable, and nobody will care.

When you need to enter a building that's a few stories high, ignore the elevator and take the stairs instead. It's great exercise for your heart as well as the rest of your body. Don't run up the stairs; take your time.

TIP

Be sure that you move around and change positions frequently in your daily life. Sure, the movie is fascinating, or maybe another project that you're working on has you mesmerized. You may feel like (or act as if) you're glued to your chair. If so, unstick yourself. At least every 15 to 20 minutes, get up and move around. And then, if you want, return to the previously intriguing activity. Moving around more frequently can help abate some of the muscle stiffness that's so common for people with fibromyalgia.

Swimming, cycling, and other choices

Swimming, cycling, and strengthening exercises are good for your muscles, your heart, and your whole body. Getting into shape can be an effective preventive tactic, helping shield you against future pain and fatigue. You can't get a new body (not yet, anyway!). So strengthen the one you have.

Analyzing aquatic exercises: Water works

Aquatic exercises range from making simple movements in the pool all the way up to swimming laps. So the range of activity choices is considerable. Aquatic exercises are easier on the body than are exercises performed out of the water, because water exerts less strain and drag on the body and allows for a greater freedom of movement. (Less strain and more movement are great selling points for people with FMS.)

TIP

One very simple water exercise is to walk around in the shallow end of the pool. Keep your arms above the water line, so they don't create too much pull and strain on your body.

REMEMBER

If you exercise in a swimming pool, the water should be comfortably warm. Many people with fibromyalgia are very sensitive to cold temperatures and find it harder to move when they're immersed in cold (or hot) water. Always check the temperature of the water with a pool thermometer before jumping in. Some experts recommend that the water temperature should be set between 83°F and 90°F. If you use a public pool, ask the staff if they have a pool thermometer you can borrow to test the temperature, because you're highly sensitive to heat and cold. You can also buy a pool thermometer for a few dollars in a pool-supply store.

If you want to take a local class in water aerobics in a warm-water pool, check your local newspaper for information or contact your local chapter of the Arthritis Foundation to find information on dates and times of classes that are offered. If you're not sure how to find your local chapter, call the Arthritis Foundation toll free at 800-568-4045 or check its Web site (`www.arthritis.org`).

Cycling to symptom reduction

Riding your bike is also a great exercise, even if it's just around the block. Or you can use a stationary bike and cycle yourself ahead many "miles" while you stay in your home and watch your favorite TV shows or a DVD, or while you listen to music, podcasts, or an audiotape of a book.

Getting stronger with strengthening exercises

If you begin practicing strengthening exercises, such as resistance exercises, you can build up your body and make it more impervious to pain. However, avoid weightlifting (using weights of even five pounds) because that may increase your pain. ***Note:*** Avoid exercising muscle groups that are painful.

If you don't already have one, you may want to buy an inexpensive exercise mat with some padding, usually available at major sporting goods stores. Avoid just lying on the hard floor.

The exercise shown in Figure 15-1 helps you strengthen your upper back and shoulder muscles, often major problem areas for many people with fibromyalgia. Here's how to do the exercise:

1. **Get down on your hands and knees on an exercise mat with your neck straight and parallel to the floor.**

   Don't do this exercise on a hard floor without a mat.

2. **Slowly stretch one arm out in front of you, keeping your arm straight and parallel to the floor, to about the height of your ear.**

   Your fingers should point at the wall on the opposite side of the room and should be together.

3. **Hold this position for 5 seconds, if possible. Then slowly return your arm to its starting position.**

4. **Repeat the exercise with your other arm.**

   Aim for ten repetitions on each side, if you can manage that many comfortably.

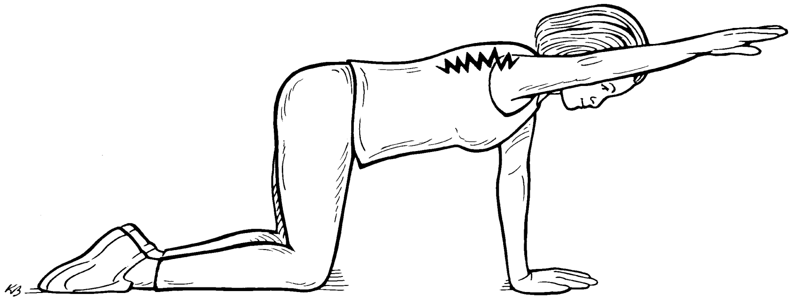


Figure 15-1: Shoulder arm extension. This exercise will help your upper back and can also improve your posture as well.

The exercise shown in Figure 15-2 is effective at toning both your side and back muscles and can be effective in preventing sudden back spasms that may result from turning or twisting the wrong way.

1. **Stand up straight with your feet about 18 inches apart.**
2. **Bend your left elbow and place your left hand on your waist.**
3. **Straighten your right arm over your head while, at the same time, trying to keep your right shoulder level with your left shoulder.**
4. **Bend slowly toward the left (toward your bent elbow), keeping your right arm above your head. Feel the pull in your right side. Hold this position for the count of five.**

   Don't push your right hip to the side as you bend. That can put extra stress on your knees. It's also cheating.
5. **Slowly return to an upright position.**
6. **Repeat on the other side.**

   Try for ten repetitions on each side.

The exercise shown in Figure 15-3 is really good for tightening your abdominal muscles, the ones that support your lower back. The mini sit-up causes your abdominals to contract and to hold at the point of maximum resistance, without overly straining your back and neck muscles.

1. **Lie flat on your back on your exercise mat.**
2. **Bend your knees, keeping your feet flat on the floor.**

   Your knees should be no more than an inch or two apart.

3. **Fold your arms across your chest and raise your head, neck, and shoulders off the floor.**

   Your head and neck will curl forward, but they shouldn't curl forward enough to cause your chin to be on your chest. (Imagine you have a tennis ball between your chin and your chest, to help you visualize this.)

4. **Suck in your stomach muscles and hold this position for a count of five.**

5. **Slowly release, and roll back down to your starting position.**

   Repeat this exercise five times, if possible.

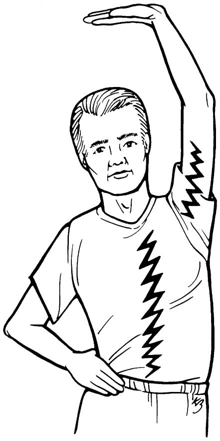


Figure 15-2: Side stretch. Stretching is important in fibromyalgia, and this exercise will help by stretching the muscles that extend from your upper arm to your hip.

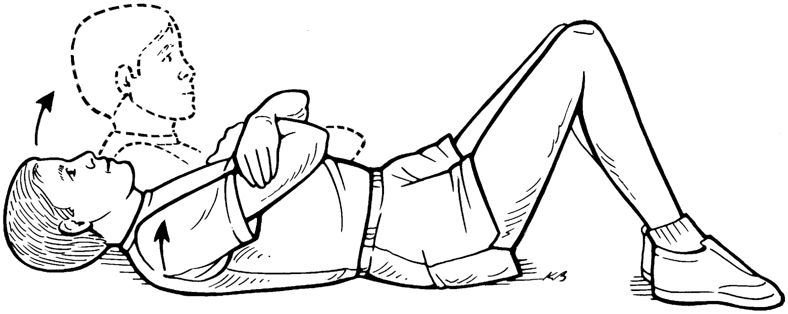


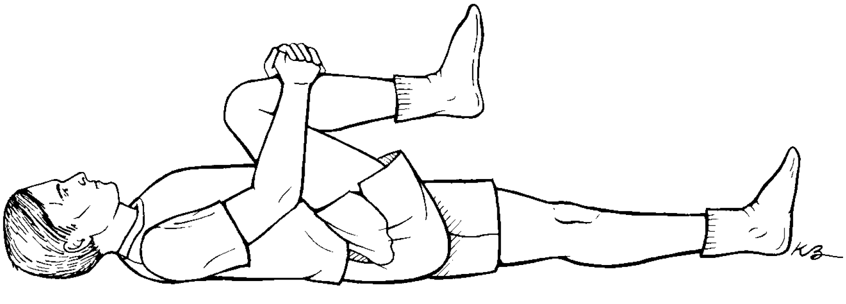
Figure 15-3: Mini sit-up. This simple exercise will tighten your abdominal muscles while avoiding placing stress on your back and neck.

The exercise shown in Figure 15-4 will loosen your hip joint while, at the same time, stretching your lower back and buttock muscles.

1. **Lie on your back on your exercise mat, legs extended and arms at your sides.**
2. **Bend your right leg, grab it with both hands just below the knee, and pull it gently toward your chest as far as you can.**
3. **Hold your leg at this maximum position for a count of five, making sure that your other leg is straight and on the floor.**
4. **Slowly release and repeat the exercise with your left leg.**

   Try for ten repetitions on each leg, if possible.

Figure 15-4: Knee-to-chest stretch. This stretching exercise is excellent for the lower back, the buttock muscles, and the hip joint.



Losing Weight to Decrease Pain and Fatigue

If you're carrying around some extra pounds (or maybe a lot of extra weight), this problem isn't actually causing your fibromyalgia. However, the additional weight can worsen the already-existing condition. Conversely, dropping a few pounds can make you feel significantly better. You don't have to lose an enormous amount of poundage. You'll feel and look better as soon as you lose a few pounds, which can motivate you to continue to lose weight at a slow and healthy pace until you reach your ideal weight.

Not only will weight loss improve (although not eliminate) your fibromyalgia symptoms, but weight loss (if you're overweight) will also decrease your risk for developing diabetes, hypertension, and many other health problems that are directly associated with obesity.

Give yourself small, doable goals. Even if you need to lose a lot of weight, shoot for 3 or 4 pounds as your initial goal. When you lose those 3 or 4 pounds, reward yourself (not with food!). Give yourself a small but nice bonus — maybe buy yourself a new outfit or hit the town for a night of dancing. Give yourself a few days or weeks to maintain that weight and, when you feel ready, set a new goal to lose another small amount of weight. Each time you reach your new goal, praise yourself lavishly in your mind. Focus on what you've achieved by losing those 3 or 4 pounds at each new level.

Figuring your ideal weight

How much should you weigh? The National Heart, Lung, and Blood Institute (NHLBI) has devised its own tables of *body mass index* (BMI), a height/weight measure. This information provides some basic guidance on how much weight is too low, just right, and over the top for your height.

You can easily determine your current body mass index by checking Table 15-2, a table of BMI levels provided by the NHLBI. The BMI is derived from a rather complicated formula, but you don't have to drag out your calculator or your old high school math book to do the equations. The nice people who made the chart have done all those calculations for you. (You can also find a handy online calculator at `www.nhlbisupport.com/bmi/`.)

Note: If you don't find your height/weight combination in Table 15-2, check out the online calculator. Another BMI chart is also available at `www.nhlbi.nih.gov/guidelines/obesity/bmi_tbl2.htm` for BMIs greater than 35.

Find out where you fit on the BMI chart, based on your height and weight. Then review Table 15-3 to see what your BMI means. In general, if your body mass index is 25 or greater, you're considered overweight.

For example, suppose that Mary is 5 feet 4 inches (64 inches) tall, and weighs 174 pounds. Her BMI is 30, which means that Mary is obese. To move down into the overweight category — which still isn't great but is better than obese — Mary would need to drop down to 169 pounds, a mere 5-pound weight loss. If Mary then decides that she wants to catapult herself all the way into the normal range, she would shoot for weighing less than 145 pounds.

Being underweight can be as unhealthy as being overweight. Instead of striving to look like your favorite movie star or Olsen twin, you want to strive for a BMI between 18.5 and 24.9.

Table 15-2 **Body Mass Index Chart**

BMI	***19***	***20***	***21***	***22***	***23***	***24***	***25***	***26***	***27***	***28***	***29***	***30***	***31***	***32***	***33***	***34***	***35***
Height (inches)	***Body Weight (pounds)***																
58	91	96	100	105	110	115	119	124	129	134	138	143	148	153	158	162	167
59	94	99	104	109	114	119	124	128	133	138	143	148	153	158	163	168	173
60	97	102	107	112	118	123	128	133	138	143	148	153	158	163	168	174	179
61	100	106	111	116	122	127	132	137	143	148	153	158	164	169	174	180	185
62	104	109	115	120	126	131	136	142	147	153	158	164	169	175	180	186	191
63	107	113	118	124	130	135	141	146	152	158	163	169	175	180	186	191	197
64	110	116	122	128	134	140	145	151	157	163	169	174	180	186	192	197	204
65	114	120	126	132	138	144	150	156	162	168	174	180	186	192	198	204	210
66	118	124	130	136	142	148	155	161	167	173	179	186	192	198	204	210	216
67	121	127	134	140	146	153	159	166	172	178	185	191	198	204	211	217	223
68	125	131	138	144	151	158	164	171	177	184	190	197	203	210	216	223	230
69	128	135	142	149	155	162	169	176	182	189	196	203	209	216	223	230	236
70	132	139	146	153	160	167	174	181	188	195	202	209	216	222	229	236	243
71	136	143	150	157	165	172	179	186	193	200	208	215	222	229	236	243	250
72	140	147	154	162	169	177	184	191	199	206	213	221	228	235	242	250	258
73	144	151	159	166	174	182	189	197	204	212	219	227	235	242	250	257	265
74	148	155	163	171	179	186	194	202	210	218	225	233	241	249	256	264	272
75	152	160	168	176	184	192	200	208	216	224	232	240	248	256	264	272	279
76	156	164	172	180	189	197	205	213	221	230	238	246	254	263	271	279	287

Source: National Heart Lung and Blood Institute (`www.nhlbi.nih.gov/guidelines/obesity/bmi_tbl.htm`)

Table 15-3 Body Mass Index Levels

Body Mass Index Category	*BMI*
Underweight	Less than 18.5
Normal weight	18.5–24.9
Overweight	25–29.9
Obesity	30 or greater

Source: National Heart Lung and Blood Institute (`www.nhlbisupport.com/bmi/`*)*

Improving your diet and exercising to shed pounds

Weight-loss medications exist for people who can't get the pounds off, no matter what they do (see the following section). But before you resort to prescribed medications and their side effects, work on exercising and changing your diet. I know, I know, it sounds boring and it's harder than popping a pill. But for most people, it's the best way.

REMEMBER

Exercise is good, but pace yourself. Because fibromyalgia is a condition with frequent ups and downs, you may make the mistake of demanding too much of yourself on days when you're feeling better.

TIP

Many people associate food with certain behaviors. Change the behavior, and you can lose weight. For example, if the coffee machine at work always has sweets around it, get your coffee and leave fast. Or better yet, bring water to work, and you won't even have to see the junk food and make a conscious decision to not eat it. Another idea: Instead of meeting friends for lunch at a restaurant, meet them at a museum or a park and walk around and chat with each other. Bring a nutritious picnic lunch to eat outside and enjoy!

TIP

Eat slowly and use smaller plates. If you chew your food more slowly, savoring it (but not so slowly that it becomes disgusting), you give your appetite time to kick in and tell you, "Stop! I'm full!" If you eat in a rush, you're more likely to overeat because your appetite hasn't had a chance to kick in. Using smaller plates may sound silly, but experts say that it works. Smaller portions don't look so small on smaller plates.

Considering some weight-loss meds

What if you've tried really hard to lose weight and increased your exercise, but gotten nowhere? Those pounds hang on like iron filings to a magnet.

Would using weight-loss drugs help you drop some of those pounds? Possibly, although you need to consider some pros and cons to their use before you start taking them. In addition, keep in mind that, despite dramatic advertising hype that you may read or see on TV, they aren't miracle drugs.

Many different weight-loss medications are on the market today. Some can be bought in your local supermarket or pharmacy and others require a prescription.

TIP

Some people have reported weight-loss success with Cymbalta, a prescribed antidepressant (generic name: duloxetine). Cymbalta is *not* a weight-loss drug, but in clinical trials, some subjects reported minimal weight loss. However, some individuals with both depression and a weight problem who take Cymbalta may enjoy a significant improvement with both problems.

WARNING!

I generally don't recommend over-the-counter weight-loss meds, despite their wonderful-sounding promises and the startling "before" and "after" pictures. The reality is that over-the-counter weight-loss remedies don't work for most people, and some remedies (such as some herbal remedies) can be dangerous or fatal. Also, in most cases, as soon as you *stop* taking an over-the-counter drug for weight loss, the pounds usually pile back on.

As for prescribed medications, the two most popular are Xenical (generic name: orlistat) and Meridia (generic name: sibutramine). These two drugs work in different ways to help people lose weight, and are usually only recommended for obese people, not for those who need to lose a few pounds.

WARNING!

Prescribed diet medications may cause aggravating side effects, such as high blood pressure and even fecal leakage. Also, you may need to take these medicines indefinitely, although their long-term effects of more than a year have not been tested so far. Even after taking the medication for a long time, you may experience weight gain after you *stop* taking the medication. Be sure to talk frankly with your doctor about prescribed weight-loss medications before you begin taking one, and be sure to discontinue the use of any over-the-counter weight-loss remedies while taking prescription weight-loss meds.

REMEMBER

People who need to lose only 3 to 5 pounds should never use weight-loss medicines of any kind. Remember, your weight fluctuates. Some people may weigh themselves at night, and the next morning, their weight could have changed by as much as 3 pounds. This is normal.

Researchers are working hard on developing and testing new medications that may enable people to lose a great deal of weight in the near future, but these drugs are still in the clinical-testing stage. They'll probably not be introduced to the general public for at least four or five years, at the earliest. These drugs seem to work well on laboratory rats, but it'll take time before researchers know whether they're safe and effective when people use them.

Discovering Dietary Effects: Good Foods/Bad Foods

You probably can't alleviate your fibromyalgia entirely by watching what you eat. However, studies have indicated that you may be able to reduce your pain level and even improve your quantity and quality of sleep by plotting a course toward certain foods and away from others.

People with FMS are different from each other, and no large-scale studies have found that some foods are good and others should be banned for people with fibromyalgia, but patterns are emerging. For example, some fibromyalgia sufferers agree that most fruits and vegetables (especially berries) and plain cereals are FMS-friendly, but chocolate, citrus fruits, and foods high in *monosodium glutamate* (MSG, a chemical regarded as a flavor enhancer), *aspartame* (an artificial sweetener), or caffeine aggravate their FMS symptoms. Check food labels to see whether MSG or aspartame is included in the product. (You may have a hard time giving up aspartame because it's in a wide variety of products, particularly diet soft drinks and reduced-calorie foods.)

If you find that MSG gives you trouble, when you eat out in restaurants, consider telling the waiter that you're allergic to MSG, and it should not be added to your food. (You can also simply request that MSG not be added to your food, but that request may be ignored. If you say that you're *allergic,* your request is more likely to be heeded. It's not a total lie — MSG *can* cause a flare-up of FMS symptoms.)

As for beverages, plain old water is best. You may think that water is really boring — but have you checked the water aisle of your supermarket lately? You can get water with lemon or other flavors added, and with carbonated water if you like bubbles. If you don't want fancy water, local tap water will work just fine.

One way to figure out whether specific foods make your symptoms worse is to keep a food diary. Each day, write down everything you eat on one side of a sheet of paper. On the other side of your paper (at the end of the day), list any symptoms that are worse than usual, such as worsened pain or greater fatigue. Keep your food diary for at least two weeks, comparing what you ate with how you felt. If you notice that you felt worse when you ate ice cream and milk and had whipped cream on your pie, maybe dairy products are a problem for you. If you felt bad when you ate pecan pie, maybe nuts bother you. If you start to see a pattern, eliminate the suspicious food for a week or two and notice if you feel any different. If you feel better without it, that food may be a problem for you and should go on your "avoid" list.

Chapter 16

Coping with Emotions: Your Own

In This Chapter

- Understanding what depression is and how to deal with it
- Making sense of anxiety disorders and knowing what to do about them
- Taking your emotional temperature: A self-test
- Finding a therapist if you need one
- Thinking about medications for emotional problems

Fibromyalgia syndrome (FMS) can be so painful, with symptoms so distressing, that the illness drives people into depression or anxiety. Depression and/or anxiety can worsen pain and other symptoms of fibromyalgia. Confronting emotional difficulties and seeking help is a much better strategy than denying or wishing them away. This active coping strategy can also lead to significant improvement of your FMS symptoms.

In this chapter, I cover common emotional problems faced by people with fibromyalgia. First I cover depression because people with fibromyalgia are often depressed. I help you identify symptoms of depression and offer advice on resolving it. Anxiety disorders are also common among people with FMS. This chapter offers advice on what to do if anxiety overwhelms you.

You may have trouble recognizing your emotional status because people often become emotionally numbed by problems. I offer a self-test to take your "emotional temperature," explaining what your answers may mean and what to do about them. I also talk about finding a therapist and cover key psychiatric medications for depression or anxiety.

Dealing with Depression

Depression is more widespread than most people realize, and many people experience clinical depression at some point in their lives — whether they have fibromyalgia or not. But people suffering from fibromyalgia are particularly vulnerable to this illness.

Defining depression and its symptoms

Depression is an extreme form of sadness that manifests in feelings of continued and severe hopelessness or helplessness. People throw around the word *depressed* to denote having a bad day, but depression is much more intense and long-lasting.

Depression manifests differently in different people. Some people cry; others yell or behave aggressively. Here are some symptoms of possible depression:

- An appetite change causing a gain or loss of 10 pounds or more in a month
- Frequent thoughts of suicide and/or a plan for suicide
- Lack of interest in activities that were considered pleasurable in the past
- A dramatic drop in energy and activity levels
- Extreme guilt
- A continued sense of hopelessness
- Excessive agitation or anger
- Sleeping excessively or difficulty sleeping

If you have any of these symptoms, see your doctor or therapist. (Turn to "Taking Your Emotional Temperature" in this chapter for more insights.)

Connecting fibromyalgia and clinical depression

The majority of people with fibromyalgia suffer some level of chronic depression. Which came first — fibromyalgia or depression — isn't always clear. What's important is identifying depression if it *does* appear and working to control it. Physicians say depression is one of the most treatable emotional problems around. It doesn't get better on its own — it requires work. Depression is more likely to occur with your fibromyalgia if you have a close family member with depression or you've been depressed in the past.

Treating depression

Linda says she stopped listening to her children and her husband, and spent most days in a fog of despair. She couldn't work, so she stayed home — she's not really sure what happened on those days. The pain and fatigue from fibromyalgia, combined with her depression, made life almost unbearable. Linda's husband insisted she see a psychiatrist, and she agreed.

The psychiatrist diagnosed depression and placed Linda on Cymbalta (generic name: duloxetine), an antidepressant that increases blood levels of serotonin and norepinephrine, brain chemicals related to mood. Cymbalta has also proven effective at decreasing *both* depression and chronic pain.

Linda's doctor recommended that she start a daily walking program and urged her to see a pain specialist to get her pain under control. Within a few weeks of following the doctor's orders, and seeing a rheumatologist experienced at treating FMS, Linda's depression began to lift, her pain levels dropped, and she began to believe that she could manage this fibromyalgia thing.

Many depressed people need to talk about emotional problems with a psychiatrist or a psychologist to resolve them. (Check out the "Finding a Therapist" section, later in this chapter, for more information.)

Cognitive-behavioral therapy and fibromyalgia

Therapy often helps people with fibromyalgia and depression or anxiety. Studies of individuals with both an anxiety disorder and fibromyalgia have revealed that cognitive-behavioral therapy (CBT), in which the therapist teaches patients to identify and challenge self-defeating ideas, is effective. In clinical studies, CBT has proven to reduce pain intensity.

Determining If It's an Anxiety Disorder

Your emotional problem may not be depression at all. Instead, you may have an anxiety disorder. According to the National Institute of Mental Health (NIMH), 40 million American adults suffer from an anxiety disorder. You may have one or more anxiety disorders — but they're all treatable.

Defining anxiety disorders

Anxiety disorders come in many forms. In the following sections, I outline the most common, their symptoms, and how they are treated.

Generalized anxiety disorder

Many people (about 6.8 million adults in the United States, according to the NIMH) suffer powerlessness, compounded with foreboding caused by *generalized anxiety disorder* (GAD). They suffer from relentless worry and fear and may have nausea, muscle aches, fatigue, and irritability. GAD differs from depression, a feeling of emotional flatness and hopelessness. Think of the anxious person as running around in circles, while the depressed person lies on the couch, having given up.

Chronic-panic disorder

Some individuals (about 6 million adults in the United States, according to the NIMH), including some patients with FMS, suffer from chronic-panic disorder, characterized by panic attacks with a racing heart and a feeling of impending doom. They may experience profuse sweating and think they're having a heart attack, increasing their anxiety further.

Obsessive-compulsive disorder

According to the NIMH, about 2.2 million American adults suffer from obsessive-compulsive disorder (OCD). People with OCD may constantly count things or wash their hands, among other symptoms. They can't stop themselves. TV's Monk is an example of a person with OCD.

Post-traumatic stress disorder

According to the NIMH, about 7.7 million American adults suffer from post-traumatic stress disorder (PTSD). Individuals with PTSD may periodically relive former traumatic experiences, such as combat, sexual assaults, childhood abuse, or other events. They may also become emotionally empty. PTSD increases the risk for fibromyalgia. In a study of 1,259 female military veterans with and without PTSD (reported in *Archives of Internal Medicine* in 2004), the 266 female vets *with* PTSD had a greater rate of fibromyalgia (19.2 percent) than female vets *without* PTSD (8 percent).

Treating anxiety disorders

Tina has fibromyalgia, and has suffered from frequent occurrences of her heart racing uncontrollably and feeling faint. But the doctor said that her heart was fine. Tina consulted a therapist and learned to avoid panicking over minor problems. She became more proactive about resolving her FMS with relaxation therapy. (Read about relaxation therapy in Chapter 13.)

Many people benefit from both medication and therapy. In addition, many find solace in talking to others with similar problems. (Read about support groups in Chapter 18.) Others find that one-on-one sessions with therapists work for them (see the "Finding a Therapist" section later in this chapter).

Sorting out anxiety versus depression

Many people are confused about the difference between depression and anxiety. Aren't depressed people anxious? And aren't anxious people depressed? Yes, some people *are* depressed and anxious. But there are differences. Table 16-1 compares the emotional and physical symptoms of generalized anxiety disorder, depression, and fibromyalgia. For example, people with GAD may sleep less because they're so worried. In contrast, depressed people may sleep less *or* more than usual. Those with fibromyalgia only may experience less sleep.

Table 16-1 Symptomatic Differences in Generalized Anxiety Disorder, Clinical Depression, and Fibromyalgia

	Anxiety	*Depression*	*Fibromyalgia*
Sleep changes (increased or decreased)	Common (Usually less sleep than normal)	Common	Usually less sleep, rather than too much
Anger	Not common	Common	Common
Hopelessness or futility	Common	Common	Common when untreated
Helplessness	Common	Common	Common when untreated
Confusion	Possible	Possible	Common (It's known as "fibro fog.")
Overall fearfulness and dread	Common	Not common	Not common
Appetite changes (eating more or less)	Common	Common	May occur
Headaches	Common	Common	Common

Taking Your Emotional Temperature

You know how to take your body temperature. What about your emotional temperature? How you feel directly affects your fibromyalgia symptoms. This section covers taking your emotional temperature.

In the preceding sections, I talk about depression and several forms of anxiety disorders, but in this section, I offer everyday examples of emotional distress. If any of these situations describes your emotional state, you may be experiencing depression or anxiety:

- **Nearly every morning, I feel like crying or screaming.** If you wake up sad, you may be depressed. If you feel so anxious that you want to scream, you may have an anxiety disorder. When you have fibromyalgia, the pain and insomnia may be making you down or anxious. Or you may have FMS symptoms *and* depression or anxiety. Talk to your doctor.
- **My family and friends constantly ask if I'm okay.** If your family and friends keep asking if you're okay, maybe they've noticed you never smile and seem distressed or agitated. Pay attention. Maybe you're getting a warning signal to heed. Talk to a doctor or therapist about this.
- **At least several times a week, I wonder if my life is worth living.** All people wonder sometimes about their value to the cosmos. But if you constantly question your personal self-worth, you may be in or headed for depression. If you've considered suicide, see a doctor or therapist right away.
- **I feel like a robot. I get up, go to work, and come home. It's so joyless.** If your life is only shades of gray, this may indicate depression. It's also a sign that you need a break. Change some patterns in your life. Call a friend and go out. If this idea has no appeal, see a therapist.
- **I can't think of anything that makes me really excited and happy.** If nothing makes you happy, and even thinking about activities that you used to like give you no reaction, you're either depressed or anxious. You could also be *both* depressed and anxious. See a doctor or therapist.
- **Many times, I feel if one more person annoys me, I may explode.** Anger is one way to exhibit depression or anxiety. If minor slights make you want to put your fist through a door, see a therapist now.
- **I've been eating more (or less), and my weight has changed considerably in the past months.** Over- or undereating can indicate depression or anxiety. If you haven't tried to gain or lose weight, but it's happening anyway, see your doctor. If medical problems are ruled out, a therapist is often your next best choice.
- **If a genie offered three wishes, I'd have trouble thinking of two requests — or one.** If you can't think of one or two things you'd want if three magic wishes were offered, you may be depressed. Get a physical exam to rule out hypothyroidism or other medical problems. If the tests are normal, see a therapist.

Finding a Therapist

When looking for a therapist, you'll find many different therapists with different orientations. The key is to find a therapist who understands your particular problems, and can help you create a plan to deal with them as effectively as possible.

No matter who you decide to work with, the therapist needs to accept that FMS is real. Your anxiety or depression may exacerbate pain and other symptoms. Conversely, fibromyalgia may worsen emotional symptoms. If the therapist has experience working with patients with FMS, fine. You may also do well with a therapist willing to learn about fibromyalgia.

Suppose you've found a good, credentialed therapist. Will she make your problems go away? Therapists aren't superhuman, but often know ways to help manage problems. Resolving emotional problems takes time, at least five to six sessions, at a minimum.

Identifying different types of mental-health professionals

Many people are confused by which professionals provide help for emotional problems. There are four primary types of helping professionals, and they vary according to their education and types of patients they treat. They have other differences as well. In the following sections, I spell it all out.

Psychiatrists

Psychiatrists are medical doctors who treat emotional problems; they're the only therapists in this section who can prescribe medication. Most psychiatrists treat a broad range of emotional problems. An initial evaluation may take an hour, but a "medication check" for established patients may last a few minutes.

Psychologists

These are individuals with PhDs or doctorates in psychology or counseling. Psychologists may specialize in treating specific types of problems, or may be generalists. Psychologists use many different types of therapies; however, the most effective one appears to be cognitive-behavioral therapy (see "Cognitive-behavioral therapy and fibromyalgia," earlier in this chapter).

Social workers

Social workers have master's degrees (and sometimes doctorates) in social work. Social workers are interested in practical ways to resolve problems. They may be adept at analyzing family relationships and helping individuals get along better.

Other therapists

Some therapists have master's degrees in psychology or counseling. Check whether a therapist you're considering has a professional license with the state licensing board. (Most state licensing boards are at a department of professional regulation in your state capital.)

Finding and screening therapists

TIP

Suppose you don't know how to find a therapist. Where do you start?

- **Ask your doctor.** The doctor won't tell the world you need a shrink. Doctors must hold your information in confidence.
- **Call the state Mental Health Association office, usually in your state capital, for a recommendation.** Find the nearest office in the United States at `www.nmha.org/affiliates/directory/index.cfm`.
- Ask your clergyperson for a recommendation.
- If they're willing to help, ask your family and friends if they can recommend a therapist.

Meeting with a therapist

The first time you meet a psychiatrist, psychologist, or other therapist, make the following determinations:

- **Do I feel comfortable with the therapist, and think she may help me?** If not, find another therapist.
- **Does the therapist have experience with pain patients?** Find out during the session, because the information may not come out otherwise.
- **What type of therapy does the therapist perform?** Ask the therapist. Keep in mind that cognitive-behavioral therapy is proven to be effective.

Treating Emotional Problems with Medication

Some people think the right pill will cure anything, while others think medications (especially psychiatric drugs) should be avoided. The reality is somewhere in the middle. Medications for emotional disorders can provide considerable relief, but rarely provide a cure. Other actions are often needed, such as psychotherapy, exercise, sufficient sleep, stress reduction, and so forth. That said, medications for emotional problems can be lifesavers.

WARNING!

Just because medications for emotional problems are needed doesn't mean they're free of side effects. (Check out Chapter 10 for common side effects with antidepressants and anti-anxiety medications.)

REMEMBER

Telling yourself to forget problems or smile through your tears isn't usually effective, unless the problem is a temporary bad mood. Antidepressant medications may help alleviate depression, and anti-anxiety drugs may help squelch anxiety.

You may need one or more drugs to combat emotional difficulties, and your doctor may try several medications (usually one at a time) before finding one that works. She'll probably start you on a low dose of one drug, to tell which drug is responsible if side effects occur. Check out Table 16-2 for a list of medications for depression and anxiety and common side effects.

Table 16-2 Common Medications for Depression and Anxiety

Medication	*Generic Name*	*Prescribed For*	*Most Common Side Effects*
Lexapro	Citalopram	Depression and anxiety	Loss of sexual desire
Zoloft	Sertraline	Depression	Loss of sexual desire
Valium	Diazepam	Anxiety	Sleepiness, physical dependence
Cymbalta	Duloxetine	Depression	Insomnia or sedation; loss of sexual desire in men and abnormal orgasm in women

(continued)

Table 16-2 *(continued)*

Medication	*Generic Name*	*Prescribed For*	*Most Common Side Effects*
Effexor	Venlafaxine	Depression	Nausea, increased blood pressure
Buspar	Buspirone	Anxiety	Dizziness
Paxil	Paroxetine	Depression and anxiety	Nausea, sleepiness
Xanax	Alprazolam	Anxiety	Sleepiness
Wellbutrin	Bupropion	Depression	Increased energy, poor sleep

Antidepressant medications may have extra benefits for people with FMS:

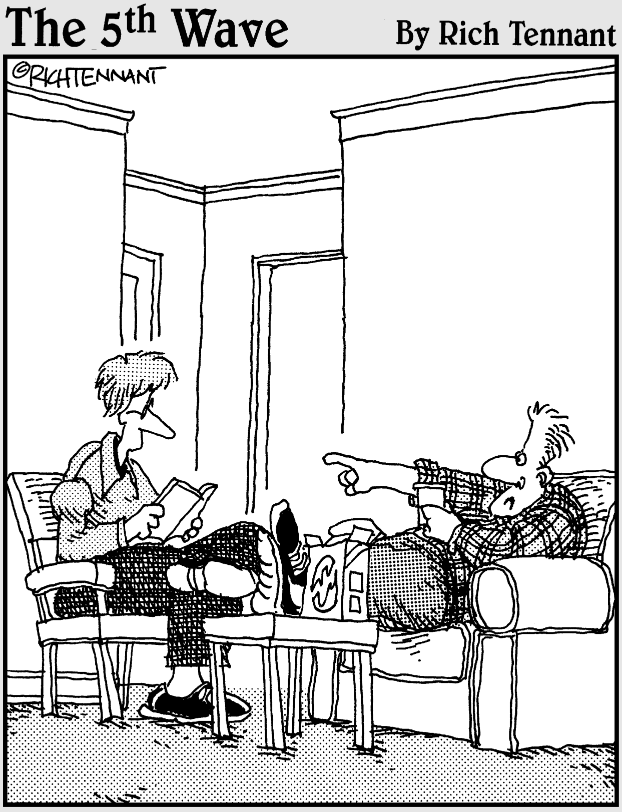
- Depression increases the experience of pain, possibly from depletion of serotonin and/or norepinephrine. Even if you're not depressed, antidepressants can improve serotonin production and decrease pain.

  Nonpsychiatrist physicians often prescribe low doses of antidepressants to patients with chronic pain. (Read more about antidepressants in Chapter 10.) But if you have depression *and* chronic pain, you may need a therapeutic dose to deal with both problems.

- People with fibromyalgia often don't get enough restorative sleep. Antidepressants or sleep remedies may help resolve this problem. (Read Chapter 14 on sleep problems and what to do about them.)

Part V

Managing Fibromyalgia at Work and at Home



"C'mon, Darrel! Someone with fibromyalgia shouldn't be lying around all day. Whereas someone with no life, like myself, has a very good reason."

In this part . . .

Because fibromyalgia affects you pretty much 24/7, both on the job and at home, this part addresses both arenas of your life. In Chapter 17, I cover fibromyalgia on the job and what to do if your symptoms bother you so much that it's hard (or impossible) to work anymore. I also offer tactics on coping with your insurance company, your boss, your co-workers, and others.

Face it: Your fibromyalgia affects your family. In Chapter 18, I explain how your fibromyalgia affects your loved ones and offer advice, including how to explain fibromyalgia to your children, what to do about your (possibly) impaired sex life, and other key issues.

Chapter 19 is for non-fibromyalgia people: those who don't have the problem but really want to help friends and family members who do. I provide comments from people who have fibromyalgia on what they wish others would know, and offer helpful hints on what to say (and *not* say) to a person with fibromyalgia. If you have fibromyalgia, you may want to discreetly leave the book open to this chapter for some key people in your life.

I also include a chapter on fibromyalgia in children and adolescents. Yes, they can and do suffer from this aggravating medical problem — yet so often, children and teenagers suffer because they go undiagnosed. I hope Chapter 20 will help rectify that problem.

Chapter 17

Working with Fibromyalgia — Or Going on Disability

In This Chapter

- Deciding whether to tell your boss and co-workers about your fibromyalgia
- Dealing with your health-insurance company when it's sticky about claims
- Thinking about applying for disability payments
- Identifying and interviewing an attorney to help you

Eva hasn't told her boss about her fibromyalgia yet, and nobody else in the company knows about it so far, either. Eva's keeping her fibromyalgia a big secret, afraid that she won't be allowed to do her job if people at work know about her fibromyalgia. Eva often works alone, using a company-owned all-terrain vehicle to get to remote work sites where she does her field research. The vehicle has broken down a few times, and she's had to hike out of the wilderness to get help on more than one occasion. Eva's afraid that if the boss knew about her medical problems, he wouldn't allow her in the field alone — and Eva may be right.

Eva also performs extremely detailed work, and sometimes the *fibro fog* (difficulty concentrating) is so thick upon her that she has to double- and triple-check her work. So far, Eva's careful work has paid off, and she hasn't made any mistakes. But she fears that just the possibility that she may make mistakes is another reason not to tell anyone about her fibromyalgia.

Is Eva right or wrong about not telling her boss about her fibromyalgia? That's a tough call to make. She's doing her job well, and so far, nobody's even suspected that she has a problem. However, Eva worries about "what if" — so much so that her overall quality of life and general happiness is impaired. And if she ever *does* have a problem and tries to make a claim, the company can say that Eva never told them about her fibromyalgia or her symptoms and problems.

Perhaps Eva's life would be a lot easier if she just came clean and told her boss about her problem with fibromyalgia. If she told her boss in a TV sitcom world, he'd understand completely, everyone would pat her on the back, unseen people would clap, and the camera would fade out. But life isn't always like that, and Eva knows it. So for now, Eva plans to continue to hide her fibromyalgia and deal with its symptoms as best she can.

As Eva's story makes clear, dealing with fibromyalgia in the workplace presents a unique set of challenges. In this chapter, I give you some guidance about how to handle work and fibromyalgia syndrome (FMS). I also give you some advice about what to do if your work burdens are so severe that you can't work full-time anymore and how to go about obtaining disability payments, if you need to take that step.

Explaining Fibromyalgia to Your Boss and Co-Workers: Should You?

Telling your supervisor and co-workers why you're taking more sick days than anyone else and why you can't always perform at your peak level may seem to you (or to others giving you advice) to be the obvious choice. But deciding whether to tell your supervisor and others at work about your fibromyalgia can be a dilemma. Will your co-workers think that you're an invalid or very disabled? Will they treat you differently? Or will telling them make your work life much better, and solve a lot of the problems that you're facing?

In general, the reaction of people at work probably won't fall into the two extreme scenarios that you may envision. Telling your boss and co-workers about your fibromyalgia generally won't solve all your problems. And, on the other hand, it usually won't create cataclysmic new problems for you, either.

Karen says that she recently told her boss about her fibromyalgia. She's an editor, and, sometimes, her work schedule must be sharply reduced because of her FMS symptoms. For example, on many days, she can work no more than five hours per day, and she says that the pain and fatigue sometimes impair her concentration. Karen says that before she revealed her problem with FMS to people at work, she often came under intense pressure to work very long hours, but she just couldn't do it. Now, her problem with fibromyalgia is out in the open, and Karen can limit her hours.

Karen's boss accepts her plight, but her co-workers can't seem to fathom what fibromyalgia is and how it affects her — especially when they feel as though they have to pick up the slack from the work that Karen's unable to do. Maybe she's paranoid, but she feels like she's noticed that some conversations seem to stop when she walks into the room, and she's noticed a few resentful looks. Karen's thinking about talking to her co-workers more about her fibromyalgia, but she isn't quite sure what to say.

Deciding whether to tell

Here are some questions to ask yourself in deciding whether to tell or not to tell your boss and/or your co-workers about your fibromyalgia:

- **Are your symptoms making your work quality suffer, so that people are wondering what's wrong?** If you can still handle the job and don't want people to know about your FMS, you can probably keep your secret. But if your work isn't quite as good as it once was, it may be best to explain why. Otherwise, people will supply their own reasons, and you may not like the reasons that they imagine are true.
- **Is the job itself worsening your symptoms?** If you work on an assembly line or have another type of job that makes your symptoms worse, you should think about your health. You can ask for a different job, shorter hours, or other changes when doing so for health reasons. Otherwise, things probably won't change.
- **Are you able to work as many hours as the job requires?** Sometimes, the fatigue and pain of FMS may drag you down. You may need to request other arrangements or even consider a different job in the company (or out of the company).

Forming an explanation

If you decide that you want to talk about your fibromyalgia with your boss, and maybe your co-workers as well, what's a good explanation? I recommend that you say that you have fibromyalgia, which is a chronic, widespread pain problem that's accompanied by fatigue and, sometimes, other symptoms. Tell your boss that a doctor has diagnosed you with this illness, and you're frequently in pain, but you'll do your best to manage your workload. But also explain that, sometimes, the pain and fatigue may make it impossible for you to continue working, and you'll need breaks or may need to stop working altogether. Initially, some people will feel uneasy around you. But when they see you soldier on without a lot of self-pity and complaints, they may express a newfound respect for you.

Deciding Whether You Should Stay at Your Job

When you have FMS, you may sometimes feel as though you're trying to press forward against a stiff wind, as you struggle to maintain a delicate balance between fulfilling your work commitments and coping with your fibromyalgia symptoms. Some people with fibromyalgia have been able to create an alternative work arrangement with their company to let them telecommute. Others have switched to *flex time* (where you set your own hours) or to part-time work, and that option has enabled them to continue working in their jobs. Others, however, continue to struggle, afraid to tell anyone at work of their medical problem.

Alternative work arrangements can be great — if they're possible. But some jobs simply aren't adaptable to telecommuting, part-time work, or even flex time. For example, if you work with others on a team, the team members usually need to be there all at once. If you work in an office that needs to be staffed from 9 to 5, you can't work the night shift, although you may be able to work part-time during the day.

Working at home works for some FMS sufferers

Carla, a programmer, says that she would've had to go on disability if her company hadn't agreed to allow her to telecommute. She says that she couldn't handle the long commute anymore. By the time she arrived at work, she had almost nothing left, energy-wise, and getting home after a long day was a nightmare.

Telecommuting is a great option for many individuals who find commuting, and working away from home, to be difficult to impossible. But don't expect an ideal world if you work at home. Your co-workers may be resentful, for one thing. That's what happened to Jennifer, who says that she was put on salary, so that she could work at home and rest when she needed to. Jennifer usually puts in more than the 40 hours she used to give the company when she worked in their building. But she says that her co-workers complained that it was "favoritism," and they don't seem to understand that the change was made to benefit not only Jennifer, but also the company. Of course, Jennifer doesn't see her co-workers much because she goes into the office only briefly every week or every other week. She's decided that she won't worry about their jealousy.

Not all jobs are conducive to working at home. However, if at least some aspect of your job can be performed at home, as is often the case, people with fibromyalgia say that telecommuting can help a lot in keeping them continuously employed. They *do* still have to complete some amount of work within a given time, and they need to be people who are self-motivated and willing to push themselves when necessary.

Considering the Family and Medical Leave Act

The *Family and Medical Leave Act* (FMLA) is a federal law that directly affects workers in most companies. This law allows workers to take up to 12 weeks of *unpaid* time off each year for medical problems that they face or to provide care to members of their family. If you take an FMLA leave, your company must also hold your job open for you or give you a comparable job when you come back to work.

Such time off can be intermittent, meaning a day off here and there; it doesn't have to be weeks at a time. However, if you want to use FMLA provisions, you must inform your supervisor of your medical problem, and you should try to guesstimate how much time off you'll need. For further information on the Family and Medical Leave Act, contact the Employment Standards Administration of the Department of Labor at Frances Perkins Building, 200 Constitution Ave. NW, Washington, DC 20210 (phone: 866-487-9243; Web: `www.dol.gov/esa/whd`).

Sometimes, the demands of the job may become impossible for a person with fibromyalgia. For example, Julie was a potter several years ago, but she had to quit pottery work. She explains that clay is extremely heavy, and she became exhausted after trying to work on the clay or even center the clay on the wheel. Often, she wouldn't go into her studio for days from sheer exhaustion. The gallery owner whom she sold her work to was angry because Julie's pottery was very popular, and the owner had actually wanted Julie to *increase* her production. But Julie just couldn't continue — it hurt too much.

So how do you know whether you have the kind of job that's usually not workable with fibromyalgia? Here are some questions to ask yourself:

- ✓ Can you take regular breaks at work, as needed?
- ✓ Can you be absent from work as needed?
- ✓ Do you need to move heavy objects or operate heavy machinery?
- ✓ Is your job especially sensitive to errors?
- ✓ Does your job require you to maintain painful body positions?
- ✓ Are others at work dependent on your being there regularly?

If you decide that you just can't stay on at your job, you have some new decisions to make. Can you work at another job in the same company? Or can you work part-time? Maybe you'd be better off at another company. And if your symptoms make it difficult or impossible to continue to work, you need to consider applying for disability payments (see the "Taking the Next Step if FMS Is Disabling" section, later in this chapter).

Getting Your Insurance Company to Pay for Treatment

Most insurance companies know that fibromyalgia is a valid diagnosis and a real medical problem. But your company may balk when you request medical coverage for treatments that it may see as "iffy," at best, or if you seek coverage for a screening test or a procedure that it doesn't generally cover. Because treatments or procedures that your doctor thinks you need may be difficult for you to pay for solely out of your own pocket, taking the time to convince the insurance company that your requests are reasonable may be worth the extra effort. This section offers advice on achieving that goal.

Providing more info

Sometimes, the initial claim for a treatment or test goes sailing right through your insurance claims department. But, sometimes, it gets flagged, and more information is required. The insurance company may send you (or your physician) a letter asking for more information. If more information is requested, the insurance company is usually specific about what it wants. Often, you can call the company and provide the information they need. Or you may be able to fax the necessary information.

TIP

If you're able to fax information to the insurance company, always send the fax to a specific person. Most insurance companies are large and very busy, and things easily get lost.

Understanding why your claim may be denied

The insurance company may deny your claim outright for an array of reasons. The company may decide that the type of claim isn't covered (such as for massage therapy or another type of service) because it has never covered that treatment before. Or it may decide that the provider (doctor, chiropractor, or other person) isn't on its approved list, so it gives your claim the old DENIED stamp. Or the company may simply make a mistake and deny a claim that would normally be approved.

An appeal, however, will require another person at the insurance company to consider the treatment or doctor, and if you've backed up your claim, often you'll succeed. For example, if you can show that massage therapy or some other therapy may help, the person reviewing the appeal may give you the thumbs-up. Maybe the doctor you want to see is the only person in the area who's knowledgeable about fibromyalgia, another reason to consider your claim. Offer facts that the average person may consider reasonable, and you have a better chance of successfully appealing the claim denial.

Appealing insurance denials: Do it!

The average person receiving a claim-denial letter from the health-insurance company is usually disappointed and takes no further action. If you think that the treatment you were denied was justified, don't make this mistake. Virtually every health-insurance company has an appeals process, and appealing a denied claim with the hope that whoever reviews the appeal will reverse the decision is often well worth the effort.

The easy way

Sometimes, the mere act of calling the insurance company and explaining that you plan to appeal the denial may cause the company to take a harder look at your request. Sometimes, you may be asked to wait, and then you may receive an approval that day or several days later. The reason: Few people like to have their work reviewed, and most hate having a decision overturned. When you appeal a denied claim, this automatically means that someone else, often a supervisor, will review the person's work and could disagree with the initial decision. To avoid this possible outcome, when you say you're going to appeal, the denying person may change her mind about your denial, transforming it into an approval. It doesn't always happen, but it's worth a try. If your denial stands, go ahead with the appeal.

If you talk to someone from your insurance company on the phone, always get the person's name and take notes. Write down the date and the gist of the conversation. Keeping this kind of a record can be very helpful later. If Jack at the Hill Insurance Company says that no one's ever talked to you, you can tell Jack that you talked to Jill at the same company on May 25, and she said whatever she said. Be confident and stand firm.

The hard way

Assuming that the verbal threat of an appeal isn't sufficient, you'll need to follow through. This may involve filling out forms that the insurance company provides. Always include a cover letter that you write to go along with any required forms. In that letter, briefly explain what you want and why you think that you should get it.

In most cases, the notification that you received that denied your claim will tell you that you have the right to appeal and will also tell you what steps to take. If that information isn't provided, ask the insurance company to send or fax you the form you need, or ask your HR department to help you locate the forms.

Don't expect instant results when you appeal a denial. It'll usually take weeks and may even take months before the case is resolved. Patience and persistence are key.

Adding letters

Back up your appeal with information contained in a simple typewritten letter. Whenever possible, think of ways that the treatment you want (or the physician you want to see) would be cost-effective for the insurance company or even save it money. You may not care about that, but the insurance company does. For example, you may have been denied a referral to see a specialist, such as a rheumatologist or a neurologist. Or you may have been denied an opportunity to be evaluated with a screening tool, such as *magnetic resonance imaging* (MRI), or some other test that may help evaluate your condition. If you believe that seeing the specialist or having the test could better pinpoint your problem, and perhaps cut back on the number of physician visits you incur (and especially if it could cut back on costly emergency-room visits), say so in your letter. If you can estimate the cost savings, do so.

Keep your letter to one page, if possible. ***Remember:*** It must be typewritten, not handwritten. If you can't type the letter because of an arthritic condition or another problem, get someone else to type it for you. Make sure that the letter is dated and that it includes your address, phone number, and health-insurance number. Provide the name of your primary-care doctor in the text of the letter. Before sending the letter, carefully proof it to make sure that the letter has no spelling errors or typos. Nothing hurts a person's credibility like a poorly written letter that's full of errors.

Don't insult the insurance company in your letter, no matter how annoyed you may be. People, not computers, will read this letter, and they'll be much *less* likely to give you what you want if you call them fools, evil people, or use other forms of name calling (even if they deserve it).

Provide factual data. Tell the company what your diagnosis is and why you and your doctor think that you need the treatment, the test, or to see the specialist who's not in your insurance company's network of doctors. State *exactly* what you want: Don't make the reader guess. You want coverage for an MRI or for a specific procedure or specialist. Also, explain *why* you want it, even if the answer seems glaringly obvious. You want it because it can further determine what your problem is, it may provide pain relief, or whatever the reason. In addition, if such a treatment or referral was ever approved in the past, for you or anyone else you know with the same health coverage, say so. Provide as many details as possible. If the insurance company thinks that a precedent was set, it's more likely to give you what you want.

TIP

You may also want to ask your doctor to write a letter explaining why you need the treatment. Ask the physician to give you the letter, so you can refer to it in *your* letter. Provide the doctor's letter as an enclosure. If the doctor insists on sending the letter directly to the insurance company, ask for a copy. Refer to your doctor's letter in your letter, and enclose the copy.

If your doctor is in a clinic or office with many doctors, sometimes one person there is responsible for pursuing insurance denials and approvals. That person may be able to help you get approval for your claim.

Taking the Next Step if FMS Is Disabling

Perhaps you just can't continue on in your work because you're too sick or because the job requires more time and is more stressful than you can cope with — or maybe because of both reasons. If you're in bad financial straits and need money to support yourself, eventually you'll have to apply for disability or take some other action to keep the dollars coming in. In that case, you may decide that the time has come to investigate a short-term or long-term disability leave from your job or to consider applying for disability payments received through the Social Security Administration.

TECHNICAL STUFF

A *short-term disability* can be an illness that prevents you from working anywhere from a few weeks to about six months, by most definitions. A *long-term disability* is generally a medical problem that prevents you from working indefinitely. However, corporate and state definitions of these terms vary.

When you have a disability, this means that a medical problem hinders or prevents your ability to work. You may need to file for a disability program, so that you can receive all or part of your income. You may also be too ill to return to work later on, and decide to apply for Social Security disability payments.

Disability programs fall into several major categories, and they vary in terms of how long they last, who administers these programs, whether the federal government or your state government is involved, and in many other ways. These categories and their many rules and ramifications are far too complex for me to delve deeply into here. But I can offer you a brief overview of disability options.

The skinny on worker's compensation

Worker's compensation (also known as *worker's comp*) is for individuals who can't work because they were injured on the job. You may be eligible for worker's comp if you believe that your job contributed to causing your fibromyalgia — for example, if you have a job that requires repetitive motions. People with fibromyalgia are more likely to go with short-term or long-term disability options rather that worker's compensation, but it *is* still an option if you truly believe that your job caused your FMS. This program generally provides that employees receive about two-thirds of the amount of their paychecks. Nearly all companies have worker's compensation programs. Worker's compensation isn't a long-term option, however. Eventually, you must go back to work or apply for a short-term or long-term disability benefit.

Questioning yourself

Each person must make his own decision about whether to apply for a disability. In general, don't think that your pain will automatically get better after you're on disability. Often, the loss of social function can have a negative impact on pain. Asking yourself the following questions as part of your decision-making process may help:

- ✓ Have you exhausted all possible therapeutic options that were given to you? Have you done everything you can to decrease your pain, including taking your medications, improving your sleep, and doing your exercises?
- ✓ Has your doctor told you that you should quit working or significantly reduce the number of hours that you work?
- ✓ Have you been taking more than four to five days off per month because of your illness?
- ✓ Are you staying the same or getting worse?
- ✓ If you're considering a short-term disability, will this time off enable you an opportunity to improve your condition?

Getting disability from work

You can often get short-term and long-term disabilities from work. Not all companies have such programs; in general, medium-size and larger corporations are more likely to offer them as part of your benefits package than smaller companies are. If you receive a disability payment from work, you'll get part or all of your salary. In general, if you're eligible for short-term disability, you'll receive your regular paycheck amount, which will be taxed. If you receive long-term disability, however, you'll receive a partial amount, but it'll generally be nontaxable. (Check with the Internal Revenue Service [IRS] and ask for Publication 907, "Tax Highlights for Persons with Disabilities," for clarification; call 800-829-3676 to have the publication mailed to you, or go to `www.irs.gov/pub/irs-pdf/p907.pdf` to view and print the publication yourself.)

WARNING!

Don't assume that you'd know if your company had you covered for disability. Ask your employer or employee-benefits representative specifically about disability coverage.

Going on Social Security

The *Social Security disability program* is a lifelong disability program for those who can no longer work at all, and for whom the possibility of ever returning to work is very slender. This federal program provides a monthly payment, as well as Medicare, for those approved. You may qualify for a Social Security disability if you've worked enough in the past and have also paid into Social Security. In addition, other family members may also be eligible for benefits, such as your children under age 18 or your spouse who's caring for your child under age 16. Whether Social Security disability income is taxable depends on many different factors. Contact the IRS (phone: 800-829-1040; Web: `www.irs.gov`) for further information.

You will need to document your disability. *You* know that you're really sick, and you're not trying to rip off your employer. But some people *are* fakers, and for this reason, proof of disability is required. You can't prove it on your own; instead, you need your doctors to back you up with written statements and other information that the Social Security Administration requires.

REMEMBER

It's especially important that you and your doctor document the ways your illness prevents you from functioning in your *occupation* — not just in a particular job. If pain prevents you from making pottery or responding appropriately to split-second decisions, and those are essential acts in your occupation (potter or police officer), write it down, tell your doctor, and make sure that the information is clear to your disability insurer or the Social Security Administration.

To find out more about Social Security disability benefits, contact the nearest Social Security Administration office (look in the federal-government section of your local phone book or call 800-772-1213) or go to `www.ssa.gov/disability.html`.

If you're still able to work at least part-time, and your gross earnings average more than $900 a month in 2007 (the limit changes each year), you automatically don't qualify for a Social Security disability. To find the most recent limit, go to `www.ssa.gov/pubs/10003.html`. ***Remember:*** After you start receiving Social Security Disability Insurance (SSDI) benefits, you can't collect worker's compensation or unemployment benefits.

According to the Social Security Administration, to apply for a disability, you need to provide the following information:

- A phone number where you can be reached as well as contact information for a friend or relative
- A list of all illnesses, injuries, and conditions that make you unable to work as well as the date when you became unable to work
- Names, addresses, and phone numbers for all physicians, hospitals, and clinics and the dates when you were seen (whether or not they were consulted for fibromyalgia)
- A list of all prescription and nonprescription drugs that you take
- A list of all the jobs you've had for the last 15 years, with a description of the job you were in for the longest period
- A list of all the education and training you've received to date
- Your complete medical records (The Social Security Administration will request this from your doctor, or you can provide it to them.)
- Your most recent Form W-2, or, if you're self-employed, your most recent tax return
- Information about family members applying for benefits, such as your minor children (Their Social Security numbers and proof of birth dates are needed.)

Don't expect immediate action on your claim: A year or even longer may pass before any action is taken, and even then, no matter how strongly documented your application is, or how ill you are, you may be denied. The whole process has several layers of application/appeal, and experts say that it's very important to not give up too early. Instead, appeal to the *reconsideration* level, the next rung up the appeals process. When your claim is reconsidered, you may *still* be denied at this level — attorneys say that many people are. If you're denied again, don't be discouraged; just keep going. The next level up is when an administrative-law judge hears your case, and experts report that this point is where many people's claims prevail.

Of course, seeing the judge doesn't guarantee anything, and I can't promise you that you'll ultimately be granted a disability payment. But if you're denied at the application point and don't appeal, you'll never know what would have happened if you'd kept going. So stay the course.

The burden of proof

Because fibromyalgia isn't a listed impairment specifically defined by the Code of Federal Regulations, if your claim is denied at a lower level and you appeal the denial, the administrative-law judge must determine whether your condition meets or exceeds those conditions already listed, in terms of causing the same degree of functional limitations of a listed impairment.

TECHNICAL STUFF

The Code of Federal Regulations is a publication of permanent government regulations by agencies of the federal government, published in the Federal Register by the Office of the Federal Register of the National Archives and Records Administration.

Under current law, the judge must give claimants increased credibility in assessing their own functional capacity. By properly documenting your claim, you stand an excellent chance for success, although the entire process may take as long as two years from start to finish.

TIP

Giving your doctors a heads-up is a good idea. Contact them by phone or by letters to let them know ahead of time that you're applying for Social Security disability, so they won't be completely surprised when they're contacted by Social Security Administration officials asking for information about your medical status.

WARNING!

If you apply for a Social Security work disability and also file for worker's compensation or unemployment benefits while your claim is pending, this action may be considered by the administrative-law judge as proof that, except for the work injury or unemployment, you remain fully employable. This may mean that you won't be approved for the disability.

According to Alec G. Sohmer, an attorney who assists individuals nationwide who have fibromyalgia and other medical conditions with obtaining disability benefits, the disability standard for adults is an *inability* to engage in any substantial gainful activity because of a medically determinable physical and/or mental impairment expected to last at least 12 months.

Finding an Attorney to Help You

Navigating the sometimes tortuous path of applying for a disability from the Social Security Administration is generally not for the inexperienced or fainthearted. Many people tell me that they needed the services of an experienced lawyer to guide them through the numerous dangers and pitfalls on the rocky way to approval of their disability claim.

Make sure that any attorney you think about consulting with is also an attorney experienced with disability claims: Don't hire someone who wants to learn on your time. Local support groups may be able to recommend talented attorneys who can assist you with your disability claim. You can also ask your physician if he can recommend a disability attorney who's experienced in helping people who seek approval for Social Security disabilities.

Keep in mind that the attorney should be willing to work on *contingency,* meaning that she'll receive a percentage of the lump sum you'll receive if you're approved (backdated to an earlier date, to be determined by the Social Security Administration). This means that, if you're approved, you'll receive a lump sum payment dated back to approximately when you first applied. Of course, your attorney, if you've hired one, will receive a chunk of that "change."

TIP

If you decide to seek an attorney to help with your Social Security disability claim, make sure that the lawyer is a member of the National Organization of Social Security Claimants Representatives (NOSSCR). Contact NOSSCR at 560 Sylvan Ave., Englewood Cliffs, NJ 07632 (phone: 800-431-2804; Web: `www.nosscr.org`), to find members in your area.

When you've found an attorney who appears to be experienced and knowledgeable about disability claims, you should still ask him a few screening questions before signing up. Here are some questions that you may consider asking your candidate:

- **About how many people have you assisted with applications for Social Security disability claims?** The lawyer should've assisted at least 20 to 30 people.
- **Of these, about what percent were approved by the Social Security Administration?** The percent should be over 50 percent of cases.
- **About how many people with fibromyalgia have you assisted?** Because the numbers may not be high, don't count out the attorney if the answer is "zero." But award that attorney bonus points if he does have experience with helping people with FMS.

Chapter 18

Helping Loved Ones Deal with Your Fibromyalgia

In This Chapter

- Knowing how your fibromyalgia can affect your friends and family
- Making things easier for other people
- Discussing fibromyalgia with your children and partner
- Getting ready for negative reactions
- Evaluating possible help from support groups

Liza says that her fibromyalgia is pretty hard on her family, in large part because they just never know what to expect from her on any given day. Will she have enough energy and a low enough pain level to go to the movies or on a picnic with them today? Or to attend the school play that her daughter has an important role in? Or is this going to be yet another really bad day, when it's better to leave Liza alone in her misery? Her family doesn't know — but then, neither does Liza herself.

Gail says that on some days, she can tackle tough problems at work and then go home and cook dinner that evening. Afterward, on those good days, Gail's able to help her children with their homework. However, on other days, Gail can barely raise her head from her pillow because the pain is too intense. Her children told her that they see her as two different people: Healthy Mom and Sick Mom. They don't seem to like Sick Mom very much, although they struggle to be fair.

This chapter is about understanding and dealing with the effects of your fibromyalgia on the people you live with and others you care about. Of course, if the other person has fibromyalgia, as some of your family or friends may, that person may be able to understand and identify with your problems very well. However, most people you care about probably *don't* have fibromyalgia, and they can only know what fibromyalgia is like based on what you tell them.

In this chapter, I help you understand how to explain your problems with fibromyalgia syndrome (FMS) to others you care about, whether they're your children, your partner, or other important people in your life. I also talk about expressing your needs to others and helping them understand how your fibromyalgia affects you. In addition, it's important for *you* to listen to your loved ones and hear how your fibromyalgia affects *them.* You may be able to make simple changes that can satisfy everyone. At the very least, you'll clear the air.

Understanding How Fibromyalgia Can Affect Your Relationships

Most people can grasp the basic symptoms of fibromyalgia, and they can also understand how fibromyalgia affects you, individually, in your daily life. Of course, people aren't solely rational beings; they have emotions, too. As a result, even if and when they fully grasp your problem logically, they may still have an emotional element to their thoughts about FMS that includes feelings of anger, resentment, sadness, confusion, and so on.

These emotions are normal in everyday interactions with family members who have problems. Even if people don't like these feelings or they want to deny that they exist, the emotions are still there anyway. As a result, friends and loved ones who sometimes react negatively to the effects of your fibromyalgia on them aren't necessarily bad or stupid or mean — instead, they're just human. But you can help them to cope with your fibromyalgia better.

Here are some ways that your fibromyalgia may interfere with otherwise usually good interactions between you and your friends and family members:

- **You may not listen to what they say (or even hear it at all) because listening is hard when you're in extreme pain.** They may think that you're not listening because you're bored or because you don't care. Tell them that you're having pain, and you simply *can't* listen well (or at all) now. When you're feeling better — and yes, at some point, you will feel better — you'll be happy to listen to what they have to say.
- **You may be more prone to saying "no" to doing fun things or managing responsibilities when your fibromyalgia symptoms are bothering you a lot.** But you'd probably say "yes" if you were feeling better. Explain your reasons for saying "no" to the people you care about, and also explain that you *want* to say "yes" and you *would* say "yes" if you were feeling better.

- **You may tend to agree to anything your family members ask for, if agreeing will make them go away and leave you alone when you're feeling bad.** (For example, you agree to requests you'd normally say "no" to, such as a sleepover your daughter has asked to go to at the home of a friend whom you've never met and know nothing about.) Or maybe, while in major pain, you'd agree if your 10-year-old son asked for permission to take the next space shuttle to Mars. Hey, why not! It'd be good for him, broaden his horizons. Fight this natural impulse to make things easy on yourself now. The long-term effects can be much worse! Avoid making decisions when you're feeling bad. If you must decide now, think about how you've decided similar issues in the past.

Be honest with yourself and your family. Accidentally slipping into using your fibromyalgia to get out of obligations that you don't enjoy can be very easy to do. But if you turn down an activity and then find energy to do other things that you like, your family will notice, and you'll undermine their sympathy. If you say "no" to going to the fast-food restaurant with your family but on the same day, say "yes" to a friend who wants to eat lunch at a new gourmet place, that's an oops! Don't make that mistake.

Moving Yourself to a Better Frame of Mind

When people have chronic illnesses, such as fibromyalgia, they often hold one of two extreme and opposite thoughts, and either way, they perceive themselves as a victim and a person unlikely to move forward:

- **At one extreme, some people believe that no one in the world can ever possibly understand or appreciate what they're going through.** Trying to explain the problem to other people just isn't even worth the trouble because they can never understand.
- **The other extreme view that people have is that everyone *should* understand the problem and somehow know exactly how tough it is for them.** People who adopt this viewpoint may become angry and resentful when others aren't as sympathetic as they supposedly should be.

Both extremes are unreasonable positions to take. For example, although people who don't have fibromyalgia really can't "feel your pain," they may have arthritis or another chronic-pain problem and, thus, can understand what chronic pain feels like, even if it's not *your* specific type of chronic pain. On some level, they should be able to grasp your problem. On the other hand, people shouldn't be expected to automatically sympathize with poor you — even when those people are your own loving family members. You're setting yourself up for disappointment if you take either of these polar positions.

To avoid adopting one of these two extremes, think about how you generally regard other people in relation to your fibromyalgia. As people who are hopeless and who could never understand? Or do you lean more toward regarding them as hopeless people who *should* understand? Try to move toward the middle. Most people are trainable and can be educated on what fibromyalgia is in general and how it affects you specifically, as well as what you need them to do.

Opening Up for Some Honest Dialogue

Because fibromyalgia can often have an intense emotional impact on your family members and friends, you need to discuss with them not only the basic facts about what fibromyalgia is but also how it makes you feel. For example, having FMS may make you feel useless, angry, upset, and so forth. You also need to give the people whom you care about a chance to tell you how your fibromyalgia and its effects make *them* feel. They may tell you that they get frustrated, upset, and confused and that they experience a wide variety of other emotions as well.

Talking about feelings doesn't mean that the time's come to assess guilt or blame. This isn't *Judge Judy,* and no one's on trial. In fact, it's best if you tell your family and friends that your illness is *not* their fault. Sure, they should already know that anyway, but sometimes, they need to hear it from you directly. In addition, you should also tell the people you care about that the symptoms of your fibromyalgia aren't *your* fault, either. (You may need to remind *yourself* of this fact periodically, too.)

The key purpose of discussing your feelings about your illness — and listening to how your friends and family feel about your illness — is to understand and accommodate each other in the best way for all of you.

One way to uncover issues and problems so you can start working on them is to call a family meeting. You'll probably need more than one meeting; maybe one or two a week until family members seem to feel generally comfortable with the way things are. The meeting should include your partner, your children, and anyone else who lives with you. They may be reluctant or suspicious about this idea but insist on their attendance.

A family meeting, as with any meeting, should have at least a general topic. If you want to get people's feelings out in the open about your fibromyalgia, then tell them that's the subject you're going to discuss. Prepare yourself ahead of time to hear some negative comments — as well as some touchingly supportive ones.

TIP

The first time you have a family meeting, set some ground rules. Everyone is allowed to talk, even your 3-year-old. But no one is allowed to give a speech. Everyone should be polite, no insulting or mean remarks are allowed, and no cursing is allowed. (A lot of information can be communicated without sarcasm, profanity, and so forth.) No one's allowed to interrupt. Everyone can speak, but everyone needs to give others a chance to talk. This rule will need to be repeated several times at first. After a while, don't be surprised when you're admonished by your 8-year-old child if *you* interrupt or speechify! Accept the criticism in good grace.

Expect some hesitation when you start because, after all, people in your family may have bottled up or censored their feelings for a long time. You can start by asking each person, in a going-around-the-circle fashion, to tell you what bothers him the most about your being sick. You can also ask each person what is the most important thing that she would like you to do when you're feeling well. You may be very surprised at the responses you get.

For example, the holidays may be coming up, and maybe you don't feel like going through the big ordeal of completely cleaning and decorating the house and preparing a big meal for all the relatives to come over and rapidly devour. But you don't want to spoil the holidays for your family. If you bring up your concern, you may find, to your surprise, that other family members say that they'd really prefer a holiday celebration for "just us." You could also ask everyone what one thing they most would like to do over the holidays — it may be something easy, like driving around and looking at house decorations or going to a religious service. ***Remember:*** Satisfying your family doesn't always have to be hard.

Don't expect every family meeting to reveal amazing or even useful information. Sometimes, they won't. Also, sometimes, important dialogue may occur *after* the meeting when members interact with each other about how they never knew that the other one felt this way.

TIP

Avoid trying to talk about your illness or resolve difficult communication problems with your friends and family during those times when you feel really bad. Tell others that you're sick now, but you'll talk to them later about these issues. And make sure you *do* talk to them later, as soon as you can.

Anticipating Difficulties

Sometimes, your children, partner, and others may react negatively or even very negatively to the effects of your fibromyalgia. They may also react negatively when you can't participate in various fun or work activities because you feel bad.

Some of the negative responses that people you love may exhibit are

- **Anger:** Perhaps family members are mad at you, but more likely, they're angry at your condition because you can't do the things they want or need from you, such as things you used to be able to do.
- **Annoyance:** This response is a milder form of anger. It may occur because you can't go places or do things that family members want you to.
- **Frustration:** Family members get frustrated because they have to accomplish many tasks that you used to do, and they wonder when or if this problem is ever going to end.
- **Fear:** The thought that things may get even worse drives fear. Will you become even more dependent on family members in the future? Will you ever get any better, or will you only get worse?
- **Guilt:** Your family members may feel as though they *should* be helping you out more, but for their own reasons, they aren't. Sometimes guilt is a motivator to do better; other times it holds people back. Talking about it can help.
- **Resentment or suspicion:** Maybe you don't have to wash the dishes, do the laundry, clean the cat litter, or do other boring or yucky jobs that are part of every household. Your friends and family can't see the pain, and may begin to wonder if it's really there.

You know how bad you feel, and you probably also know that your family members are frustrated and upset that you can't do activities with them that may have been easy for you to do in the past. You can't help being sick, and it's not your fault. But your partner and your children may find it hard to cope with the effects of your illness, especially if they don't understand why you're in pain. It's important for you to understand and accept this fact.

Knowing How to Respond to "Helpful" Comments

Denise says that she's tried to explain to her friends how her fibromyalgia makes her feel, but they often respond by telling her that she should eat a healthier diet or get herself into better physical shape. One friend said, "Oh, fibromyalgia. That's what doctors say when they want to tell you that you have something, but they don't know what it is." Denise says that these kinds of comments really hurt her. It makes her feel like people think her doctor is incompetent or that she's a hypochondriac imagining her condition.

So, what do you do when people say such things? You have two primary choices. You can say nothing and let it bother you. Or you can say something, preferably something that won't antagonize people but will clear the air. Table 18-1 has some suggestions for how to respond to comments that you'd rather not have heard.

Table 18-1 What People May Say to You, and How You Can Reply

When They Say . . .	***You Can Respond . . .***
You should eat a healthier diet.	Even the best diet in the world can't make fibromyalgia go away forever.
I've heard that fibromyalgia is fake.	I've heard that, too — but it's wrong. Fibromyalgia is a real medical problem. Studies have shown this.
If you lost weight, that would solve your problem.	Losing weight probably would make me feel better, although it wouldn't cure my fibromyalgia. And exercising can be very hard when you're in pain.
Mind over matter is what I always say! Think yourself well.	A positive mental attitude is a good thing. But it can't cure chronic illnesses like fibromyalgia, arthritis, diabetes, and others.
You should try _____. It will make you better.	Some remedies work well for some people, and they don't work at all for others. I'm following my doctor's recommendations.

Helping Your Significant Other Cope

Fibromyalgia is very tough on you, but it's usually no day at the beach for your partner, either. Often, you can't do your share of the housework, and you may not be able to work full-time, part-time, or at all. If you have children, your partner may have to take them places and resolve their petty squabbles at home — as well as participate in the fun stuff, such as watch your child win a prize or make a touchdown, without you there because you're too sick.

Fibromyalgia can also put a major crimp in your sex life. Who wants to make mad, passionate love when your body feels like you contracted the flu — right after you were run over by a truck? Probably not you. On the other hand, your partner probably still *does* feel like having sex sometimes. In addition, your partner needs some personal attention. He needs you to listen when he needs to discuss work and family problems, as well as fears, goals, and aspirations. But listening and interacting can be hard to do when your brain seems to be stuffed with cotton balls and you feel like the village idiot. (If you're really feeling out of it, tell your partner that you'll talk later. And then do it, as soon as possible.)

The key is to share your feelings, without blaming your partner or yourself for your medical problems, and to also *listen* to how your partner feels, without taking offense at what she says or feeling as though you must defend yourself. Using that tactic, Colleen says that her husband Tom told her one day that he felt very sad and left out because she saved up all her "smiley-face time" for everyone else but him.

Colleen thought a lot about what Tom said, and she realized that he was right. She'd been expending all her energy on their children or her co-workers and job. By the time her husband came home at night, Colleen was nearly always collapsed on the sofa, virtually incapable of any communication and basically only good for staring blankly at the television set.

Colleen decided to cut out some activities. For example, she arranged for other parents to drive her daughter to soccer practice and her son to Cub Scouts. At work, when asked to collect money for charity, she said that she couldn't do it this year. Colleen also cut back on her work hours, deciding that her own health and her relationship with Tom were more important than trying to be a fast-track worker. Colleen also learned to say, "No, I can't do that." She discovered that, in most cases, she didn't need to apologize or give 47 reasons why she couldn't do something. She just had to politely refuse — that was enough. This was an amazing revelation to her.

Another change: Colleen resolved to *not* try so hard to hide her fatigue and pain from others. Like many other people with fibromyalgia, she hadn't ever mentioned her problem to others, so they'd assumed that she could carry a full load. Hiding her pain and fatigue had been exhausting. Now she stopped hiding it, and they could see how she felt. After they found out about Colleen's fibromyalgia, the demanding expectations of her co-workers decreased. With these changes, Colleen managed to hold on to some energy for Tom when he came home at night. Things were a lot better between them after that.

And what about sex? As with many people with fibromyalgia, Colleen's sex drive was usually slim to none, although she hoped that her reduced schedule might eventually change that. She also decided that she didn't have to feel 100 percent like having sex to participate in it with Tom. After all, if she waited for intense passion to overwhelm her, they might *never* have sex. Colleen talked to Tom frankly about sex and her problems with fibromyalgia.

She asked Tom to be very gentle and take it slowly when they had sex, and he agreed. She was surprised to find out that, sometimes, even though she'd been feeling pretty blah about sex, her interest was aroused after they started. Of course, when Colleen's symptoms were really bad, sex just wasn't going to happen. And Tom understood and accepted that fact.

Explaining Fibromyalgia to Your Kids

Debbie says that she wishes she could just be a normal mother — she'd like to go outside and play basketball with her children, for example. She feels that she's deprived her children of a lot of their childhood because they've had to take on extra chores that she just can't handle. She's also not so sure that they really understand why she feels so bad much of the time.

Sometimes, you have trouble understanding fibromyalgia yourself. You may feel terrible on some days, okay on others, and, once in a while, almost normal. It doesn't seem to make sense. So how can you explain this seemingly nonsensical problem to your children? It's doable! Read on.

TIP

If you lose your temper, largely because your symptoms of fibromyalgia are making you feel so bad, and you blurt out mean words to your child, just apologize. Don't wallow in guilt, don't castigate yourself out loud as the worst parent on the planet, and don't spend a lot of time explaining or trying to excuse your behavior. Just say you're sorry. That's usually enough.

Keep it simple

Most children, including adolescents, don't need a lot of complicated and theoretical explanations about the causes of fibromyalgia, symptoms that people with FMS experience, and so forth. They don't need charts or diagrams, and you shouldn't expect them to read books on fibromyalgia, either. (If they *want* to read something about FMS, this book is a good start.)

REMEMBER

Your children need to know that your fibromyalgia is a chronic medical condition, and they also need to know how it affects you personally, what your specific symptoms are, and what they can do (or shouldn't do) to help you cope with your illness.

For example, if loud music really bothers you when you're sick, tell that to your children. They can use headphones, or they can turn the music down. And don't forget to ask your children how you can help them cope with your illness. For example, would they prefer to spend time at a friend's house when you're feeling your worst, or can they think of other solutions that might work for you both?

Stress that it's chronic

Explaining the *chronic* part of your illness is very important because most children, and even many adolescents, consider medical problems as here today, gone tomorrow. A leg is broken, it's set in a cast, it heals, and then it's fine. A person gets a cold, suffers from sneezing, coughing, and wheezing, and then gets well. Unless a child suffers from a chronic medical problem herself, most children perceive illness as something that improves and then goes away. The fact that some illnesses do *not* go away, but instead, require continued treatment, can be a difficult concept for many children.

Part of the difficulty for children in understanding a chronic illness is their own time frame of reference, which is now and, perhaps, later. (And *later* means this afternoon or tomorrow. It usually doesn't mean weeks or months from now, and it almost never means years from now.) This different time frame of reference doesn't mean that they *can't* understand — it just means that explaining a chronic illness may take more effort.

Clarify that they didn't make you sick

Be sure to tell your children, if they're still young, that your fibromyalgia isn't their fault. Children frequently have *magical thinking,* which means that they think that if they have "bad" thoughts, bad consequences can happen to other people. For example, your small child may think that you're sick because she was mad at you one day and wished to herself that you'd be punished. Tell your children that having angry thoughts is normal, even though it doesn't seem so nice. But having those bad thoughts can't make other people sick because thoughts can't do that.

Another concern is that your children may think that your illness is fatal. They won't necessarily tell you that they're worried you could have cancer or another illness that can kill you. Joanie, whose mom has fibromyalgia, developed a fear of going home after school. She'd begun to fear that one day, she'd come home and find her mother dead on the couch. After all, Mom was so sick all the time. Maybe she had cancer like her friend's mom who had died. When Teresa, her mother, realized what was going on, she reassured Joanie: Yes, she was sick. But no, she didn't have a terminal illness.

Anticipate questions

It's understandable and normal if your children have many questions about your fibromyalgia. When you open the topic to questions, you may be surprised at the floodgate that's released. Sometimes, questions will come right away. Other questions may come tomorrow or a week from now.

Your children may ask how long you're going to have this condition (you don't know) and when you're going to get better (you're working on it, but again, you don't know the answer to this question, as much as you'd like to), as well as many other questions.

Your children may ask you if they're going to get fibromyalgia, too. Although fibromyalgia isn't a contagious disease, certain studies indicate that FMS runs in families. However, the only way to know if someone has fibromyalgia is for that person to see a doctor.

Vary your approach with the age of your child. For example, if the child is up to about 8 or 9 years of age, you may want to use the analogy of a glass, giving a concrete example of you when you're "spilling over" with pain and tiredness. Fill the glass up in the sink and let it spill over. The glass represents you on a bad day. Then, fill it up short of the brim. This is you when you have some extra energy to give your family. Older children won't need to see a demo: You can explain the spilling-over concept in words. On one of your bad days, you can tell your children, "It's a spilling-over day for me today. Sorry!"

Joining a Support Group

Support groups can provide you with valuable information, moral support, and a feeling that you aren't alone. At the same time, some support groups can be constraining. And sometimes, people who attend support groups say that some people in those groups complain nonstop and offer no solutions to their problems.

Don't go by what others, including your best friends, think about particular support groups. Instead, find out for yourself. Take a "test drive" of a support group before joining up by attending a meeting, observing what happens, and seeing whether you think that you'd feel comfortable as a member. You may also find considerable help with an online group, where you don't have to find babysitters, go out in the rain or blizzard, and so forth.

Some areas have support groups with meetings that are moderated by professionals, such as psychologists and social workers. These groups generally cost money, but the presence of a skilled leader can enhance the effectiveness of the group and decrease the experience that people are "just complaining." If you can't find a good, free support group, consider trying a professionally moderated group (if you can find one nearby). Your insurance company may even cover the cost. Ask your doctor if she knows of such a group.

Looking at the pros and cons of support groups

Nearly every type of support group, no matter what type of members the group is supporting, has both pros and cons.

If you're eager to hear the latest opinions on fibromyalgia treatment, from a layperson's point of view, people in support groups often are among the first to know what's hot, what's worked for them, and what failed miserably. They may also be knowledgeable about the most recent studies, journal articles, medications, alternative remedies, and any other info you'd like to know about FMS.

But support groups aren't for everyone. On the downside, support-group members may have little or no medical expertise, and they may be unable to screen out the scams from the bona fide treatments for fibromyalgia. So always take the advice of nonphysicians with a grain — or maybe a pound — of salt.

Lydia says that she went to a local support group for people with fibromyalgia several times, but she always felt much worse afterward. Carmen says that the members of her support group were all so physically ill, miserable, and hopeless that she couldn't stand to be in the room with them. She much prefers an online support group, where she can exchange ideas with others who are also sick but really trying to get better. Deanna says that she gained a great deal from her support-group meeting: When she heard about a great doctor who treated FMS, she called him for an appointment, was treated, and now feels much better.

Deciding whether to take others with you to meetings

If you find a good local support group where you feel comfortable discussing your FMS symptoms and where other members offer helpful suggestions on how to feel better, this group is one to treasure. Because you like it so much, you may think that taking your children, your spouse, or others to a meeting would be a great idea. By going, they could understand what fibromyalgia is all about. Taking people who don't have fibromyalgia with you to a support group has pros and cons. I cover a few major ones here.

The key advantage of taking a person who does *not* have fibromyalgia along with you to a support group is that your partner or family member can see with his own eyes that many other people have the same kinds of symptoms and problems that you have. You're not an anomaly. In fact, you may be a lot better off than some of the other members, in terms of energy levels and how you're coping. If so, your loved one can gain a whole new view of how fibromyalgia can impact a person's life (and how lucky you both are).

You may also be worse off than other members, and that can be useful information to your family member or partner as well. She may not have realized how difficult your symptoms were and how hard you've been struggling to cope with your illness.

Taking your partner or loved one with you to a support-group meeting also has some disadvantages. He may be uncomfortable and unhappy and may also become upset about viewing the misery and pain of so many people. Some individuals who *do* have fibromyalgia say that seeing the pain of others has distressed them greatly, so it's fair to say that a person who *doesn't* have fibromyalgia may also become very upset.

If a meeting (or most meetings) becomes a gripe session about how awful the family members, spouses, and partners are, your loved one will likely find the discussion to be very distressing, especially if that loved one is doing the best that she can to be supportive and helpful. Being perceived as the "enemy," when you know you're really trying to help, can be very hard to handle.

Children and teenagers may become upset and distressed about the frank discussions that occur in support groups. And they really don't need to hear individuals talk about their sex lives (or lack thereof).

Before you even consider bringing your partner, your child, your teenager, or anyone else whom you love to your support group, attend a few meetings. Make sure that it's a visitor-friendly, or at least a visitor-neutral, environment and one your loved one may gain insight from. He won't benefit from a mentality that sees people without FMS as the bad guys. But he may gain from an environment where people are open to sharing information in a positive manner.

Getting e-support

Online support groups can take two forms: *listservs* (Internet special-interest organizations in which you receive all messages by e-mail) or *newsgroups,* which are areas on the Internet where people can read and leave public messages.

`Alt.med fibromyalgia` is a popular online newsgroup. One way to access newsgroups is to go to `http://groups.google.com` and then type in the name of the group. You could also type in **fibromyalgia** to find an array of groups. Reading messages on newsgroups doesn't cost extra, nor do you pay membership fees. Your only expense will be what it costs to use the Internet.

Another possibility is Fibromyalgia Community, which has a listserv. To find out about this group, go to `www.fmscommunity.org` and click on the listserv information link.

The key advantage to these groups is the wealth of information they provide, as well as discussions about feelings and issues related to fibromyalgia. In addition, participants frequently provide Web links that you can click on to move to interesting Web sites or to journal or newspaper articles.

Keep in mind that anyone who uses the Internet, anywhere on the globe, will be able to read your postings, so don't post anything that you wouldn't want a complete stranger (or your gossipy neighbor down the street) to read. It's also important to realize that some people who post messages online are trying to promote a particular product that they may have a financial interest in. So keep your thinking hat on and your skeptical brain in gear.

Internet groups that discuss fibromyalgia and provide information can be treasure troves. But keep in mind that they're nearly always dominated by people who aren't physicians and who have no medical training. Reading the postings, as well as asking questions and getting responses, can be educational and helpful. But don't take medical advice from people who aren't physicians. Always consult your doctor before starting or ending any over-the-counter or prescribed medications.

Chapter 19

Helping Someone You Care About Who's Hurting

In This Chapter

- Helping people you care about when *they* have fibromyalgia, but you don't
- Controlling your feelings about how fibromyalgia affects your loved ones
- Acknowledging that your loved one's symptoms indirectly hurt you, too
- Deciding whether to attend group meetings for people with fibromyalgia

Carly doesn't have fibromyalgia, but her best friend, Shannon, has been diagnosed with fibromyalgia syndrome (FMS). So many times, Carly has wanted to sympathize with Shannon and with the pain, fatigue, and other symptoms that she's obviously going through. But Carly is often afraid to say something because she may say the wrong thing. Is Carly right to be so worried about being politically correct around Shannon — so much so that she's basically tongue-tied, even when Shannon is clearly hurting?

The answer is no. And yet, it's also yes. *No* because feeling like you're avoiding a topic that looms so large in the life of your friend or loved one isn't good. But *yes,* with regard to holding back comments, because many times, people blurt out comments that *they* think sound kind or helpful, but that aren't taken that way. For example, saying, "I know just how you feel," when you don't have a clue how the person feels, can be upsetting to a person with fibromyalgia.

In this chapter, I talk about how you can understand how friends, family, and others feel when they have fibromyalgia, without actually having fibromyalgia yourself, and what you can do to help them. I also talk about expressing gentle affection for the pain that your loved one is going through. But don't worry! You don't need to adopt a permanent hands-off policy. I explain how to handle the touching/nontouching aspect of your relationship.

I also cover *your* feelings in this chapter, and discuss whether you should tag along to an FMS support-group meeting or check out online groups devoted to FMS. Going to such an actual or virtual meeting when you don't have FMS yourself has pros and cons that I describe.

Understanding without Feeling Their Pain

If you don't have fibromyalgia yourself, you really don't want to "feel the pain" of someone else who does have it. The fact that your friend or family member must put up with it is bad enough. However, when you don't have FMS, you can't fully understand what she's going through. Instead, you must rely upon your observations of her behavior, what she tells you, and what you can find out about fibromyalgia. (Reading this book is a very good start!)

Knowing what to say, what not to say, and when to say nothing at all can be a challenge. Should you express concern for how bad your loved one feels or show sympathy with a smile? I can't provide one right answer for every situation, but the following section offers ideas that may help.

Empathizing without saying that you know how FMS feels (because you don't)

How can you be truly sympathetic when you can't really experience how your friend or loved one feels? You can talk openly with your friend about his FMS, asking questions, making supportive comments, and listening attentively. Try to understand what he's going through as best you can. Attempt to relate his problem with difficulties you've had — problems that other people didn't understand or relate to.

REMEMBER

You'll never say the perfect thing at all times — no one does. But you can try to avoid saying annoying things and work on making supportive statements.

Here are a few examples of what you can say to help a person you care about who *does* have FMS. (Use your own wording.) These simple comments may help or, at least, may start a dialogue between you and your loved one. (See the "Helpful/nonhelpful statements to make to someone with FMS" sidebar, later in this chapter, for more helpful statements.)

- Fibromyalgia sounds really difficult to deal with.
- How can I help?
- I'm sorry that you have this problem.
- It must be hard to *look* normal but feel really bad on the inside.

After your friend responds, summarize what he's said to you. Doing so shows that you've been listening. When you summarize what you think that your friend has said, even if you get it wrong, at least the person can tell that you're making a sincere effort to understand. For example, you may say, "It sounds like you're having a really hard time right now." He may agree and try to explain his problem, or may nod in relief that someone cares.

Knowing what not to say

Avoid making comments that deny or diminish the pain of the person with FMS, such as "It can't be that bad!" or "Tomorrow will be a better day." She feels really bad right now and doesn't need to hear unsupportive and hurtful comments. Read on for more information on what not to say.

For starters, do *not* say that God or fate or karma gives problems only to people who can handle them. Even if you think it's true, consider how negative such a comment may sound to other people. It sounds like you're saying, "If you're strong, you deserve to be punished for being strong."

Also, when talking with your loved one who has fibromyalgia, don't fall into an unconscious one-upmanship, such as "I know someone sicker than *you* are." You may think you'd *never* do this, but it's so easy to do! For example, if your friend talks about his pain and fatigue, don't say that, yes, that's pretty bad, but your sister's cousin's husband *really* has a severe problem, because blah, blah, blah. Think how you'd feel if someone did this to you. If you start to say something that fills this bill, then stop!

TIP

To better relate to your family member or friend who has fibromyalgia, remember how you've felt when friends or others have glossed over a distressing illness or disturbing problem that you had. Maybe other people told you to cheer up and get over it or that it was really no big deal. Maybe you felt like you didn't have permission to feel the emotions you were experiencing. Recall the emotions you felt when your pain was denigrated. And work on *not* diminishing the feelings of your loved one with fibromyalgia.

Leaving them alone: Sometimes, solitude helps

Sometimes, having company is great. And other times, it's not so great, like when you feel sick, cranky, overtired, and so forth. Normally, your loved one would love to spend time with you. But when her FMS symptoms flare up, sometimes company is just too much to bear.

Lorna has fibromyalgia, and she wishes people would understand that she doesn't want them to try to "fix" her (she already knows that they can't). Instead, she wishes they'd just leave her alone when she has a flare-up of her FMS symptoms. Lorna says she does so much better by going into "hibernation" for the few days when her symptoms are really acting up. Afterward, she emerges, much more congenial with her family and friends.

So how do you know when to steer clear of your friend or family member who has fibromyalgia? Usually, it's not that hard to tell, when you know somebody. But here are some indicators:

- **Your friend doesn't make eye contact.** He could be angry or upset with you — *or* he could be exhausted or in pain.
- **Your loved one has a slumped-over posture and a dejected appearance.** You think she may be depressed, but she says that she's "just tired" — and she may really mean it.
- **Your family member is responding in one-word answers and doesn't seem to be "here."** He may want to be alone.
- **Your loved one asks you the same questions repeatedly.** She may be deep in a *fibro fog* (a temporary lack of concentration — a symptom of FMS) and may need some downtime alone at home.

When hugging hurts

What's the normal and natural response when you're feeling sad for someone you care about who's in pain? For many people, their first reaction is to reach out and hug the hurting person.

WARNING!

Force yourself to resist the impulse to hug a person in the throes of a fibromyalgia flare-up. Even a little hug can feel like the grip of a grizzly bear to a person in pain from fibromyalgia. Always ask a person with fibromyalgia *first* if it's okay to give a hug. And if it *is* okay, keep it gentle. No bear hugs allowed, unless the person says that he wants one.

REMEMBER

Just because you can't offer a person you really care about a big, enthusiastic hug doesn't mean that it's hands-off forever. Instead, when your loved one is really hurting, a gentle butterfly-like touch to the shoulder or (preferably) the hand can be seen and appreciated as the warm and affectionate gesture that you mean it to be. When your friend or loved one feels well enough, she will usually welcome a gentle hug — but ask for permission first!

You can communicate positive emotion and support with other types of body language, such as:

- **Looking directly at the person as he speaks:** Most people don't look at each other because they're actually thinking of something else, like what they're going to eat for lunch. Try to really pay attention to what your loved one is saying. People feel like you're paying attention and you care about what they're saying when you actually *look* at them.
- **Smiling sympathetically, without making any comments:** This simple act shows your friend that you're supportive and really care. A simple smile can mean a lot.
- **Leaning forward slightly:** When people are really paying attention to what's being said, they often lean slightly forward and toward the person who's talking. This gesture shows your family member that you're truly interested.

When you're talking to someone, you have your own basic self-talk going on in your mind. Whether your basic thoughts are trivial or deep ones, you do your friend or loved one credit by actually listening to what she's saying and then responding. And if you can't listen now, because you're stressed out or worried or tired, tell your friend that you're distracted now, but you'll really listen later today or tomorrow — and follow through!

Paying attention to body language

Although words do matter, what someone says isn't the only thing that counts.

In addition to paying attention to what your friend or family member with FMS says, also pay attention to what he *doesn't* say: Watch his body language. These gestures and postures indicate how he really feels, despite what he may say. For example, a person who's standing with his arms crossed over his chest is often annoyed or impatient (or both). A person who's leaning forward toward you as you talk is truly interested in what you're saying.

Observe your loved one's body language when you're interacting with each other. For example, if you've asked her to go shopping or invited her to come with you to a family party, and she's said that she'd love to come, but you see that she's slumped over and her eyes are glazed over, here's the reality: The mouth is saying yes, but her entire aura is emphatically saying no. Make some excuse about *not* going, and you'll usually see at least a glimmer of relief wash over your pal.

What people with FMS say they wish others would know, say, or do

Because you don't have fibromyalgia yourself, knowing what to say or do to help your friend or loved one with this aggravating condition can often be hard. Here's some advice from people with FMS who've offered what they wish that others would know, say, or do:

- Grace says that she wants people to know that she's really doing the best that she can, and on some days, just getting out of bed is a major accomplishment for her.
- Charles says that he can't abide whining himself, but he thinks it certainly helps if others can see that simple tasks require much more effort and discipline from a person with fibromyalgia.
- Lola says that she'd like it if people wouldn't get upset if she forgets things or asks the same question ten times when she's in the middle of a fibro fog.
- Frank says that it's important for other people to understand that their pain and exhaustion from other problems isn't the same as his. And also, just because he's feeling pretty good one day doesn't mean that he'll feel okay the next day. Fibromyalgia is a chronic problem, with good days and bad days.

Coping with Your Own Emotions

You know that your friend or family member with FMS is hurting, and you feel sad for him. You probably also feel some other emotions as well — some that you may prefer to ignore because maybe you don't feel so proud of them. I'm talking about negative emotions, such as anger, frustration, resentment, and so forth. Or maybe you feel guilty for being healthy when your friend or loved one is feeling terrible.

Negative emotions are normal in life, and coping with them by confronting them head-on is ideal. Don't pretend that everything is perfect and that you really don't have these feelings at all. Instead, deal with the anger, frustration, and guilt so that you can better support your friend or loved one who's suffering. Read on for advice on how to do just that.

Dealing with anger

Anger is a common emotion for people who see people they care about in the grips of pain. Sometimes, you may get angry at the *person* who has fibromyalgia, possibly for complaining so much and for seeming so totally focused on the pain — so that not much else seems to matter. Other times, you may be angry at the FMS or the unfairness of it.

The best way to deal with your anger and to avoid a nonhelpful escalation of anger is to first acknowledge and accept that the fibromyalgia is here, and it's real. Next, try to pinpoint whom or what you're really angry at. Are you angry with yourself for not being as understanding and caring as you think that you're supposed to be? Or are you angry at the person with FMS, for shutting you out and focusing on the pain and other symptoms?

After you determine who or what you're angry at, stand back and think objectively about what's going on. For some people, making a list of reasons why you're angry helps. Making a list may sound silly, but I recommend that you try this simple tactic anyway — you may find that it helps take some of the steam out of your anger and also clarifies the issues.

Write down, "I am angry because . . ." and then just write whatever comes to mind, without censoring your thoughts. You may find that you're angry because your friend or family member can't go to as many places with you as he did in the past or isn't as attentive as he once was to you. Or the source of your anger may be something else altogether. You may think that you're very angry and upset about your friend and his sufferings with fibromyalgia, but the feelings actually stem from something that has nothing to do with him at all.

As you write, you may also find that you're not just angry, but you're also feeling sad, frustrated, anxious, and a host of other emotions. Identify and acknowledge these emotions. No, they won't evaporate, but they're often much easier to deal with when you realize how you really feel.

Fighting frustration

Feeling powerless and confused when you care about someone who has fibromyalgia is normal. These emotions fall under the category of *frustration.* Certainly, when someone you care about is in pain, excessively fatigued, suffering from a lack of sleep, and has many or all of the other symptoms that are the features of FMS, you want to help. And when you can't think *how* to help, you're frustrated because you feel like you can't do anything.

You may wish that you had a magic wand that you could wave about dramatically, complete with magic words to say to instantly end all the torment for your loved one. Sadly, magic wands or special incantations won't make someone's fibromyalgia disappear.

Positive thoughts and even prayer may help you deal with your frustration because they help you focus on your inability to magically resolve your loved one's problem and allow you to give up the illusion of control. The positive energy that's conveyed through prayer (or meditation) may also be helpful as well. If you're a religious person, you'll be comforted that your request to God will be heard; the problem will pass from you to God.

Getting rid of your guilt

Many people feel guilty when their friends, family members, or other loved ones are sick. They may have an irrational fear that they somehow *made* the person ill, through something that they did or didn't do and should have done.

Many people also experience a minor form of survivor's guilt. If you're feeling pretty healthy and fit, but your loved one is suffering a lot, maybe you wonder why you're fortunate enough to not be sick when your loved one, who's just as good of a person as you are, is suffering. Is it fair? No. But then illness isn't really a question of fairness.

You need to get rid of your guilt because it's not helpful for you or your loved one. It's not your fault that she's sick — you didn't make it happen. And it isn't your friend or loved one's fault, either. Even if you think that you were mean or uncaring at one point or failed to do something, that lapse still didn't make your loved one develop fibromyalgia.

Get rid of your guilt by trying the following tactics:

- **Adopt as a mantra the statement, "It's not my fault."** FMS in someone else really *isn't* your fault!
- **Don't accept responsibility for alleviating your loved one's illness.** Provide sympathy and help. But realize you can't cure him.
- **Acknowledge to yourself what you *are* doing to help your loved one.** When guilt feelings crowd in, think about how you drive her to the doctor's office when she's sick, cook dinner if she's too tired, and so forth. Give yourself some mental pats on the back. You deserve it!

Going to Support Meetings

Maybe your friend or family member has suggested that you attend a meeting for people with fibromyalgia, so that you can gain a deeper understanding of what it's really like. Or maybe you've come to this conclusion yourself because you want to have a better grasp of how your loved one feels. Maybe you can discover some new positive ideas that will help you to help your loved one feel much better.

If you don't have time to attend support meetings, maybe you can visit online groups. You can read what others think and feel and avoid the worry of anyone challenging you.

Is attending an FMS support-group meeting in person when you don't have it yourself a good idea? It depends. Ask yourself the following questions before you go to a support-group meeting with your hurting friend:

- **Do you really *want* to go?** If you do, fine. If you're just going because you feel like you *have* to go, and you'd rather watch grass grow or clean the attic (or another activity not in your top 100 favorite things to do), rethink accompanying the person with FMS to the meeting. Sometimes resentment crowds out positive feelings that you may have.
- **Is it convenient to go, or are you making a heroic effort that may cause you major resentment if you don't have a good time?** If you think that you're making a giant sacrifice to go, think again about attending.
- **Are you curious about fibromyalgia and eager to meet other people with FMS, to better help your loved one?** This mindset is a thumbs-up indicator for going.
- **Can you cope with people in the group who may see you as someone who can't possibly understand or even someone who's part of the problem?** Find out if other people who don't have FMS also go to the meetings and if others (people who don't have fibromyalgia) are perceived as outsiders and intruders. If so, you may want to reconsider.

When you live with a person with FMS

When you're the partner of a person with fibromyalgia, being sympathetic, kind, and loving all the time can be hard. Here are a few guidelines for partners:

- **If you find yourself occasionally flaring up or saying something mean or unfair, give yourself a timeout away from the person with FMS.** Later, when you've cooled down, apologize.
- **Try to help your partner work toward solutions to resolve her symptoms, but realize that it's not up to you to make everything better.** In fact, you can't. You can offer sympathy and support, but when it comes to acting, the ball is in her court, not yours.
- **Ask your partner what he needs when he feels ill.** Sometimes, people think that everyone somehow knows (or should know) what they need, whether it's a kind word, driving them somewhere because they don't feel well enough to drive, or something else. You're not a mind reader. If you ask but your partner won't tell you what he needs, then don't worry about it. Playing guess-what-he-wants is too frustrating.
- **Don't expect your partner to be superhuman.** Often, you'll see her struggling with goals, and you may feel like the problem is that she isn't taking good care of herself. Although FMS patients greatly benefit from a disciplined lifestyle (exercising, eating right, sleeping enough, avoiding stress, and so forth), they can't be perfect at all times. Sometimes it's okay to slip up and watch TV all day, eat junk food, and so forth.

Chapter 20

Parenting a Child or Adolescent with Fibromyalgia

In This Chapter

- Comparing children's fibromyalgia symptoms to those of adults
- Finding a good doctor
- Regarding treatments that work
- Coping with the emotions of your other children
- Handling fibromyalgia and school
- Dealing with other children

Tommy is a 13-year-old boy who's been diagnosed with fibromyalgia. He says that he's had aches and pains ever since he can remember, and his doctor had always told his concerned parents that Tommy was having "growing pains." Tommy first found out that he might have fibromyalgia when his allergist noticed characteristic symptoms and recommended that Tommy see a rheumatologist. The rheumatologist examined Tommy, ran some tests, and diagnosed him with fibromyalgia syndrome (FMS).

Tommy says that having fibromyalgia can be pretty tough sometimes. The pain and fatigue are difficult to put up with, and other kids don't seem to understand. His teachers haven't been sympathetic either, and he thinks most of them have never heard the word *fibromyalgia,* or at least not in relation to kids. Sometimes they seem to think that he's trying to get out of things, like homework assignments.

As Tommy's story shows, children and adolescents can have fibromyalgia, although the juvenile version has some differences from the adult kind, based on the few studies performed on children. In fact, in the case of children, their illness is technically called *juvenile primary fibromyalgia syndrome.*

In this chapter, I talk about what fibromyalgia is like in children and teens, and offer advice on how to help your child. I also talk about dealing with your other children who don't have fibromyalgia and avoiding the problem of their concluding that you have to be sick to get any attention. Communicating with teachers is another issue; you need to know what to tell them (and what not to tell them) in order to achieve the best outcome. Peers and what they think can also be a problem, so, in this chapter, I discuss ways to handle other children.

Keep in mind that, no matter how great a parent you are, you can't magically make fibromyalgia disappear, nor can you make everything "all better" for your child. Also (and this is important, so make it your mantra if you need to), *it's not your fault.* Help your child as much as you can, but realize that you can't make the illness go away.

Looking at Fibromyalgia Symptoms in Children and Teens

If you think that your child or adolescent may have fibromyalgia, what sort of symptoms should you be watching out for, and how is juvenile FMS different from, or the same as, adult fibromyalgia? In many cases, fibromyalgia in children is pretty much the same as FMS in adults. But as in Tommy's case, many pediatricians may dismiss muscle aches and pains and tiredness, perceiving them as normal unspecific pains, or they may ignore other common fibromyalgia symptoms, such as trouble getting to sleep.

In this section, I talk about the major symptoms seen in children with fibromyalgia, including some similar to and different from those seen in adults with FMS.

Showing fewer tender points than adults

Although the tender points of fibromyalgia (see Chapter 8) are present when kids have FMS, some pediatric rheumatologists say that children with fibromyalgia have fewer tender points than adults, and the tender points that they do have are most likely to be found in the neck area. Children are *less* likely than adults to have tender areas in the lower back. Of course, if your child is a teenager, she *may* have low-back tender areas; as children grow closer to adulthood, they may develop more tender points, mimicking the tender points seen in adults with FMS.

Suffering from more stomachaches

Some research indicates that children with fibromyalgia suffer from a greater incidence of stomachaches and abdominal pains than adults who have FMS.

Perhaps the stress of fibromyalgia increases the rate of this problem, or maybe it's something else altogether. If your child is having many stomachaches, make sure that he or she gets a medical checkup.

Having poor sleep (like adults)

Most adults with FMS have a tough time with insomnia, and unfortunately, children with fibromyalgia share this symptom. Children with juvenile fibromyalgia may be more likely to have sleep disorders than other children. In a study of children diagnosed with juvenile fibromyalgia (reported in a 2000 issue of *Pediatrics*), researchers performed sleep studies of 16 children with fibromyalgia and compared their results to 16 children without fibromyalgia. The children with fibromyalgia had significantly more sleep problems.

For example, the FMS children took much longer to fall asleep, and had increased levels of wakefulness during sleep. Of the 16 children diagnosed with fibromyalgia, 6 were positive for a sleep disorder known as *periodic limb movements in sleep* (PLMS). PLMS refers to an excessive level of leg movements while asleep. The researchers recommended that children diagnosed with juvenile fibromyalgia should be evaluated in sleep clinics to determine whether they experience treatable sleep problems.

In addition, it seems logical that children diagnosed with sleep problems should also be evaluated for fibromyalgia. Keep in mind that erratic sleep patterns sometimes occur in healthy adolescents and, by themselves, probably don't indicate fibromyalgia unless the teen also has muscle aches and other symptoms of FMS.

Is it FMS, or a way for a child to get out of going to school? One possible screening mechanism is to look for a sustained pattern of fibromyalgia symptoms. For example, if Dylan or Caitlin has aches and pains on a school day, but feels fine at the end of the day or on weekends and holidays, fibromyalgia most likely isn't the problem!

Discovering other key FMS symptoms

Experts say that if your child has all or most of the following symptoms, the underlying problem may be fibromyalgia. These symptoms may be troubling enough that the child really can't cope with going to school on some days, or, with some children, on many days:

- Widespread pain
- Back and neck pain

- Joint pain without apparent swelling
- Fatigue
- Morning stiffness
- Frequent headaches
- Abdominal complaints, such as diarrhea or constipation

Accurately Diagnosing the Problem

Of all the groups of people who may have FMS, children may have the most difficult time getting a proper diagnosis. This situation can make it hard on both parents and their hurting children. Diagnosing fibromyalgia in children can be problematic because:

- **Few people, including doctors, realize how prevalent it is.** About 2 percent to 8 percent of school children qualify for the diagnosis of fibromyalgia.
- **Many pediatricians know little about the disease, and some don't believe that FMS is a valid medical problem among children.** It always must be something else, in their view. And if it's not medical, it must be a psychological problem. (Actually FMS *can* lead to depression, although that makes the fibromyalgia itself no less real.)
- **Parents are unfamiliar with the diagnosis and may find it hard or impossible to believe that their children could have FMS.** They may believe what others tell them — that FMS is just another fad diagnosis. They're wrong, but, sadly, perceptions can be powerful. This means that children who have fibromyalgia continue to hurt.

REMEMBER

The pediatrician or other physician should never rush into a diagnosis of juvenile fibromyalgia. Your child may have another serious medical problem, such as arthritis, thyroid disease, an infection, an injury, or another medical condition. Doctors should perform a physical examination, take a complete medical history, and rule out other diseases with medical tests, such as tests of the blood or urine. Sometimes, the child will need more-specialized tests.

If your child is diagnosed with FMS, the next step is to find help for her.

Finding Help for Your Child with FMS

Suppose that you're convinced that your child has fibromyalgia. What's the first step? When deciding where to get help for your child or teen, start with his pediatrician, even though some pediatricians are wary of diagnosing fibromyalgia in children. If you find that your child's pediatrician is completely unsympathetic and unwilling to seek out the cause of your child's symptoms, you may want to look for another pediatrician. My guidelines for finding a new doctor, in Chapter 7, can be adapted to finding a new pediatrician.

Your child's pediatrician may also decide that the child needs to see another physician. In most cases, the child with FMS-like symptoms should see a pediatric rheumatologist or a pediatric neurologist, specialists experienced with treating joint and muscle disorders, including fibromyalgia, in children. If your child needs to see a pediatric rheumatologist, your pediatrician can provide a referral for that.

A *pediatric rheumatologist* is a physician trained in medical problems of the joints and soft tissues and who specializes in treating children and adolescents with these problems. Fibromyalgia is a condition that pediatric rheumatologists are trained to diagnose and treat.

Treating a Child with Fibromyalgia

Children with fibromyalgia are treated much the same way as adults, although, of course, any medication dosages must be adjusted for the child's weight, and the doctor should also take into account any other drugs the child is taking. When thinking about what medications to prescribe or what over-the-counter drugs to recommend to parents, doctors should always consider potential problems that may occur with a person who's still growing and maturing. If the doctor doesn't mention it, ask her about potential side effects that can affect growing children. Drugs do have side effects, so no one should be nonchalant about prescribing medication for children.

It can be very hard on parents when their children have medical problems that others are suspicious about. The child says that she's in pain or is too tired to get up, but your mother says that she's just lazy, and your uncle says that you're coddling her. Maybe you have some underlying doubts about whether your daughter is faking it, or if she could be a hypochondriac. These attitudes are the same kind that adults with FMS face. But if the doctor has confirmed that fibromyalgia is present, assume that it's real. And stop worrying about what everyone else thinks or feels. Your ill child urgently needs you to be her advocate.

Using medication

Low doses of mild antidepressants, such as Elavil (generic name: amitriptyline), administered in the evening, may help your child with sleep difficulties and also ease pain. However, the child may complain of feeling very sleepy in the morning with this medicine, and some children also complain of headaches.

Non-steroidal anti-inflammatory drugs (NSAIDs), over-the-counter or prescribed, may be considered as well. These include over-the-counter drugs like ibuprofen and prescribed drugs like Celebrex (generic name: celecoxib) or Mobic (generic name: meloxicam).

Pediatricians report that NSAIDs usually are more effective at treating arthritis in children than they are with treating kids with juvenile fibromyalgia, although NSAIDs may give some relief to some children with FMS. The primary side effect identified with NSAIDs is stomach upset, and continued use of NSAIDs can result in *gastritis* (stomach inflammation). (You can read more about over-the-counter drugs for fibromyalgia in Chapter 9 and about prescribed medications for FMS in Chapter 10.)

Trying therapy

Because depression or anxiety often accompanies fibromyalgia, the child or adolescent may benefit from receiving therapy as well as from taking antidepressants. As with adults, *cognitive-behavioral therapy* (CBT), which teaches the child how to challenge irrational or negative thoughts, is one of the most effective types of therapy. According to a study of 67 children with fibromyalgia, reported in a 2005 issue of the *Journal of Pediatric Psychology,* CBT given over eight weeks significantly reduced the children's pain, fatigue, and anxiety, as well as improved their sleep quality.

A child psychologist can provide CBT. However, a child psychiatrist is the most suitable professional to prescribe medications, such as antidepressants or anti-anxiety drugs, as well as other medications used to treat emotional problems. Medical doctors who aren't psychiatrists can also prescribe medications, but they're not usually as knowledgeable about medications for emotional problems as are child psychiatrists.

Your child doesn't have to be mentally ill in order to see a child psychiatrist or psychologist. Psychiatrists and psychologists often see children with minor to major emotional problems, and depression is very common among children.

WARNING!

If you take your child with fibromyalgia to see a therapist, make sure that the therapist understands that the pain and symptoms of FMS are not solely created by the child's depression, anxiety, conflicts with parents or school, or other emotional issues. Symptoms may be worsened by such problems, but they don't *cause* the pain. If the therapist accepts that operating assumption, your child is more likely to succeed with the therapy that's provided.

Getting rebellious teens to take their meds

Because many adolescents automatically want to do the opposite of what their parents tell them to do, getting your teen to cooperate in taking his fibromyalgia medications can be difficult. Here are some basic do's and don'ts that may help.

Don't:

- Tell the teen to take the medicine because you said so. That's a reason for many adolescents *not* to take it.
- Tell her you'll give her a gift if she takes the medicine for a week or some other time frame. (She'll continue to expect prizes for taking her meds, and that's not a pattern you want to have to live with long-term.)
- Threaten him that if he *doesn't* take his meds, he'll be grounded. This can foster resentment and also viewing of medications as negative.
- Tell your adolescent that the medication will help her sleep much better at night and go to bed easily. Most teens think sleeping at night is a waste of time—although sleeping late when morning hits seems like a great idea.
- Lie and say the medication will cure your teen. Fibromyalgia is a chronic disease and even the best treatment can't provide a complete cure.

Do:

- Find a tailor-made reason for your teen to take the medication. For example, if your son loves video games, tell him that the medicine is likely to ease his pain and improve his score. If your daughter wants a more active social life, tell her the medicine may make this possible.
- Work with the doctor to tie medication times to meals, such as breakfast or dinner, or other specific time ranges, such as just before or after school. This will make it easier for you both to remember the medicine and get your teenager into a routine.
- Listen to your teen if he complains about side effects. Maybe the dosage needs to be decreased or the medication changed.
- If your teen is supposed to take an antidepressant or anti-anxiety medication, tell her that the drug is meant to decrease sadness and confusion — although adolescence is still a tough time.
- Dispense the medication yourself, instead of handing the bottle over to your teen. An adolescent can easily forget (accidentally or on purpose) to take medication.
- Give your adolescent a glass of water with the medication. He's more likely to take it when handed both the water *and* the med. If your teen says he'll take it later, take the pill back and say you'll return in an hour. Often the teen will grab the pill from you right then and there and swallow it down.

Children up to the age of adolescence (and sometimes even teenagers!) may enjoy drawing a picture of an imaginary figure, Mr. Fibro, as a way of communicating how they feel. Tell the child to draw a picture of a person with bad fibromyalgia symptoms. After the child finishes the drawing, you and the child can briefly discuss Mr. Fibro. Don't deny his or her feelings, and let your child do most of the talking. (Adults often tend to jump in before they're needed.)

Including Your Children Who Don't Have Fibromyalgia

When your child has a chronic medical problem, and it's one that your other children don't have, you may feel like you're balancing on a tightrope sometimes. You don't want to pay so much attention to the sick child that the healthy children think that they should act sick to be heard and seen. But at the same time, you can't ignore FMS, just as you can't ignore other chronic medical problems your child may have, such as diabetes, asthma, and so on.

Try to make sure that every child gets "special time" with you, tailoring the amount of time and the activity to the child. A teenager may need less time and would probably cringe in horror at the idea of going to a movie with her parents (and sitting *next* to them), while a younger child may love this idea. A walk with your teenager (far away from where you can be seen by anyone he knows!) may be a good idea instead. And explain that you don't love the sick child more or less than your other children. It's just that, sometimes, the child with FMS needs a little extra help. If you still see a little resentment in your kids without FMS, accept that you've done your best to mitigate it.

Working with Your Child's Teacher

The school is a key arena where problems can crop up. If your child is constantly saying that he can't do schoolwork or can't participate in gym, teachers may think your child is faking it. What should you do?

Should you tell your child's teacher that your child has fibromyalgia? You may think that the answer is an obvious *yes* (or, for that matter, an obvious *no*), but you have to consider some consequences that may occur, whatever you do (or don't do). Discussing the illness with the teacher is really an individual choice, but do keep in mind several factors:

- **Teachers are prone to the same wrong ideas adopted by the general public.** They may think fibromyalgia isn't a real illness or it's something only adults can get.
- **The teacher may treat your child differently — not in a good way — if she thinks that your child is disabled, making the workload too easy (or sometimes harder) for the child.** You want your child to get a good education and not be given a free pass. Yet, at the same time, you don't want your child to feel overwhelmed or physically ill from trying to reconcile her fibromyalgia symptoms with school demands. As a parent, this path sometimes can be a tough one to navigate.

Children aren't allowed to bring any drugs to school in their wallets, purses, or elsewhere, no matter how benign the drugs may seem to you. Even bringing one aspirin to school is usually forbidden, and a child can be suspended or expelled for violating this policy. If your child needs to take medication during school hours, she's not alone. Bring a doctor's note or a prescription bottle with the child's name on it to the school nurse, and explain what's needed. And don't worry. Many children have to take medicine during school for all sorts of reasons.

Sharing information with teachers

If your child is missing a lot of school due to fibromyalgia, you may decide that you have to tell the teacher. Most schools have a limit of how many days can be missed before alarm bells go off in the school system, and someone, somewhere, may start to suspect that your child is playing hooky.

If you do decide to tell your child's teacher about the fibromyalgia, consider the following points:

- **Describe to the teacher what fibromyalgia is.** She may never have heard of it. Explain that it is a problem that both adults and children can have, with key symptoms of pain, fatigue, muscle stiffness, and sleep problems. And many children with FMS have frequent headaches as well.
- **Tell the teacher that you don't want your child to avoid doing his schoolwork.** If he can't handle the work during school time, ask the teacher if your child can bring it home or have a few days of extra time to complete the work.
- **Offer to help ensure that your child completes her schoolwork.** This offer may present an extra burden on you, but it'll usually pay off in terms of getting cooperation and respect from your child's teacher.
- **Explain to the teacher that you don't expect your child to be permanently excused from physical education.** On some days, the child may be able to cope with his regular schoolwork, but he won't be able to handle the demands of gym class.
- **If the teacher expresses doubt about fibromyalgia, don't flare up and call him an ignoramus.** Instead, tell him that you understand his concerns. But point out that, in past years, many people didn't realize that children could suffer from ulcers, depression, and other medical problems. Tell him that FMS is a similar case.
- **Offer to share this book with the teacher (or buy her a copy), so that she can find out more about fibromyalgia.** Point out this chapter to her. Sometimes, when people read information in a book, it has more credibility than when you tell them the same thing.

Holding off on informing teachers

Maintaining a total nondisclosure policy about your child having an illness can become difficult after a while, and saying nothing usually isn't a good idea because teachers may think that your child has a worse problem than she has or that something terrible is occurring at home. But you may not want to share *every last detail* or even the exact diagnosis. So can you be partially forthcoming, without spilling all the beans? It's harder, but it's possible. Consider the following choices:

- Tell the teacher that your child has some medical problems that make it hard for him to concentrate right now. You're working on helping the child resolve these problems.
- Tell the teacher that your child has an illness that's similar to a mild form of arthritis.
- Ask the teacher to keep your information confidential. (Even when you've told her practically nothing.) Be sure to tell her whether she may (or may not) tell the other children or other teachers.

Not telling the teacher (or limiting what you tell him) has several benefits. Children are often embarrassed by information about them that's given by parents to teachers, especially if they think it's negative. They may also fear being regarded as weak or disabled, and some teachers might treat them that way if they knew about the fibromyalgia. Other teachers may regard children with fibromyalgia as hypochondriacs, no matter how hard you work at educating them. Teachers are part of the world, too, and they have their flaws, although most are understanding.

Handling difficult teachers

Sometimes, no matter how well you explain your child's problem and how helpful you try to be with the teacher, the situation deteriorates. The teacher starts telling others, including (worst case) other children, about your child's medical problem. Or she doesn't believe that Caitlin is really sick, and says so aloud to others. Other problems may also develop.

In such cases, the best thing to do is to ask for a meeting with the principal and the teacher to share your concerns. Don't be scared to ask for such a meeting! Write down the main one or two points you'd like to discuss at the meeting to make sure that you cover them. Plan ahead to be polite but firm.

Don't be intimidated, even if you're forced to sit in a little chair meant for a small child. Your initial reaction, when you come to the meeting, may be to feel like *you've* been called to the principal's office. Remind yourself that you asked for this meeting.

Take notes in case the teacher or principal offers any good suggestions or agrees to some of your ideas. At the end of the meeting, summarize what you've agreed upon. "Okay, so my understanding is that Ms. Jones won't talk about Dylan's health to the other children anymore," or whatever it is.

Dealing with Jeers from Peers

One of the toughest criticisms your child will have to face, whatever her problems, is that of her own peers. Children can be very cruel, taunting each other because they're fat (or skinny), wear glasses (or squint because they should wear glasses), are average (or are smart), and so on. When a child has a medical problem, such as fibromyalgia, kids may see this as just another thing to pick on. The child with fibromyalgia usually looks normal to others, but when he hangs back from activities because of pain and fatigue, the other kids will notice. It is particularly difficult when the child is a teenager, although kids can be mean at any age.

Other children aren't necessarily evil bullies (although it may seem that way to the child who's being verbally attacked). More often, the children are frustrated or upset about something else and take out their powerlessness on other children. It's not your job to analyze troubled children — focus instead on helping your own child.

Seeing your child unhappy is heartbreaking. So what should you do? Here are a few suggestions, with the warning that they don't always work. Sadly, I can't offer you the one magic phrase that makes the blinders fall from the eyes of other children — or adults. But I hope they help.

If your child is bullied

Most assaults aren't physical, but it's *not* true that "sticks and stones may break my bones, but names will never hurt me." Name-calling *does* hurt, and it often hurts a lot. You may think that reasoning or explaining the fibromyalgia to the other child can help — sometimes it does, but often it doesn't. Name-calling is about power — it's not about understanding. And don't think girls are exempt from making verbal attacks. Actually, some girls can be quite emotionally abusive.

Of course, explaining to your child that he has a disease that's like arthritis may help in some cases, so that's one way to go. Teach your child simple explanations of what fibromyalgia is — for example, that it's a medical problem that causes the body to hurt and get tired fast. Avoid complexities. Of course, if your child is an adolescent, more details will be needed. But keep in mind that many teens think in either/or terms — things are wonderful or they're terrible — so don't expect comprehension of subtleties.

Sometimes, ignoring (or pretending to ignore) other children can help because they usually get bored or tired of the teasing. Most children have a fairly short attention span, and if the object of their bad attention seems unaffected, they'll move on to something or someone else.

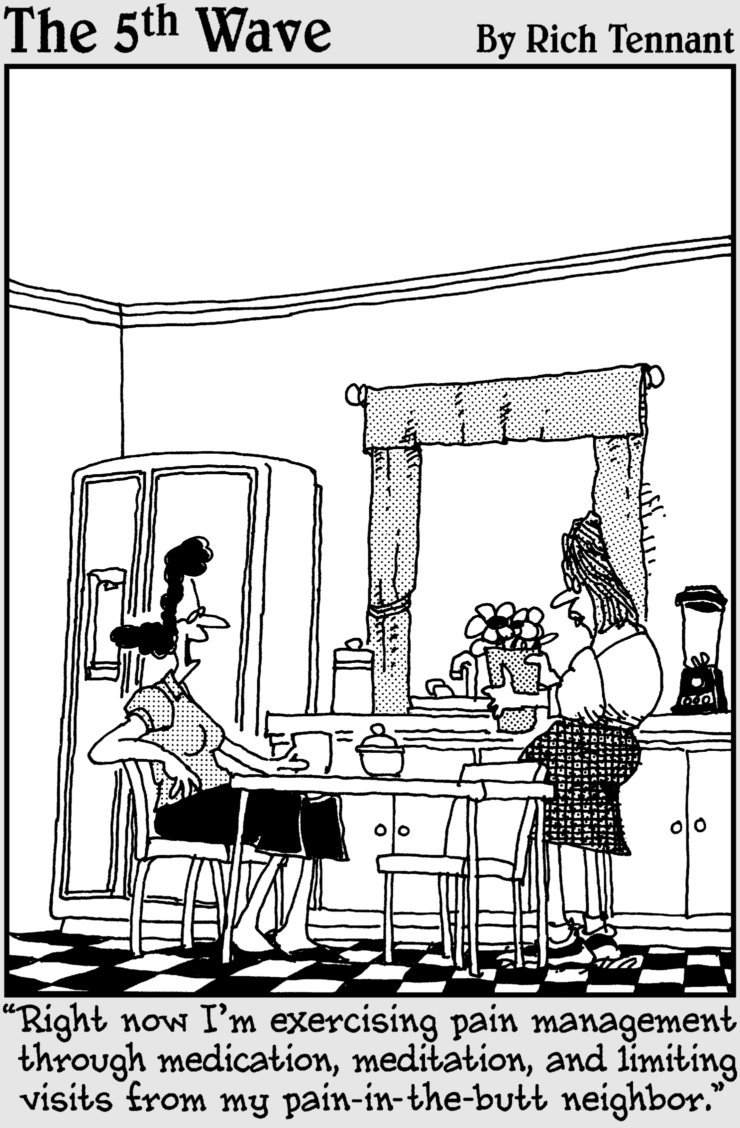
If the teasing becomes constant and chronic, you can talk to the child doing the bullying, if you keep it non-threatening and simple. You can also talk to the child's parents, who may be horrified to find out about the verbal abuse. Some of them won't be, however — they may actually be part of the problem. If the bullying occurs on school grounds, talk to the teacher. Many schools have anti-bullying policies, which may cover the child from when she starts to walk or ride the bus to or from school all the way through the time she's actually *at* school.

If your child is physically attacked

Sometimes, other children or adolescents can become physically abusive, and taunting may escalate to pushing and even punching. If this type of violence happens to your child, it's illegal. Report it to the school authorities if it happens at school, and if the abuse is beyond a few minor pushes, report it to the local police as well. Remind yourself that a bullying child who can be stopped and rehabilitated now is less likely to grow up to become an adult who assaults others. But above all, protect your child from physical harm. That's part of your job as a parent.

Part VI

The Part of Tens



"Right now I'm exercising pain management through medication, meditation, and limiting visits from my pain-in-the-butt neighbor."

In this part . . .

What would a *For Dummies* book be without the famous Part of Tens? If you like quick and easy-to-read lists of things to do or not do, you'll love this part. Part VI provides ten pieces of advice on alternative remedies and fibromyalgia, ten mistakes to avoid when you have fibromyalgia, ten ways to cope with the confusion (*brain fog* or *fibro fog*) of fibromyalgia, and ten myths about this medical problem. I offer some valuable advice in this don't-miss part of the book.

Chapter 21

Ten Alternative Remedies That Help People with Fibromyalgia

In This Chapter

- Spotting dangerous remedies
- Considering alternative remedies for sleep
- Rubbing out the pain and fatigue
- Smelling your way to health with aromatherapy
- Mudding out the pain
- Homeopathizing to improve your fibromyalgia symptoms
- Electrically stimulating pain to reduce it

Most people with fibromyalgia actively seek relief from their insomnia, pain, fatigue, and brain fog. Often, that relief comes in the form of alternative remedies, such as supplements and herbs, homeopathic remedies, aromatherapy, mud baths, and other treatments. In fact, in one study of 289 patients with fibromyalgia syndrome (FMS), 98 percent said they had used some type of alternative therapy to cope with their symptoms in the past six months.

That said, many people think anything labeled as "natural" is automatically good. But poison ivy is natural, and you wouldn't want to rub it all over your body. Another common misconception is that if a product is sold in the United States, it must be safe. Yet federal laws on vitamins and supplements are less restrictive than laws on prescribed and over-the-counter medications.

Ask questions about alternative remedies before using them. Consider using online databases, such as the Office of Dietary Supplements, for information. Go to `http://ods.od.nih.gov/factsheets` for information on many herbal remedies. At the very least, find answers to the following questions:

- **What are the side effects of this remedy?** Every drug — including "natural" ones — has potential side effects.
- **Is this remedy likely to interact with my other medications?**
- **Is this remedy okay for someone with my health history?**
- **How long should I use this remedy before expecting results?** Some remedies act fairly quickly, while others have a more cumulative effect.

Avoid any remedy sold by someone promising an instant cure. If there *were* an instant cure for fibromyalgia, its success wouldn't be trumpeted solely on some obscure Web site. Stay away from any remedy sold by people urging you *not* to tell your doctor you're taking it. Honest people won't give such advice. Instead, they'll offer studies and/or information to *share* with your doctor. (For tips on avoiding alternative-remedy scams, read Chapter 12.)

I've discussed the downside of alternative medicine, but what about the positive aspects? There are definite benefits to using alternative medicine when you have fibromyalgia, such as the symptom relief you may get from using supplements and herbs, as well as the relief you can get from (gentle) massage therapy, acupuncture, and other options.

Herbs

Difficulty getting and/or staying asleep is a major problem for many people with fibromyalgia, who may turn to alternative remedies that have sedating properties, such as:

- **Melatonin:** Melatonin is a supplement that's similar to natural melatonin, which is made by the pineal gland in the brain. It's sometimes used by jet-lagged travelers whose day/night cycle has gone awry. *Potential side effects:* Melatonin may cause headaches.
- **Valerian:** Used since the time of the ancient Greeks, this herbal remedy may sedate you so that you can get the sleep you need. *Potential side effects:* Valerian is generally safe to use for four to six weeks, according to the National Center for Complementary and Alternative Medicine. However, it can cause headaches, upset stomach, and dizziness.
- **Chamomile:** Generally taken as a tea, chamomile has sedating qualities that may help you sleep. *Potential side effects:* Chamomile may slightly decrease blood clotting and should not be taken by those on blood thinners.

Magnesium

Some supplements may help with pain; for example, magnesium is used by some patients with FMS, particularly those who may be slightly deficient in this mineral. Magnesium may improve fibromyalgia symptoms.

WARNING!

Avoid megadoses, because magnesium can also cause stomach upset and diarrhea. (Follow your doctor's recommendations.)

Echinacea

What if your primary problem is not insomnia or pain but rather excruciating fatigue? Echinacea may help you. It's a popular herb among people with fibromyalgia who need to *increase* their energy levels. Among patients in a *Mayo Clinic Proceedings* study published in 2005, of those ages 18 to 24 years old with fibromyalgia, 29 percent used echinacea to decrease fatigue. Fatigue-reducing remedies should not be taken within three hours of when you want to sleep.

WARNING!

Echinacea is generally safe but it may cause allergic reactions. Stomachaches are a more common reaction from echinacea than are allergic reactions.

Green Tea

Many people with fibromyalgia use herbal remedies to decrease their symptoms of both pain and fatigue. Based on a survey of fibromyalgia patients published in *Mayo Clinic Proceedings* in 2005, green tea was the most frequently used herb, used by 24 percent of all respondents. Green tea can increase energy.

WARNING!

Green tea should be taken in moderation because it can cause insomnia, upset stomach, and anxiety, and may raise blood pressure. It can also reduce the effects of anti-clotting drugs such as Coumadin (generic name: warfarin).

Massage Therapy

Many people with FMS find that massage therapy helps relieve pain and stress, whether they hire professional massage therapists or enlist the aid of a loved one.

Whoever gives you a massage should be sure *not* to rub too hard on your tender points! (Read more about massage therapy in Chapter 11.)

Aromatherapy

Inhaling the scent of lovely flowers or other pleasant smells may temporarily elevate your mood as well as help you relax. Proponents of *aromatherapy* (using odors to improve overall general health) are convinced that this is true.

You can purchase aromatherapy products in many different places. Even local pharmacies and supermarkets offer many different types of fragrances in the form of oils, lotions, and many other options. Lavender is a popular choice to help to calm and destress you, as are jasmine, geranium, or patchouli.

You may also want to consult an aromatherapy expert. Ask your local health-food store for names of people in your area who are experts in aromatherapy.

Mud Baths

It may remind you of making mud pies in kindergarten, but sitting in a hot mud bath may give you some relief from fibromyalgia symptoms. A 1999 study conducted in Italy indicated that mud baths, combined with antidepressants, gave subjects significant relief from fibromyalgia symptoms. Mud baths are more popular in Europe than they are in the United States. Generally, in the U.S., you can find spas with mud baths on the West Coast, particularly in California.

Further study is needed before scientists will know if mud baths are a valid treatment for fibromyalgia. But don't tell that to Mandy, a long-time FMS sufferer. She says she feels great after her mud bath, which she receives in a spa every few weeks. She soaks in a hot tub of peat moss for 20 minutes. Afterward, she washes up and rests for half an hour so she'll be alert enough to drive home. Relief lasts for days, although Mandy can't afford mud-bath treatments more frequently than every other week, because they cost $80 a shot. (Prices vary from one spa to the next.)

Acupuncture

Many people with fibromyalgia and other chronic pain conditions have turned to acupuncture, a therapy in which tiny pins are inserted at or near the pain sites. Some studies have shown that acupuncture is effective in temporarily decreasing the pain of people with fibromyalgia. (Read more about acupuncture in Chapter 11.)

Homeopathy

Some people with fibromyalgia swear by *homeopathy,* which is based on the principle that a substance that would normally be dangerous may be beneficial in tiny amounts. For example, if along with your fibromyalgia symptoms you also suffer from chronic headaches, homeopathic doses of belladonna (normally a poison) may help you feel better. (Read more about homeopathic remedies and fibromyalgia symptoms in Chapter 12.)

Transcutaneous Electrical Nerve Stimulators

Some patients obtain significant relief by using Transcutaneous Electrical Nerve Stimulator (TENS) units. TENS units are devices that emit low-level electrical pulses, which can decrease your pain significantly. In fact, TENS is nearly a mainstream remedy and is used by physical therapists and other medical professionals. (Read more about TENS in Chapter 11.)

Chapter 22

Ten Mistakes to Avoid When You Have Fibromyalgia

In This Chapter

- Failing to get a diagnosis as you try to ignore your symptoms
- Believing a doctor who says your symptoms are "all in your head"
- Trying one medicine or therapy, and if it doesn't work, giving up altogether on treatment
- Obsessing about fibromyalgia as the cause of all your problems
- Assuming that somehow you (or others) caused your symptoms

Debbie, age 40, said that when her fibromyalgia symptoms first started about three years ago, she ignored them. They got much worse as time passed, but she figured, hey, mind over matter, and she was a strong person who could tough it out and cope. Eventually, the symptoms became so severe that Debbie decided, "That's it. I have to go see a doctor." After taking a careful medical history and doing a complete workup, the doctor diagnosed Debbie with severe fibromyalgia syndrome (FMS). He also asked her why on earth she had waited so long before seeking help.

Debbie made the mistake of trying to ignore her chronic medical problem, rather than seeking a diagnosis and getting treatment and, as a result, she suffered unnecessarily. That's one common mistake made by many people with symptoms of fibromyalgia. But there are others as well, such as believing a physician who mistakenly tells you that fibromyalgia is an imaginary problem, and that your pain isn't real. Or assuming that your symptoms are all your fault or the fault of others in your life. I discuss these and other common mistakes in this chapter, explaining why they *are* mistakes and what you should do instead.

Ignoring Your Pain and Hoping It Goes Away

Many people try to ignore their pain and the other symptoms of fibromyalgia, hoping they'll somehow magically go away. In fact, many minor pains that people experience eventually *do* go away, such as a temporary stomach upset from something that you ate, a bruise from a minor fall, and so forth. But when your pain and other symptoms hang on, continue to escalate, and become harder and harder to ignore, pretending they're not there is a mistake.

Chronic pain is an indication that something is wrong and that you should consult a physician. (Read Chapter 4 for further information on the pain of fibromyalgia.)

Believing a Doctor Who Says Fibromyalgia Is "All in Your Head"

Although most doctors now realize that fibromyalgia is a legitimate medical problem, some physicians continue to think that your symptoms are "all in your head." If you keep complaining, such doctors may eventually send you to the nearest psychiatrist for treatment or may put you on mild antidepressants or anti-anxiety medications. In fact, you could also have depression or an anxiety disorder, and these medications could help you. (Read more about depression and anxiety disorders in Chapter 2.)

But what you really need is a good diagnosis and a treatment plan for your underlying main problem. If it's fibromyalgia, then you need a diagnosis of FMS and a treatment plan for it. So if you find that your doctor isn't listening to you or tells you that your symptoms are imaginary and you're really just fine, find another physician. (Read Chapter 7 for some tips on identifying a good doctor.)

Trying One Medication or Therapy, and If It Doesn't Work, Giving Up

Some people are willing to try one medication or therapy to resolve their fibromyalgia symptoms, but if that one particular drug or treatment doesn't give them any relief, they decide that there's nothing they can do but learn to live with the chronic pain and fatigue of fibromyalgia. Don't make this mistake!

In the case of drugs, physicians can prescribe many different types of medications, such as painkillers, antidepressants, anti-anxiety drugs, and other medications. There are also many individual medications within those types, which may help you. For example, if one painkiller doesn't work or causes serious side effects that are intolerable for you, a different painkiller with few or no side effects may help you. And if one antidepressant doesn't ease your symptoms, a different antidepressant may give you the relief that you truly long for.

Give the medicine that your doctor prescribes a fair trial of a week or two (unless you have severe side effects), and then, if you see no improvement, tell your doctor it's just not working. Ask her what your other options are. If she recommends another medication, seriously consider her suggestion. Keep in mind that many people with FMS need more than one medication, and that you may need to take two or more drugs to gain control over your FMS symptoms.

An array of other therapies may improve your symptoms as well, such as acupuncture, icing or heating the painful areas, using Botox injections, and many other options. Some people may try one form of therapy, and if they get no relief, they give up. But another therapy could provide them with considerable symptomatic relief. (Read about acupuncture and icing and heating in Chapter 11; turn to Chapter 12 for more on alternative remedies such as Botox injections.)

Assuming That the Problem Is All Your Fault

Some people with symptoms of fibromyalgia assume that they somehow caused the problem themselves. They may think that they're weak or bad and that the pain is some sort of retribution that the body is taking out on them. They may also think that if only they didn't drink/smoke/overeat/something else, then they'd be just fine. Of course, it's a bad idea to smoke, drink alcohol, or eat to excess, but it doesn't mean that these actions directly caused your fibromyalgia. And certainly fibromyalgia is not punishment for your past sins.

When you think you deserve to suffer, you can get mired in that suffering. Liberate yourself. See your physician and work on identifying the means to relieve your symptoms.

Assuming That the Problem Is Everyone Else's Fault

Sometimes people don't think that their FMS symptoms are their fault at all. Instead, they think that the symptoms are everyone else's fault. If only your boss were nicer or your children would just do what you tell them to do. If only your spouse or partner would remember that you hate broccoli and stop buying it. In other words, if everyone else were perfectly nice to you, then you'd feel just fine.

There are several problems with this belief. First, everyone else can't be nice to you all the time. Secondly, even if they could be, fibromyalgia is caused by a problem from within your body. Sure, stress can make it worse. (Read Chapter 13 for more on stress.) But, with the exception of post-traumatic stress disorder (PTSD; see Chapter 3), caused by an extreme emotional crisis, everyday stress doesn't *cause* FMS in the first place. So if you're making the mistake of blaming everyone else for your symptomatic flare-ups, stop it — right now. Instead, work with your doctor to create a plan to improve your situation.

Turning to Alcohol or Other Substances

Some studies have shown that people with fibromyalgia have a risk of turning to alcohol or other substances. The pain may be so severe that they seek a temporary respite from it. The problem with this "solution" is that alcohol and some other substances (such as excessive use of painkillers or the use of illegal drugs) can be habit-forming or even addicting, and they can only temporarily take away your pain. So you actually don't resolve your fibromyalgia with substance abuse. Instead, you add yet another problem on top of your FMS problem.

If you find yourself thinking, when you're in pain from your fibromyalgia, that maybe having a few drinks would help you feel dramatically better, then think again. The risks can be very severe with alcohol or drug dependence. You could lose your driver's license, your spouse or partner, your children, and even your life, such as in a car crash or other accident. If you think you may have a problem with substance abuse, get an evaluation and get some help now.

Believing That All Your Problems Are Caused by Fibromyalgia

Some people with chronic diseases, including fibromyalgia, develop the wrong idea that *all* their medical problems (and sometimes even all their personal problems as well) are caused by their FMS. It's a one-stop shop for blaming everything that has gone wrong. The reality is that although fibromyalgia can cause many distressing symptoms for you, you should not attribute every bad thing that happens in your life to your fibromyalgia.

Also, keep in mind that you could have another medical or psychological problem altogether, and it may not stem directly from fibromyalgia. For example, many people with FMS also suffer from arthritis, chronic headaches, irritable bowel syndrome, or other medical problems. (Read more about other medical problems in Chapter 2 and Chapter 6.) You need to get these other problems identified so that they can be treated, too.

Overeating to Make Yourself Feel Better

Some studies have demonstrated that people with FMS, particularly women, are more likely to be obese than people without fibromyalgia. The reasons for this aren't known, but I'm willing to offer some speculation.

Sometimes when a person has severe chronic pain that doesn't improve (possibly because she hasn't obtained a diagnosis of fibromyalgia or hasn't gotten any treatment), she becomes depressed and upset. Instead of seeking treatment, she seeks solace in candy, cakes, pies, and other high-calorie and high-fat foods. Such foods may provide a temporary good feeling — but it's one that doesn't last.

These individuals also usually fail to exercise because of their pain and fatigue, which further contributes to being overweight — and is a mistake! Overeating provides only a very temporary respite from the symptoms of fibromyalgia, and a lack of exercise increases the pain. (Read Chapter 15 for information on weight loss and exercise.)

Feeling That You're a Defective Person Because of Your Fibromyalgia

Some people with fibromyalgia are ashamed and embarrassed by their disorder. They may not think that they're bad people who somehow deserve the disorder (as discussed earlier in this chapter), but they still feel that they aren't as effective as the other people they know at work or in their families.

The reality is that most people, at some time in their lives, have a serious and chronic medical problem. It may be arthritis, it may be diabetes, it may be chronic headaches, or it may be something else — but nearly everyone at some point has a "weak spot." In your case, your weak spot is fibromyalgia. FMS is nothing to be embarrassed about. It just *is.* As long as you're working to control your symptoms as best you can, then you're doing the right thing. So mentally pat yourself on the back! You deserve it.

Trying to Hide Your Symptoms from Family, Friends, and Others

Some people with fibromyalgia think that they're behaving well, even nobly, if they try to completely hide all their symptoms of pain, fatigue, and fibro fog from others. They assume that if they don't complain about their symptoms, then others won't notice anything. The fatal flaw in this reasoning is that others who are close to you nearly always do notice that something is going on with you. But they may mistakenly believe that you're angry or upset with them for something that they've done or haven't done. Or they may mistakenly believe that your problem is much worse than fibromyalgia, and that you have cancer or another terminal illness that you aren't talking about, for some reason.

Don't make this mistake of hiding your symptoms and attempting to be a martyr. Although you don't need to report every twinge of pain to your family members and friends, it's another story when you're in severe pain. It's okay (and a good idea) to tell others that your fibromyalgia is bothering you a lot today and that you hope tomorrow will be a better day to go to the movies/go out to dinner/engage in other activities. (Read Chapter 18 for more suggestions on how to help your loved ones understand and cope better with your fibromyalgia symptoms.)

Chapter 23

Ten Ways to Beat the Effects of Brain Fog

In This Chapter

- Overcoming your mental malaise
- Defining the important tasks
- Working with others to help you stay on task

Laurie says the forgetfulness, confusion, and overall brain fog that seem to go together with fibromyalgia syndrome (FMS) drive her crazy, and she'd love some helpful hints on how to pull herself together when she starts lapsing into la-la land. What she'd really like is for the brain fog (and the fibromyalgia) to evaporate like morning mist — except forever (mist comes back the next day). Barring that, some coping techniques are her order of the day.

This chapter offers Laurie (and you) some basic guidelines on helpful ways to stay present and focused in the here and now and to achieve most (if not all) of what you need to get done. If brain fog washes over you anyway, which often happens, these techniques can help you maintain some semblance of order in your life. In this chapter, I offer ten basic helpful hints for beating back your brain fog or averting the effects when you can't avoid it.

Avoiding Brain and Energy Drains When You're Hurting or Tired

This piece of advice may sound like a no-brainer, but I'll say it anyway: Don't try to tackle difficult problems when your symptoms are in the red (very high) zone of pain. Many people feel that they must *still* help their children with complicated science projects, drive five hours to family reunions, or perform other difficult tasks that require more brain power and energy than anyone can reasonably give when in pain. Is it any wonder, in such cases, that you become confused and a little foggy?

Think of your mind and body like a glassful of water, brimming with your active life. Then imagine trying to add *more* water (work) to the glass because you think that you should. You get a mess spilling over into your personal and professional lives. Also, while you're struggling to take on the big jobs, you may be ignoring easy and doable tasks that are still within your capabilities, such as work or household tasks that need to be done.

TIP

The best policy is to keep it simple when you're sick. If you do, you'll be far more likely to avoid forgetfulness and confusion and to stay focused. If you really *must* do something hard, break it down into smaller tasks, doing some now and some later.

Asking Others to Help You Stay On Task

If you're periodically short-circuiting in terms of mental alertness because of your FMS symptoms, consider making an ally at work or at home who can help you return to planet Earth. Ask this person to notice if you seem to be lost in space, brainwise, and to send you a signal if he does. The signal can be a gentle touch on the arm, a word or phrase that grabs your attention, or something else.

You can also try a more general approach of telling people that, sometimes, you get lost in thought and, if you seem inattentive, to please call on you by name more loudly than usual. (No screaming allowed.)

Making Lists and Checking Them Twice

Listmaking is an efficient procedure for most busy people, and it can really help a person constrained by fibromyalgia. The only downside of lists is that many people are overly ambitious about what they can perform in a day or a week. Write down what you absolutely *must* do today, and then prioritize these items from the most important down to the least important. (Don't make your first task a nearly impossible one.)

A list can help you focus. And if you're having a bad day, often you'll still have succeeded at doing at least a few things on your list, and you can pat yourself on the back. No name-calling of yourself, however, if you can't accomplish your list items. ***Remember:*** Nobody's perfect.

Banning Self-Blame

Many people become inordinately angry with themselves when they're sick and can't remember to do things (or simply *can't* do them, even if they remember them). Don't make this mistake — you're likely to worsen your brain fog when you cloud your mind with negative self-talk. Does anyone work better when she's yelled at? It may work if you're joining the Marines, but being yelled at makes most people more confused. Don't chastise yourself, either. Do the best you can and let the rest go until tomorrow.

Avoiding Blaming Others

In addition to a tendency to blame yourself for not doing everything you think that you should be doing, sometimes, when you're sick, you may find yourself blaming others for not making your life sufficiently easy. Whether you self-blame or blame others, you're likely to worsen your fibro fog. Avoid this problem. Don't let others get away with not doing what they're supposed to do at home or at work. But don't blame them just because you feel lousy. It's not their fault — or yours.

Getting Enough Sleep

I emphasize the importance of getting enough sleep in other chapters throughout the book, and guess what? Here it is again. Sufficient sleep (at least seven hours a night) is vitally important for the brain and the body. You concentrate better and think more clearly when you've thoroughly rested your entire body through the process known as sleep. If you don't get enough sleep, however, you'll find it much harder to wrap your mind around even the simplest of concepts — let alone concentrate on serious issues. Get the sleep you need on a regular basis, and often, the fibro fog will clear up.

Keeping a Calendar of Activities

Another good idea is to keep a calendar of what you're supposed to do and when. On a day when you're not overwhelmed with symptoms, record your numerous doctor appointments (as well as birthdays and other important dates and activities that you really need to pay attention to) directly on your calendar. Forget relying on those little cards doctors give people. You can easily lose them. Instead, when you get home from a doctor's appointment, immediately write down the dates and times of your next appointments on your calendar. Or staple the cards to a daily calendar.

Watching What You Eat

How can foods that you *eat* affect your brain's performance? Simply put, some foods can impair productivity, making you more sluggish. Others make sleeping more difficult. (And some foods, such as turkey or milk, can help you fall asleep.) Read more about good foods/bad foods in Chapter 15.

The following foods can worsen brain fog:

- Caffeine, such as in soft drinks, tea, coffee, and chocolate, hype you up, making it hard for you to sleep.
- Excessive sugar can make you tired and cranky — definitely *not* good for brain fog.
- Foods with additives, such as MSG, can cause agitation. Avoid them.

Putting Things in Their Places

If you're distracted by your symptoms and prone to misplacing things like your car keys and important papers, start putting the most important items in the exact same places. Concentrate on the two or three most important items you need, but which you keep losing in your fibro fog. For many people, car keys are a biggie. Some people place their car keys on a ring by the door, and others put them in another particular place. If you always put the item in the same place, you're less likely to waste your time searching for it when you're feeling major pain.

Catching Yourself Slipping Away

Sometimes you can actually catch yourself in the act of slipping into a brain fog and come back to full awareness. Some people use auditory signals to help, such as an alarm that goes off every half-hour or hour. You can buy special watches that beep or pulsate at preprogrammed intervals, or program your cellphone to jolt you back to the real world by ringing, beeping, or vibrating. Realize, however, that everyone daydreams or tunes out the world sometimes, and doing so can be a good thing, as long as it's just once in a while.

Chapter 24

Ten Myths about Fibromyalgia

In This Chapter

- Mastering the myths and realities of fibromyalgia
- Helping others understand what's real and not real
- Maintaining your perspective

I talk about some fibromyalgia myths in other chapters throughout this book. Some of these myths are that fibromyalgia is imaginary, and that people who think they've got it are either lazy or crazy. Another myth is that people who say that they have fibromyalgia syndrome (FMS) are attention seekers or that they're seeking narcotics to get high. Of course, you've probably heard many more myths yourself.

Plenty of myth-busting needs to be done when it comes to fibromyalgia. I believe that knowledge is power. After you understand what's most important to know about fibromyalgia from your *own* perspective, you may want to share this information with others and empower them, too.

In this chapter, I cover ten key myths about fibromyalgia and explain why these myths aren't valid. You'll probably recognize at least some of them, and you may have an "Aha!" reaction with all or most of them.

People with Fibromyalgia Are Lazy or Crazy

One of the most common myths about fibromyalgia is that it's an escape clause for lazy people who don't feel like working or for hypochondriacs imagining that they're sick. The "lazy or crazy" myth is even believed by a few doctors, although most physicians know that it isn't true. Studies indicate that people with FMS are about as active as people who don't have fibromyalgia, *except* when they're in the middle of a major flare-up of pain and fatigue.

It only makes sense: When you feel really sick, you can't work as well as usual, or maybe you can't work at all. A truly "lazy" person is physically fit, but she prefers to do nothing, despite good health.

Nor are people with fibromyalgia delusional (or "crazy") about their symptoms. What they feel is real, and it's no figment of the imagination. It's true that many people with fibromyalgia *do* suffer from problems with depression or anxiety (see Chapter 2), or from stress (see Chapter 13). But none of these problems alone makes people develop FMS. Something else causes fibromyalgia.

Fibromyalgia Symptoms Are a Way to Get Attention

Another myth that drives people with fibromyalgia wild is that they're "just trying to get attention." Some patients with FMS agree that they'd rather be in solitary confinement than to suffer a severe flare-up of fibromyalgia. Their suffering is in no way an attempt to get onto center stage with their friends and relatives so they can get lots of attention.

People with FMS Just Want Drugs

Because many people with fibromyalgia need painkilling medications at least some of the time, some people may assume that people with FMS are really "druggies" seeking an excuse to take strong painkillers or narcotics. Although some painkilling drugs *can* be habit forming and they do need close monitoring by physicians, the reality is that people with fibromyalgia who take strong drugs do so to cope with their severe pain rather than to get high.

Looking Well Means You Are Well

Charlotte was always well dressed, and her general demeanor gave no indication of the pain that she suffered from fibromyalgia. If you looked *really* closely, however, you may sometimes see a tightness around the mouth and eyes. You may also notice that Charlotte didn't smile a lot and she rarely laughed. People thought that Charlotte was a distant kind of person, but the reality was that she suffered from fibromyalgia. When people told her how well she looked, she always thought, "If they only knew!"

Some illnesses aren't readily apparent from the outside, and fibromyalgia is one of them. Most people who have such medical problems may be told that they look fine, even when they don't go to great lengths to hide their illness, like Charlotte. Telling someone that you feel awful only to hear in response, "But you look so great!" can be truly maddening. Remember (and tell your friends): Looking wonderful can be the same as feeling wonderful. But when you have fibromyalgia, that often isn't the case.

Pain Is Pain: It's All the Same

All pain is not created equal. If your cousin has pain from arthritis or a bad back, he may think that his pain is about the same as your pain from fibromyalgia. (Or he may think that his pain is far worse than yours!) But studies indicate that the pain from fibromyalgia can be far more intense than other forms of muscle or joint pain, and it often lasts longer as well. Some studies have demonstrated that people with fibromyalgia feel pain more intensely and for a longer period than others.

Feeling Good Today Means You're Well

Fibromyalgia is a frustrating kind of disease because it's so unpredictable. Today, you feel lousy; tomorrow, you feel worse; the next day, you feel okay or even close to normal. When you tell people that you're finally having a good day, many will assume that at long last, you're "all better." Many people have a hard time grasping a medical problem that has a lot of ups and downs to it, especially when there aren't any external signs of illness that you can point to. But that's the nature of the illness. As with many chronic illnesses, fibromyalgia isn't something you just get over. However, you can cope with the disease in many ways to minimize your pain, such as getting better sleep, exercising (when you're well enough to exercise), taking medications, and using therapies such as acupuncture and other options.

Relaxing Will Cure What Ails You

When your symptoms from FMS are really bothering you, many people will tell you that you're working too hard, that you need to ease off. They may advise you that a week on a cruise or a nice vacation to a pleasant place will fix you right up. In fact, you *may* be working too hard right now, and stress certainly *can* exacerbate fibromyalgia. Maybe some rest and relaxation would make you feel much better. But when you have fibromyalgia, a vacation can't cure you. You could win the lottery and retire tomorrow, and you'd still have periodic flare-ups of the problem — although it beats working a day job at the office with your FMS!

Taking Some Pills Should Fix You Right Up

Some people become annoyed when you tell them about your pain, and they advise you to "take a pill," whether it's Tylenol, Aleve, or another medication. Many people are very drug-oriented — they think that the right pill or combination of pills will solve just about any problem. This can be good in that people are willing to take medications that can help them, and many medications are available to treat fibromyalgia. But thinking that swallowing a few pills will completely resolve your problem is not a valid assumption. Medications are short-term fixes for the long-term problem of fibromyalgia. (I discuss over-the-counter and prescription medications in Chapters 9 and 10 as well as in Appendix B.)

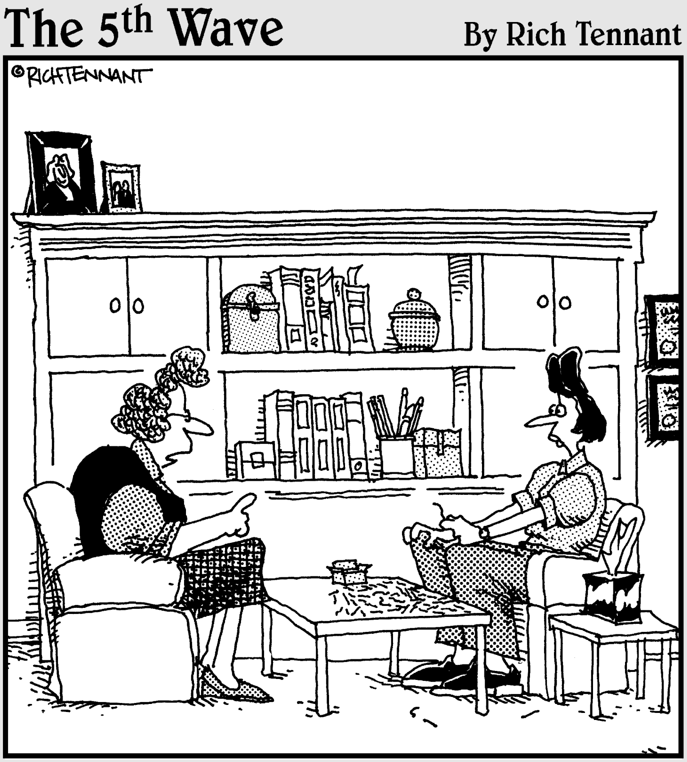
Ignoring the Problem Will Make It Go Away

Your partner or your friends may tell you that you're dwelling on your symptoms far too much. Distract yourself, think about something else, and you'll feel better. To a certain extent, if you're able to distract yourself with interesting work, hobbies, or family tasks, you may succeed at ignoring some pain. But most of it will still be there, whether you ignore it or not.

Therapy Always Works

Some people think that the answer to any long-term problem is therapy, and that a good therapist can help you work through all your problems. Although a therapist can certainly help you if you have problems with anxiety, depression, or stress, that same therapist can't cure your fibromyalgia. You probably will feel *some* better after talking to a therapist — but not *all* better.

Part VII
Appendixes



"The reason I think stress might be a factor in your FMS is because of research, statistics, and the fact that you've straightened out an entire box of paper clips during our conversation."

In this part . . .

The last part of this book includes appendixes. In Appendix A, I offer you a glossary of terms, so you can easily look up the definitions for key fibromyalgia-related words.

In Appendix B, I provide a very helpful and up-to-date list of medications, both over-the-counter and prescribed drugs, which are often recommended to people with fibromyalgia. You may know these medications by either their brand name or their generic name, so I give you both, along with the main side effects that these medications may cause.

If you want to uncover even more information on fibromyalgia after you've finished reading this book, check out Appendix C. It lists organizations with helpful information, publications that may intrigue you, and sources for fibromyalgia-related info online.

Appendix A

Glossary

acupuncture: A form of treatment in which tin y needles are inserted into muscle to stimulate the production of *endorphins* (natural painkilling biochemicals). Several studies have supported acupuncture as an effective treatment for fibromyalgia.

alternative medicine: Treatments or medications that may not have a scientific explanation for their effectiveness. Alternative medicine includes the use of vitamin, herbal, and mineral supplements; acupuncture; and homeopathy; as well as other remedies and treatments.

anxiety disorders: Psychological problems often causing chronic distress, including generalized anxiety disorder (GAD), obsessive-compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD), and specific phobia disorder. Individuals with fibromyalgia often suffer from one or more anxiety disorders. Read about anxiety disorders in Chapter 6.

arthritis: An illness affecting the joints. Many people with osteoarthritis, rheumatoid arthritis, and lupus have joint pain and inflammation. (For more on arthritis, check out *Arthritis For Dummies,* 2nd Edition, by Barry Fox, Nadine Taylor, and Jinoos Yazdany [Wiley].)

Arthritis Foundation: A nonprofit organization providing information on fibromyalgia and arthritis to consumers and medical professionals that has funded clinical studies on fibromyalgia and arthritis. (For more information, visit the Arthritis Foundation Web site at `www.arthritis.org` or call 800-568-4045 or 404-872-7100.)

benign joint hypermobility syndrome (BJHD): A common disorder of the joints that causes hyperflexion/extension and often causes excessive pain. It may be confused with fibromyalgia in some cases.

Botox injections: Injections of minute amounts of botulinum toxins into the muscles and other areas of the body where patients feel pain. This treatment is controversial, and its use in fibromyalgia is not approved by the Food and Drug Administration (FDA).

chronic fatigue syndrome (CFS): A disorder in which symptoms are primarily characterized by extreme exhaustion and pain. It is often confused with fibromyalgia. (For more on CFS, check out *Chronic Fatigue Syndrome For Dummies,* by Susan R. Lisman, MD, and Karla Dougherty [Wiley].)

cortisol: A stress-related hormone that has been found in abnormal levels in many people who have fibromyalgia.

depression: A serious, chronic form of despair beyond the normal feelings of sadness. Many people with fibromyalgia suffer from depression, but it's highly treatable.

dextromethorphan: A medication commonly used to treat coughs. Some research has indicated that it may provide some pain relief in fibromyalgia.

electroconvulsive therapy: A treatment using electrical pulses to decrease major depression. Studies have shown that such therapy may be effective for fibromyalgia.

fibro fog: Mental confusion and forgetfulness that can accompany a flare-up of fibromyalgia symptoms. Also known as *brain fog.* (Read about fibro fog in Chapter 2.)

fibromyalgia: Chronic pain condition characterized by tender points, widespread pain, fatigue, morning stiffness, sleep disturbances, and distress. *See also* tender points.

guaifenesin: A medication commonly used to treat coughs, and also used by some physicians to treat fibromyalgia. Studies have not validated this use. (Read about guaifenesin in Chapter 9.)

Gulf War syndrome: A condition characterized by fatigue and widespread pain and body aches related to active duty in the 1991 Persian Gulf War. Some Gulf War veterans have fibromyalgia and may be eligible for compensation from the Veterans Administration.

headaches: Head pain related to muscle tension, migraine attacks, or a problem arising from the neck/cervical spine (as with cervicogenic headaches). Many people with fibromyalgia have at least one type of chronic headache. (For more on migraines, check out *Migraines For Dummies,* by Diane Stafford and Jennifer Shoquist, MD [Wiley].)

heartburn: Chronic burning in the gut or chest that often results from gastroesophageal reflux. Stomach acid backs up into the esophagus and causes pain. Many people with fibromyalgia have heartburn.

heating therapy: A form of treatment in which painful areas of the body are stimulated with heat (such as a heating pad). Heating can be an effective method of treating fibromyalgia.

hydrotherapy: A form of treatment that uses water to provide temporary relief from the pain of fibromyalgia, such as pool walking and exercises performed in the pool, as well as the use of whirlpool baths and hot tubs.

icing therapy: A form of treatment in which painful areas of the body are stimulated with ice. Icing can be an effective method of treating fibromyalgia.

interstitial cystitis (IC): A chronic unspecific illness of pain with urination and increased urgency. Some people with fibromyalgia may also have IC.

irritable bowel syndrome (IBS): A chronic bowel condition often characterized by abdominal pain in conjunction with constipation and/or diarrhea. Many people with fibromyalgia suffer from IBS. (For more on IBS, check out *IBS For Dummies,* by Carolyn Dean, MD, ND, and L. Christine Wheeler, MA [Wiley].)

Lyme disease: A bacterial illness spread by a deer tick that can cause severe rashes, joint pain, and tiredness. Because of similar symptoms, Lyme disease may be confused with fibromyalgia. A blood test confirms Lyme disease.

massage therapy: A form of treatment in which painful areas are gently rubbed to help with relaxation and pain management. Massage therapy can be very helpful in treating fibromyalgia.

mononucleosis: An infectious disease that can cause high fevers, sore throat, and extreme lethargy that may be confused with fibromyalgia or chronic fatigue syndrome. Mononucleosis can be diagnosed with a blood test.

multiple chemical sensitivities syndrome (MCSS): A condition in which the person has become extremely sensitive to many environmental substances that were never a problem before, such as odors, foods, and other common items.

myofascial pain syndrome: A condition characterized by regional pain as well as by focal muscle-tissue abnormalities (called *trigger points*) that the doctor can identify upon touching them. In contrast, the tender points of fibromyalgia are highly sensitive to touch but do not consist of abnormal tissues.

pain diary: A written daily record of when pain is most severe, which helps patients and doctors track conditions that may trigger pain, such as activities, stress, or other items.

painkillers: Over-the-counter or prescribed medications taken to reduce pain from fibromyalgia. Narcotics are painkilling medications, as are non-steroidal anti-inflammatory drugs (NSAIDs).

pain management: Techniques for reducing chronic pain to a tolerable level, with medications, injections, massage therapy, physical therapy, and other treatments.

post-traumatic stress disorder (PTSD): A disorder arising from extreme stress from abuse, injuries, war, or other distressing situations that may continue long after the distressing incident. People with PTSD may develop fibromyalgia immediately after the incident (or sometime later). Similarly, many patients with fibromyalgia have PTSD.

relaxation therapy: A technique that allows a person under stress to decrease high physical and mental tension. Lowering high levels of stress usually improves the symptoms of a person with fibromyalgia.

sleep disorders: Difficulty getting to sleep and/or staying asleep. Sleep disorders are extremely common among people with fibromyalgia.

Social Security disability compensation: Monthly compensation and medical insurance (Medicare) provided by the Social Security Administration (Web: `www.ssa.gov`; phone: 800-772-1213) to eligible individuals who cannot work because of fibromyalgia or other medical problems.

Substance P: A neurochemical whose levels have been shown to be three times higher in the spinal fluid of patients with fibromyalgia compared to pain-free individuals.

supplements: Minerals or herbs that may provide relief to people with fibromyalgia. Some research has indicated that supplemental magnesium is helpful to some patients with fibromyaglia.

tai chi: A Chinese exercise technique mimicking movements of animals. Most people with fibromyalgia can tolerate performing these exercises.

tender points: Specific areas of the body that are painful when lightly pressed if a person has fibromyalgia. People with fibromyalgia generally have pain at 11 or more of the 18 tender points. (For a diagram, see Chapter 8.)

thyroid disease: Malfunction of the thyroid gland that results in either abnormally high or low levels of circulating thyroid hormone. Symptoms of thyroid disease may be confused with fibromyalgia and other illnesses. (For more on thyroid disease, check out *Thyroid For Dummies,* 2nd Edition, by Alan L. Rubin, MD [Wiley].)

valerian: An herb used to induce sleep.

Appendix B

Fibromyalgia Medications

In this appendix, I provide listings of both prescribed and over-the-counter medications that may be recommended to you and others with fibromyalgia syndrome (FMS). I include the following information:

- The brand name of the drug
- The generic name of the drug
- Primary side effects that may occur, although side effects aren't experienced by everyone

Note: In a few cases, a drug's brand name and generic name are the same, as with guaifenesin and dextromethorphan.

I provide these listings for your information only. Don't consider this information to be any sort of a substitute for consulting with your own physician and following his medical recommendations.

Pondering Prescribed Medications

Whether you have severe pain, fatigue, and/or sleep problems from your fibromyalgia or just minor discomfort, at some point, you'll need prescription drugs to treat your FMS symptoms. You may need meds on a regular basis, or you may need to take them only when symptoms flare up. Whatever your needs, I provide information about different types of prescription medications prescribed for fibromyalgia.

Sometimes, anti-anxiety medications (see Table B-1) can help with the pain generated by fibromyalgia as well as with sleep problems that many people with FMS struggle with.

Table B-1 Anti-Anxiety Medications

Brand Name	***Generic Name***	***Comments***
Atarax	Hydroxyzine	May cause sedation and nightmares.
Ativan	Lorazepam	May cause sedation and nightmares.
Klonopin	Clonazepam	May cause sedation and nightmares.
Librium	Chlordiazepoxide	May cause sedation and nightmares.
Matarax	Hydroxyzine	May cause sedation and nightmares.
Serax	Oxazepam	May cause sedation and nightmares.
Valium	Diazepam	May cause sedation and nightmares.
Vistoril	Hydroxyzine	May cause sedation and nightmares.
Xanax	Alprazolam	May cause sedation and nightmares, may be especially habit forming.

Often, antidepressants (see Table B-2) are prescribed for people with fibromyalgia because they can help with the pain and insomnia experienced by most people with FMS.

Table B-2 Antidepressants

Brand Name	***Generic Name***	***Comments***
Adapin	Doxepin	May cause sedation, weight changes, and stomach upset.
Asendin	Amoxapine	May cause sedation, weight changes, and stomach upset.
Celexa	Citalopram	May cause sedation, weight changes, and stomach upset.
Cymbalta	Duloxetine	May cause sedation, weight changes, and stomach upset.
Effexor	Venlafaxine	May cause sedation, weight changes, and stomach upset.
Elavil	Amitriptyline	May cause sedation, weight changes, and stomach upset.

Brand Name	*Generic Name*	*Comments*
Lexapro	Escitalopram	May cause sedation, weight changes, and stomach upset.
Pamelor	Nortriptyline	May cause sedation, weight changes, and stomach upset.
Paxil	Paroxetine	May cause sedation, weight changes, and stomach upset.
Wellbutrin	Bupropion	May cause sedation, weight changes, and stomach upset.
Wellbutrin XL	Bupropion	May cause sedation, weight changes, and stomach upset.
Zoloft	Sertraline	May cause sedation, weight changes, and stomach upset.

Anticonvulsive medications (see Table B-3) can sometimes relieve pain and muscle aches experienced by people with fibromyalgia.

Table B-3 Anticonvulsive Medications

Brand Name	*Generic Name*	*Comments*
Lamictal	Lamotrigine	May cause sedation, dry mouth, and dizziness.
Lyrica	Pregabalin	May cause sedation, dry mouth, and dizziness.
Neurontin	Gabapentin	May cause sedation, dry mouth, and dizziness.
Topamax	Topiramate	May cause sedation, dry mouth, and dizziness.

Muscle relaxants (see Table B-4), which are often prescribed for people with fibromyalgia, can offer some relief from muscle aches and pains.

Table B-4 Muscle Relaxants

Brand Name	*Generic Name*	*Comments*
Baclofen	Baclofen	May cause sleepiness, sedation, diarrhea, and stomach pain.
Flexeril	Cyclobenzaprine	May cause sleepiness, sedation, diarrhea, and stomach pain.
Norflex	Orphenadrine citrate	May cause sleepiness, sedation, diarrhea, and stomach pain.
Skelaxin	Metaxalone	May cause sleepiness, sedation, diarrhea, and stomach pain.
Soma	Carisoprodol	May cause sleepiness, sedation, diarrhea, and stomach pain.
Zanaflex	Tizanidine HCl	May cause sleepiness, sedation, diarrhea, and stomach pain.

Non-steroidal anti-inflammatory drugs (NSAIDs; see Table B-5) are prescribed for pain relief.

Table B-5 Non-steroidal Anti-Inflammatory Drugs (NSAIDs)

Brand Name	*Generic Name*	*Comments*
Celebrex	Celecoxib	May cause gastrointestinal pain, gastrointestinal bleeding, and diarrhea. May have a lower risk of gastrointestinal problems than other NSAIDs.
Feldene	Piroxicam	May cause gastrointestinal pain, gastrointestinal bleeding, and diarrhea.
Mobic	Meloxicam	May cause gastrointestinal pain, gastrointestinal bleeding, and diarrhea. May have a lower risk of gastrointestinal problems than other NSAIDs.
Naprosyn	Naproxen sodium	May cause gastrointestinal pain, gastrointestinal bleeding, and diarrhea.
Relafen	Nabumetone	May cause gastrointestinal pain, gastrointestinal bleeding, and diarrhea.

People with FMS often suffer from major pain and need a drug that targets pain symptoms (see Table B-6).

Table B-6 Painkillers

Brand Name	Generic Name	Comments
Demerol	Meperidine	A narcotic. May cause sedation. May be habit forming.
Duragesic	Fentanyl	A timed-release skin patch. May be addictive.
Fiorcet	Butalbital, acetaminophen	May cause sedation.
Percocet	Oxycodone with acetaminophen	May cause sedation. May be habit forming.
Percodan	Oxycodone with aspirin	May cause sedation. May be habit forming.
Tylenol 3	Acetaminophen with codeine	May cause sedation and constipation. May be habit forming.
Ultracet	Tramadol with acetaminophen	May cause sedation. May be habit forming.
Ultram	Tramadol	May cause sedation. May be habit forming.
Vicodin	Hydrocodone	May cause sedation. May be habit forming.

Most people with fibromyalgia struggle to get to sleep, and sometimes nothing seems to work. As a result, doctors may prescribe sleep remedies (see Table B-7).

Table B-7 Sleep Medications

Brand Name	Generic Name	Comments
Ambien	Zolpidem	May cause sedation, dizziness, and diarrhea.
Lunesta	Eszoplicone	May cause sedation. Should be avoided by those with depression or respiratory disease. Seniors may need a lower dose.
Restoril	Temazepam	May cause sedation.
Rozerem	Ramelton	May cause sedation. No risk for addiction. Should be avoided by those with liver disease.
Sonata	Zaleplon	May cause sedation, migraines, or bronchitis. Avoid if allergic to FD&C Yellow No. 5 dye.

Other Medications That May Help

Other drugs ease fibromyalgia pain, including Lidoderm, a skin patch, as well as several medications to treat Parkinson's disease. I cover all these other options in Table B-8.

Table B-8 Off-Label Prescribed Medications for FMS

Brand Name	*Generic Name*	*Comments*
Lidoderm (skin patch)	Lidocaine, 5 percent	Apply directly over aching muscles. May cause some skin irritation.
Mirapex	Pramipexole	May cause temporary anxiety and weight loss.
Requip	Ropinirole	May cause nausea, agitation, depression, and dizziness.

Reviewing Over-the-Counter Medications

Over-the-counter (OTC) drugs are often recommended to patients with fibromyalgia because they can help relieve pain and sleep problems. Of course, just because a drug isn't prescribed doesn't mean it's automatically safe or will help you. Every medication has side effects to consider before taking the drug.

Some physicians may recommend cold remedies (see Table B-9) to help alleviate some FMS symptoms.

Table B-9 Cough/Cold Remedies

Brand Name	*Generic Name*	*Comments*
Delsym	Dextromethorphan polistirex	Includes alcohol. May cause sedation.
Dextromethorphan	Dextromethorphan	May cause itching and rashes.
Guaifenesin	Guaifenesin	May cause itching and rashes.

You may not want or need a prescribed drug to deal with your pain, and common OTC painkillers (like the ones listed in Table B-10) may do the job just fine.

Table B-10 Painkillers

Brand Name	*Generic Name*	*Comments*
Aleve	Naproxen potassium	May cause headaches, ringing in the ears, and stomach ulcers.
Aspirin	Acetyl-salicylate	May cause easy bruising and gastrointestinal bleeding.
Motrin	Ibuprofen	May cause nausea, stomach upset, and stomach ulcers.
Tylenol	Acetaminophen	Excessive use can damage the liver. Avoid alcohol when using this drug.

Appendix C

Resources and Support

In this appendix, I provide you with lists of organizations and Internet resources that may be of interest to people with fibromyalgia syndrome (FMS), as well as to their family and friends and others, such as co-workers. I don't personally endorse any of these listings (nor does the publisher), and I'm not responsible for their content, but I hope that you find them useful and helpful.

Organizations

National and international organizations throughout the United States, Canada, the United Kingdom, and other countries provide a wealth of information, educational materials, and morale-boosting offerings. Most of these organizations also provide newsletters, brochures, and other publications. (Some of the publications are free, and some items are available for a fee.) Here's a rundown on some key groups with an interest in fibromyalgia:

- ✓ **American Chronic Pain Association (ACPA),** P.O. Box 850, Rocklin, CA 95677 (phone: 800-533-3231; Web: `www.theacpa.org`)
- ✓ **Arthritis Foundation,** P.O. Box 7669, Atlanta, GA 30357 (phone: 800-568-4045; Web: `www.arthritis.org`)
- ✓ **The Arthritis Society,** 393 University Ave., Suite 1700, Toronto, Ontario, M5G 1E6, Canada (phone: 800-321-1433 or 416-979-7228; Web: `www.arthritis.ca`)
- ✓ **CFIDS Association of America, Inc.,** P.O. Box 220398, Charlotte, NC 28222 (phone: 704-365-2343; Web: `www.cfids.org`)
- ✓ **Fibromyalgia Association UK,** P.O. Box 206, Stourbridge, DY9 8YL, Great Britain (phone: 0870-752-5118; Web: `www.fibromyalgia-associationuk.org`)
- ✓ **National Center for Complementary and Alternative Medicine (NCCAM) Clearinghouse,** 9000 Rockville Pike, Bethesda, MD 20892 (phone: 888-644-6226; Web: `www.nccam.nih.gov`)

- **National Fibromyalgia Association,** 2200 North Glassell St., Suite A, Orange, CA 92865 (phone: 714-921-0150; Web: `www.fmaware.org`)
- **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Clearinghouse,** 1 AMS Circle, Bethesda, MD 20892 (phone: 877-226-4267; Web: `www.niams.nih.gov`)

To find local support groups interested in fibromyalgia, ask your local reference librarian for help — not the librarian at the front desk, but the person who works at the reference section of your library. (If you call the library, ask for the reference desk.) Also, ask your doctors who treat fibromyalgia and any friends or relatives who have fibromyalgia if they know of any local groups. Local support-group meeting times may also be published in free weekly newspapers that are often distributed to neighborhoods or available at convenience stores.

Finding Information on the Internet

On the Internet, you can find a variety of places to gain information, share what you know about fibromyalgia, and meet other people with similar interests. The key formats of these options are Web sites, e-mail lists, newsgroups, and forums.

WARNING!

Spotting the frauds, scams, and just plain crazy ideas on the Internet isn't always easy — but it's often possible. Keep a few basics in mind:

- **Try to determine who's running the Web site by locating the Contact Us link or by looking on the main page.** If you can't find such a link and no matter how hard you look, you can't find a name, mailing address, or a telephone number, alarm bells should ring. Those alarms are saying: Don't buy anything with your credit card from these people.
- **Try to determine the primary purpose of this site.** Is it an information-only site, or are you bombarded with offers to buy this and that wonder cure? If so, watch out. And speaking of wonder cures, if you're offered a quickie and forever cure, then run away. Sorry, but managing fibromyalgia just isn't that easy.

If you're still not sure whether you should buy a product that you're told that you need "RIGHT NOW!" try this: Imagine that the site was offering products for another medical problem, one that you don't have, such as diabetes or asthma. Would the offers still seem credible? If not, you need to say goodbye. Also, be sure to talk to your doctor about any products that you buy over the Internet. Some products could be harmless, while others could interact dangerously with your other medications.

Checking out Web sites

Hundreds of different Web sites on the Internet have either a direct or indirect concentration on the subject of fibromyalgia. Some popular sites include the following:

- **American Fibromyalgia Syndrome Association, Inc.:** `www.afsafund.org`
- **Arthritis Foundation:** `www.arthritis.org`
- **Fibrohugs Fibromyalgia Support Site:** `www.fibrohugs.com`
- **Fibromyalgia Network:** `www.fmnetnews.com`
- **Fibromyalgia Resource Center:** `www.healingwell.com/fibro`
- **MEDLINEplus:** `www.nlm.nih.gov/medlineplus/fibromyalgia.html`
- **Missouri Arthritis Rehabilitation Research and Training Center:** `http://marrtc.missouri.edu`
- **National Fibromyalgia Association:** `www.fmaware.org`
- **National Fibromyalgia Research Association:** `www.nfra.net`
- **University of Florida Fibromyalgia Research Information:** `www.med.ufl.edu/rheum/`

Looking at e-mail lists

An e-mail list, also called a *listserv,* is an arrangement whereby you join as a member and automatically receive all e-mails sent by every member. (Sometimes, e-mail lists provide you the option of going to a special Web site to read all the messages if you don't want to receive a large number of e-mails.)

TIP

Before joining an e-mail list, consider the pros and cons of doing so. Here are some of the positive aspects of joining e-mail lists:

- **You may gain information that's difficult or impossible to obtain elsewhere.** Some *posters* (people who send e-mail to the list participants) are medical professionals.
- **You may feel a strong kinship to others who are going through problems that you are facing.**

As with almost everything in this world, e-mail lists also have a few strikes against them:

- **You must wade through a large number of responses.** An active list can generate many messages! My coauthor told me that she joined a listserv once and received 100 messages the first day and even more the second day! On the third day, she begged to be removed from the list because she just couldn't keep up. Not all listservs are overwhelmingly active, but some are.
- **People who post messages may act as if they are knowledgeable about a topic, but they may know little or nothing about it.**

Check out the following table for examples of e-mail lists.

Content Focus	***List Name***	***Web Address***
General fibromyalgia	Fibrom-L	`http://www.fmscommunity.org/fibromlhelp.htm`
Guaifenesin	Guai-Support Group	`www.psha-inc.com/guai-support`
Fibromyalgia and chronic fatigue syndrome	Co-Cure (Cooperate and Communicate for a Cure)	`www.co-cure.org/ccabout.htm`

Noting newsgroups

A *newsgroup,* also known as a *Usenet group,* is an online special-interest group that usually doesn't require you to subscribe, fill out any forms, or agree to anything. You can read all the messages without ever making any public comments or revealing your presence. Or you can post messages and read replies. Some newsgroups are moderated by one or more people who set rules and make sure participants obey them; if not, they're warned and then may be thrown off. Many groups, however, aren't moderated, and it's a free-for-all kind of atmosphere. This can be good or bad, depending on your viewpoint.

Here are some of the good things you can gain from joining a newsgroup:

- **Newsgroups often offer good or at least interesting information (as long as you read everything skeptically).**
- **Newsgroups give most readers strong moral support.**
- **Posters offer direct Web links to useful journal articles that you'd probably never find on your own.**

When you find pros, you often find cons:

- **Newsgroups are open to the world at large, and consequently, some people write obscene and/or ridiculous and insulting messages.** This can cause considerable distress.
- **Some individuals try to sell their own products, either overtly or covertly.**
- **People who aren't knowledgeable may offer cures or solutions that don't work or even exist.**

Contact your Internet service provider (ISP) to determine how to reach newsgroups. You can also find links to many newsgroups (including `alt.med.fibromyalgia`) at `www.makoa.org/usenet.htm`.

Following forums

An online forum is a place where people with a special interest can usually find a great deal of information, read messages, and post their own messages. Forums are also known as *message boards, discussion boards,* or *bulletin boards.* At least one person usually moderates forums.

If you type **fibromyalgia** into your favorite search engine (such as Yahoo! or Google), you'll likely find too many listings to help you. Instead, try such sites as `www.fibrotalk.info` and click on the subject links that fascinate you the most. If you're in Canada, go to `http://fibromyalgia.ncf.ca`.

Pondering Publications

As of this writing, several national newsletters or magazines are dedicated to fibromyalgia:

- ***AFSA Update:*** Published by the American Fibromyalgia Syndrome Association, Inc., 6380 E. Tanque Verde, Suite D, Tucson, AZ 85715 (phone: 520-733-1570; Web: `www.afsafund.org`)
- ***Fibromyalgia Aware:*** Published by the National Fibromyalgia Association, 2200 N. Glassell St., Suite A, Orange, CA 92865 (phone: 714-921-0150; Web: `www.fmaware.org`)
- ***Fibromyalgia Frontiers:*** Published by the National Fibromyalgia Partnership, P.O. Box 160, Linden, VA 22642 (phone: 866-725-4404; Web: `www.fmpartnership.org`)
- ***Fibromyalgia Network:*** Published by the Fibromyalgia Network, P.O. Box 31750, Tucson, AZ 85751 (phone: 800-853-2929; Web: `www.fmnetnews.com`)

Index

• A •

accidental injuries, 24, 37–38, 39
acetaminophen, 125–126, 313
acid reflux (GERD), 34–35
acid-blocking medications, 35
ACPA (American Chronic Pain Association), 315
acupressure, 168
acupuncture, 87, 166–168, 285, 303
acute pain, 58
Adamec, Christine *(How to Stop Heartburn),* 35
Adapin (doxepin), 140, 308
addiction, drug, 134–136, 137, 138, 143, 144, 298
ADHD (attention deficit/hyperactivity disorder), 27
Advil (ibuprofen), 86, 126, 138, 313
AFSA Update (American Fibromyalgia Syndrome Association publication), 319
age and fibromyalgia risk, 71–73, 74
alcohol
  aggravating fibromyalgia, 49
  avoiding with headaches, 34
  avoiding with heartburn, 35
  avoiding with muscle relaxants, 132
  avoiding with Tylenol, 126
  sleep disorders not helped by, 195
  stress-related drinking, 179, 290
  withholding drinking from doctor, 108
Aleve (naproxen potassium), 127, 313
allergic reaction, 50
alternative medicine
  acupressure, 168
  acupuncture, 166–168, 285, 303
  analyzing remedies, 162–163, 281–282
  Botox injections, 169–172, 303
  defined, 303
  herbs and supplements, 163–166, 282–283
  homeopathy, 169, 285
  magnet therapy, 174
  neurofeedback, 173
  neuromodulation, 173
  phony, 161–162, 184
  popularity of, 161
  questions to ask about, 162–163
  tai chi, 172–174, 306
  telling doctor about, 163–164
Ambien (zolpidem), 145, 201, 311
American Academy of Medical Acupuncture, 168
American Chronic Pain Association (ACPA), 315
American College of Rheumatology, 107, 112
American Fibromyalgia Syndrome Association, 317, 319
American Massage Therapy Association, 153
anemia, 84
anger, 222, 248, 262–263
annoyance, 248
anti-anxiety medications, 143–144, 202, 225–226, 308
antibiotics, 31, 89, 139, 171
antibodies, 42–43
anticonvulsive medications, 143, 309
antidepressant medications
  advantages and disadvantages, 141–142
  for arthritis, 87
  combining for increased relief, 140–141
  for fibromyalgia, 140–142
  future remedies, 146
  for gastroesophageal reflux disease, 35
  libido diminished by, 142
  other actions needed with, 225
  overview, 36
  for pain relief, 219
  side effects, 142, 225–226
  for sleep disorders, 201–202, 226
  SNRIs, 140, 141
  tables summarizing, 225–226, 308–309
  types of, 140
  usefulness of, 226, 227
antihistamines, 50, 128, 144
anti-inflammatory medications, 32, 86, 138–139, 272, 310

anti-malaria medications, 86
anxiety. *See also* emotional problems
  anger with, 222
  in children, 272–273
  chronic-panic disorder, 220
  depression versus fibromyalgia or, 221
  disorders, defined, 303
  finding a therapist, 223–224
  generalized anxiety disorder, 15, 220, 221, 303
  about magnetic resonance imaging, 116
  medications, 143–144, 202, 225–226, 308
  in MFS versus fibromyalgia, 81
  obsessive-compulsive disorder, 220, 303
  phobias, 116, 303
  prevalence of disorders, 219
  PTSD, 41, 46, 220, 306
  symptoms of disorders, 220, 222
  treating disorders, 220
appearance of sufferer, 298–299
appointments, calendar for, 295
aquatic exercises, 87, 207–208
aromatherapy, 284
arthritis
  defined, 303
  diagnosis, 32
  fibromyalgia versus, 82, 83–84, 85
  with Lyme disease, 89
  medications, 32, 86
  morning stiffness, 23, 83
  osteoarthritis, 32, 83, 85, 86, 87
  overview, 32–33, 82–85
  rheumatoid, 32, 82, 83–84, 85, 86–87, 114
  symptoms, 83
  treating, 33, 86–87
  types of, 82
Arthritis For Dummies (Fox, Taylor, and Yazdany), 86, 303
Arthritis Foundation, 208, 303, 315, 317
Arthritis Society, 315
Asendin (amoxapine), 308
aspartame, 216
aspirin
  advantages and disadvantages, 126
  oxycodone with (Percodan), 135, 311
  for polymyalgia rheumatica, 86
  side effects, 313
  in topical remedies, 129, 130
Atarax (hydroxyzine), 144, 308
Ativan (lorazepam), 79, 308
attention, disease as ploy for, 298
attention deficit/hyperactivity disorder (ADHD), 27
attorney for disability claims, 241–242
autoimmune disorders, 31, 83, 114
autoimmune reaction, 43–44

• B •

back pain, 91
Baclofen (liorisol), 133, 310
bacteria, healthful, 171
bacterial infection, 42, 46
bedding, 159, 198
Benadryl (antihistamine), 128
benign joint hypermobility syndrome (BJHD), 33, 303
Bennet, Robert (rheumatologist), 123, 127
benzodiazepines, 202
Berger, Joseph *(Healing Yourself with Self-Hypnosis),* 186
Bextra (valdecoxib), 139
biking, 208
biofeedback, 173, 181–184
biometeorology, 28
bladder infection, 31
bladder spasms, 31
blame, 268, 289–290, 291, 295
blood tests. *See* laboratory tests
Bodian, Stephen *(Meditation For Dummies),* 187
body language, 261
body mass index (BMI), 212–214
bone diseases, 116
boss, explaining fibromyalgia to, 229–231
Botox injections, 169–172, 303
brain abnormalities, 116
brain fog. *See* fibro fog
breathing technique for sleep, 192
bulletin boards, online, 319
bullying of child, 277–278
Buspar (buspirone), 226

• C •

caffeine, 34, 90, 216, 296
calendar, keeping, 295
Caprio, Frank *(Healing Yourself with Self-Hypnosis),* 186
capsaicin, 129
Cardura (doxazosin), 90
carpal tunnel syndrome, 40
causes of fibromyalgia
  chemical imbalance, 47–50
  difficult pregnancy, 41–42
  environmental, 50–52
  exercise, 24, 53–54
  genetics, 52–53, 55
  Gulf War syndrome, 45–47
  illness, 40, 54–55
  infection, 42–45
  injuries or traumas, 24, 37–42
  overview, 11
cayenne, 129
CBC (complete blood count), 115
CBT. *See* cognitive behavioral therapy (CBT)
Celebrex (celecoxib), 86, 139, 272, 310
Celexa (citalopram), 308
CFIDS. *See* chronic fatigue syndrome (CFS)
CFIDS Association of America, 79, 315
CFS. *See* chronic fatigue syndrome (CFS)
chamomile tea, 282
chemical imbalance, 47–50
chemical sensitivities, 51, 91–92, 305
children
  abuse of, 38, 39–40, 278
  cognitive behavioral therapy for, 272–273
  diagnosing fibromyalgia in, 270
  explaining fibromyalgia to, 251–253
  faking symptoms, 271, 274
  fibromyalgia not your fault in, 268
  fibromyalgia symptoms in, 268–270
  finding a doctor for, 270–271
  medication for, 271–272, 273
  partner as caretaker, 249
  peer problems, 277–278
  questions from, 252–253
  siblings, special time with, 274
  sleep disorders in, 269
  stomachaches, 268–269
  taking to support group, 254–255
  tender points fewer in, 268
  treating fibromyalgia in, 271–273
  working with teacher of, 274–277
chiropractors, 159–160
chocolate, 49, 216
chronic fatigue syndrome (CFS). *See also* fatigue
  defined, 304
  diagnosis, 78
  fibromyalgia versus, 77, 78–79
  with Gulf War syndrome, 46, 47
  irritable bowel syndrome with, 78
  medications, 79, 80
  overview, 26, 77–78
  symptoms, 77–79
  from thyroid hormone imbalance, 50
  treating, 79–80
Chronic Fatigue Syndrome For Dummies (Lisman and Dougherty), 79, 304
chronic pain, 24, 57, 58, 59, 61
chronic-panic disorder, 220
circadian rhythm, 190
claustrophobia, 116
cognitive behavioral therapy (CBT), 36, 181, 219, 223, 272–273, 300
cold remedies, 127–128, 312
cold sensitivity with Raynaud's, 90
cold therapy, 87, 148, 149–150, 305
colonoscopy, 30
communication. *See also* interviewing
  to boss and coworkers, 229–231
  to children about fibromyalgia, 251–253
  with child's teachers, 274–277
  with doctor, 107–110, 163–164
  hiding symptoms, 229–230, 292
complete blood count (CBC), 115
computerized tomography (CT), 116
constipation, 30, 142, 164
controlled medications, 134–135, 137
cortisol, 50, 80, 190, 192, 304
coworkers, 230–231, 294
COX-2 inhibitors, 86, 139
cranberry juice, 31
cryotherapy (cold therapy), 87, 148, 149–150, 305
Cymbalta (duloxetine), 36, 140, 141, 215, 219, 225, 308

• D •

Dean, Carolyn *(IBS For Dummies),* 31, 305
deep sleep, 191, 192, 193, 194
Delsym (dextromethorphan polistirex), 128, 312
delusions, 136, 298
Dement, William C. *(The Promise of Sleep),* 191
Demerol (meperidine), 311
depression. *See also* antidepressant medications; emotional problems
  anger with, 222
  anxiety versus fibromyalgia or, 221
  CBT therapy for, 36
  in children, 272–273
  defined, 218, 304
  diagnosis, 35–36
  finding a therapist, 223–224
  linked to fibromyalgia, 218
  in myofascial pain syndrome versus fibromyalgia, 81
  overview, 35–36
  symptoms, 218, 222
  treating, 36, 218–219
Desyrel (trazodone), 140, 201
dextromethorphan, 127–128, 304, 312
diabetes, 114
diagnosis
  arthritis, 32
  checking doctor's knowledge, 94, 102
  chronic fatigue syndrome, 78
  computerized tomography for, 116
  criteria for, 102, 107
  depression, 35–36
  differential, 112
  of fibromyalgia in children, 270
  of fibromyalgia in men, 73–74
  gastroesophageal reflux disease, 34
  headaches, 33–34
  hypothyroidism, 87, 88, 114
  interstitial cystitis, 31
  irritable bowel syndrome, 30
  laboratory tests for fibromyalgia, 113–117
  laboratory tests inconclusive, 22–23
  lower-back pain, 91
  Lyme disease, 89
  MCSS, 92
  medical history for, 106
  mononucleosis, 92
  MRI for, 34, 91, 116
  self-test for, 13–16
  tender points identification, 110–113
  ultrasound for, 117
diarrhea, 30, 164, 171
diary
  food, 216
  pain, 63–64, 305
dietary recommendations, 216
dieting, 214
differential diagnosis, 112
disability benefits, 237–242
discussion boards, online, 319
disease-modifying antirheumatic drugs (DMARD), 86
doctor shopping, 103
doctors
  approaches to fibromyalgia, 94–96
  asking questions of, 110
  attitude toward guaifenesin, 123
  bad attitude in, 16, 95–96, 288
  for children, 270–271
  communicating with, 107–110, 163–164
  consulting before exercise, 204
  disability benefit help from, 239
  documenting pain for, 62–64
  finding, 16, 97, 99–101, 270–271
  good attitude in, 16, 94, 95–96
  hesitant to prescribe painkiller, 134, 136–138
  inexperienced, 94
  in insurance network, 99
  interviewing, 100–101, 102–103
  letter to insurance company from, 237
  medical history interview with, 106
  for pain management, 61–66, 98
  primary-care, 94–96
  recording appointments with, 295
  referrals from, 100–101
  shopping for, 103
  specialists, 97–99, 100–101
  touching tender points, 111
  true believer, 16
  when to call, 66
  when to change, 96–97
Dougherty, Karla *(Chronic Fatigue Syndrome For Dummies),* 79, 304
dreaming, 190, 192, 194, 200

dry heat, 148
duodenal ulcer, 133
Duragesic patches (fentanyl), 134, 135, 311

• E •

ears, ringing in, 25, 126
echinacea, 283
Effexor (venlafaxine), 140, 226, 308
egg crate mattress, 159
Elavil (amitriptyline), 30, 31, 34, 140, 201, 308
electroconvulsive therapy, 304
e-mail lists (listservs), 256, 317–318
embarrassment, 292
emotional problems. *See also* anxiety; depression
  active coping strategy for, 217
  affect on relationships, 243, 244–245
  blame, 268, 289–290, 291, 295
  dialogue about, 246–247
  in family and friends, 262–265
  family and friends concerned about, 222
  finding a therapist, 223–224
  medications for, 225–226
  in MFS versus fibromyalgia, 81
  negative reactions to fibromyalgia, 248
  overeating with, 222, 291
  paying attention to, 18
  self-assessment, 221–222
  self-perception, 245–246, 289, 292
  therapy not always enough for, 300
  weight loss with, 222
Enbrel (etanercept), 32, 86
endocrinologist, 87
endorphins, 152, 157, 167
endoscopy, 35
enterovirus, 42–43
environment
  causes of fibromyalgia, 50–52
  chemical sensitivities, 51, 91–92, 305
  shared, 53
ephedra, 165
epilepsy, 156
Epstein-Barr virus, 45, 92
erythrocyte sedimentation rate (ESR), 78, 84, 89
eucalyptus, 129
exercise
  aquatic, 87, 207–208
  with arthritis, 87
  benefits of, 203
  biking, 208
  as cause of fibromyalgia, 24, 53–54
  consulting doctor before, 204
  fatigue without, 25
  with myofascial pain syndrome, 82
  overview, 15, 203–204
  pain from, avoiding, 205
  preparing for, 205
  programs for, 204, 205–206
  sleep aided by, 195
  strengthening, 208–211
  stretching, 209, 210, 211
  tai chi, 172–174, 306
  tips, 204–205
  walking, 204, 205–207
  weightlifting, avoiding, 208
  yoga, 187–188
expectorant, 122

• F •

fainting (syncope), 77, 116
family and friends. *See also* partner; support groups
  affect of fibromyalgia on, 243, 244–245
  analyzing fibromyalgia in family, 55
  asking if you're okay, 222
  attending support group, 264–265
  blaming, 290, 295
  body language in, 261
  communicating with, 19
  cuing for fibro fog, 294
  discussing emotions with, 246–247
  doctor referral from, 101
  emotional problems in, 262–265
  family members at risk, 53
  fibromyalgia as excuse with, 245
  genetics and fibromyalgia, 52–53, 55
  hugging sufferer, 260
  ineffective interactions with, 244–245
  leaving sufferer alone, 259–260
  listening to sufferer, 258–259, 261
  negative reactions to fibromyalgia, 248

family and friends *(continued)*
  stress and relationship to, 179
  supportive comments from, 258–259, 262
  sympathizing with sufferer, 258–262
  taking to support group, 254–255
  unhelpful remarks by, 248–249, 257, 259
Family and Medical Leave Act (FMLA), 233
fatigue, 25, 211, 270. *See also* chronic fatigue syndrome (CFS)
fear, 248
feet, tingling, 25
Feldene (piroxicam), 138, 310
Feuerstein, Georg *(Yoga For Dummies),* 188
fibro fog
  ADHD versus, 27
  asking for help, 294
  defined, 11, 21, 304
  feeling out of it, 26–27
  inattention from, 27
  mental confusion with, 28
  in MFS versus fibromyalgia, 81
  sense of humor about, 26
  tips for coping with, 293–296
  work issues, 229
Fibrohugs Fibromyalgia Support Site, 317
Fibromyalgia Association UK, 315
Fibromyalgia Aware (National Fibromyalgia Association publication), 319
Fibromyalgia Community support group, 256
Fibromyalgia Frontiers (National Fibromyalgia Partnership publication), 319
Fibromyalgia Network (Fibromyalgia Network publication), 319
The Fibromyalgia Network, 97, 317, 319
Fibromyalgia Resource Center, 317
fibromyalgia syndrome (FMS)
  acknowledging, 10, 72
  anxiety or depression versus, 221
  arthritis versus, 82, 83–84, 85
  associated medical problems, 11, 13, 23, 29–30, 75–76, 90
  CFS versus, 77, 78–79
  coping, 18–20
  defined, 304
  depression linked to, 218
  diagnostic criteria for, 107
  diseases confused with, 12–13, 75–76
  ignoring, 287, 300
  lupus versus, 84
  Lyme disease versus, 89
  mistakes to avoid, 287–292
  myofascial pain syndrome versus, 81
  myths about, 297–300
  number of sufferers, 1, 70
  overview, 1
  people at risk for, 12, 53, 70
  Raynaud's phenomenon with, 90
  self-test for, 13–16
  thyroid disease versus, 87, 88
  unpredictability of, 299
  validity of, 9–10
Fiorcet (butalbital with acetaminophen), 135, 311
flex time, 232
Flexeril (cyclobenzaprine), 132, 202, 310
flu-like pain, 1, 89, 92, 95, 127
FMLA (Family and Medical Leave Act), 233
food
  aggravating fibro fog, 296
  aggravating fibromyalgia, 30, 49, 216
  aggravating headaches, 34
  aggravating heartburn, 35
  aggravating IBS, 30
  diary, 216
  dietary recommendations, 216
  sleep disorder aids, 197
forgetfulness, 26, 294, 296
forums, online, 319
Fox, Barry *(Arthritis For Dummies),* 86, 303
friends. *See* family and friends
frustration, 248, 263
Fuentes, Manny *(T'ai Chi For Dummies),* 174

• G •

gastritis, 126, 133, 272
gastroenterologists, 30, 35
gastroesophageal reflux disease (GERD), 34–35
gastrointestinal distress, 133, 139, 268–269
gel packs, 148, 150
generalized anxiety disorder (GAD), 15, 220, 221, 303
genetics, 52–53, 55, 90
Gingko biloba, 165
giving up on treatments, avoiding, 288–289

green tea, 283
growth hormone
  future remedies, 146
  low with fibromyalgia, 47, 50, 79
  secretion during sleep, 190, 191, 192
guaifenesin, 51, 121–125, 304, 312
guilt, 248, 264
Gulf War syndrome, 45–47, 304

• H •

Halcion (triazolam), 202
hallucinations, 136
hands, tingling, 25
headaches
  from antidepressants, 142
  avoiding TMS, 156
  with chronic fatigue syndrome, 77
  defined, 304
  foods to avoid, 34
  ibuprofen for, 126
  ice pack for, 150
  treating, 34
  types of, 33–34
Healing Yourself with Self-Hypnosis (Caprio and Berger), 186
heartburn, 34–35, 182, 304
heat therapy, 87, 147–149, 151, 305
hepatitis B or C, 44–45, 115
herb therapy, 163, 164, 165, 199–200, 282, 283
hiding symptoms, 229–230, 292
homeopathy, 169, 285
hormones. *See also specific hormones*
  blood test for, 114
  defined, 42
  muscle stiffness from imbalance, 48
  secretion during sleep, 190, 191, 192
  stress hormones, 42
  stress inhibiting production of, 47
  thyroid, 14, 48, 50, 88
  in veterans, 47
hot baths, 151
How to Stop Heartburn (Minocha and Adamec), 35
hugging, 260
Humira (adalinumab), 32, 86
hydrocortisone, 80
hydrotherapy, 150, 305
hyper-arousability, 51–52
hyperglycemia, 114
hypertension, 115
hyperthyroidism, 26, 114
hypervigilance, 41
hypnotherapy, 184–186
hypocortisolism, 80
hypoglycemia, 114
hypotension, 77
hypothyroidism, 87–88, 114

• I •

IBS (irritable bowel syndrome), 30–31, 47, 78, 305
IBS For Dummies (Dean and Wheeler), 31, 305
ibuprofen, 86, 126, 138, 313
IC (interstitial cystitis), 31, 305
icing (cold) therapy, 87, 148, 149–150, 305
ignoring pain, 287–288
Iknoian, Therese *(T'ai Chi For Dummies),* 174
immune system
  aided by painkillers, 134
  autoimmune disorders, 31, 83, 114
  autoimmune reaction, 43–44
  boosting, 43
  less effective in family, 54–55
  pain as weakening to, 59
infection
  acupuncture risk for, 167
  antibodies, 42–43
  autoimmune reaction, 43–44
  bacterial, 42, 46
  cause of fibromyalgia, 42–45
  Epstein-Barr virus, 45
  in Gulf War syndrome, 46
  hepatitis B or C, 44–45, 115
  Lyme disease, 45
  in polymyalgia rheumatica, 85
  screening for, 115
  viral, 42–43, 46
infectious mononucleosis, 92, 305
injuries or traumas, 24, 37–42
insurance
  appealing denial, 234–237
  for Botox injection, 172
  for chiropractic, 159
  denial of claims, 234–237

  doctors in network, 99
  documenting phone calls, 235
  information for claims, 234–235
  for massage therapy, 151, 154
  telling boss about fibromyalgia, 229
  for TENS, 158
  veterans' health benefits, 47
  written letters for, 236–237
interferon, 43
Internet resources
  alternative medicine info, 282
  Arthritis Foundation, 303
  BMI info, 212
  disability benefit info, 239, 240, 242
  e-mail lists (listservs), 317–318
  fibromyalgia publications, 319
  fibromyalgia sites, 317
  finding information, 316–319
  forums, 319
  Mental Health Association, 224
  ordering guaifenesin, 124
  self-hypnosis info, 186
  supplement info, 166
  support groups, 256, 316, 317–319
interstitial cystitis (IC), 31, 305
interviewing
  acupuncturist, 168
  asking questions of doctor, 110
  attorney, 242
  chiropractor, 160
  doctors, 102–103
  family about FMS, 55
  massage therapist, 153–154
  medical history interview, 106
  mental health professional, 224
  specialists, 100–101
irritable bowel syndrome (IBS), 30–31, 47, 78, 305

• J •

job. *See* work
juvenile primary fibromyalgia syndrome, 267. *See also* children

• K •

Kandel, Joseph (neurologist), 170–171
kava kava, 200
kidney disease, 115
kids. *See* children
Klonopin (clonazepam), 79, 143, 308

• L •

laboratory tests. *See also specific tests*
  for arthritis, 83
  for chronic fatigue syndrome, 78
  for fibromyalgia, 22–23, 113–117
  for hypothyroidism, 87, 88, 114
  for lower-back pain, 91
  for Lyme disease, 89
  for mononucleosis, 92
  for polymyalgia rheumatica, 84
Lamictal (lamotrigine), 143, 309
law enforcement issues for doctors, 137
lawyer for disability claims, 241–242
laziness, 297–298
legislation, veteran, 47
legs, 25, 269
Lexapro (citalopram), 140, 225, 309
Librium (chlordiazepoxide), 308
Lidoderm patch (lidocaine), 138, 312
lifestyle changes. *See also specific kinds*
  for chronic fatigue syndrome, 79
  for fibromyalgia (overview), 17–18
  sleep-related, 17, 197–198
light sensitivity, 51–52, 77
light sleep, 191
Lisman, Susan R. *(Chronic Fatigue Syndrome For Dummies),* 79, 304
listmaking, 294
listservs, 256, 317–318
liver, 126, 200
Lunesta (eszoplicone), 145, 201, 311
lupus, 33, 43, 82, 84, 114
Lupus Foundation of America, 84
Lyme disease, 45, 89–90, 115, 305
Lyme titer, 89
Lyrica (pregabalin), 143, 309

• M •

ma huang, 165
magazines, fibromyalgia, 319
magnesium, 34, 164, 283
magnet therapy, 174
magnetic resonance imaging (MRI), 34, 91, 116
massage therapy
  for arthritis, 87
  benefits of, 151–152, 283–284
  chiropractic, 159
  defined, 305
  finding a therapist, 152–154
  mechanical massagers for, 151
  painful, avoiding, 154–155, 284
  from partner, 156
  stripping for, 155
Matarax (hydroxyzine), 308
mattress, 159
MCSS (multiple chemical sensitivities syndrome), 91–92, 305
mechanical massagers, 151
medical centers and universities, 101
medical history, 106
medications. *See also* antidepressant medications; painkillers; *specific medications*
  acid-blocking, 35
  addiction to, 134–136, 137, 138, 143, 144, 298
  anti-anxiety, 143–144, 202, 225–226, 308
  antibiotics, 31, 89, 139, 171
  anticonvulsive, 143, 309
  antihistamines, 50, 128, 144
  anti-inflammatory, 32, 86, 138–139, 272, 310
  anti-malaria, 86
  for arthritis, 32, 86
  benzodiazepines, 202
  for bladder infection, 31
  for children, 271–272, 273
  for chronic fatigue syndrome, 79
  cold remedies, 127–128, 312
  controlled or scheduled, 134–135, 137
  doctor's knowledge about, 94, 102
  for emotional problems, 225–226
  faking need for, 298
  future remedies, 146
  getting teens to take, 273
  giving up on, avoiding, 288–289
  for headaches, 34
  heartburn aggravated by, 35
  immune-boosting, 43
  informing doctor about, 29–30, 109–110
  interactions, 29–30, 109–110
  for irritable bowel syndrome, 30
  law enforcement issues for, 137
  for lupus, 86
  for Lyme disease, 90
  muscle relaxants, 33, 132–133, 310
  for myofascial pain syndrome, 82
  need for, 17, 308
  not a cure for fibromyalgia, 300
  NSAIDs, 86, 138–139, 145, 272, 310
  for osteoarthritis, 86
  phosphate reducing, 51
  for polymyalgia rheumatica, 86
  for Raynaud's phenomenon, 90
  for rheumatoid arthritis, 32, 86
  for sleep disorders, 17, 145–146, 199, 200–202, 311
  SNRIs, 140, 141
  taking at school, 273
  for thyroid disease, 88
  topical remedies, 129–130
  weight-loss drugs, 214–215
meditation, 172, 187
Meditation For Dummies (Bodian), 187
MEDLINEplus Web site, 317
melatonin, 200, 201, 282
men
  conditions less common in, 28, 30, 83, 85
  diagnosing fibromyalgia in, 73–74
  myofascial pain syndrome in, 80
menopause, 72–73, 74
menstruation, 72
mental confusion. *See* fibro fog
Mental Health Association, 224
menthol, 129
Meridia (sibutramine), 215
message boards, online, 319
metabolic syndrome, 72
methadone, 134, 135
methyl salicylate, 129
MFS (myofascial pain syndrome), 80–82, 142, 305
middle-aged women, 71–72

migraine headaches, 33–34, 156, 305
Migraines For Dummies (Stafford and Shoquist), 34, 304
milk, 187
minerals
  deficiencies, 114
  magnesium, 34, 164, 283
  telling doctor about, 109–110
Minipres (prazosin), 90
Minocha, Anil *(How to Stop Heartburn),* 35
Mirapex (pramipexole), 144, 312
Missouri Arthritis Rehabilitation Research and Training Center, 317
Mobic (meloxicam), 139, 272, 310
mononucleosis, 92, 305
monsodium glutamate (MSG), 216, 296
morning stiffness, 23, 44, 48, 83, 270
Motrin (ibuprofen), 86, 126, 138, 313
MRI (magnetic resonance imaging), 34, 91, 116
mud baths, 284
multiple chemical sensitivities syndrome (MCSS), 91–92, 305
multiple sclerosis, 114
muscle relaxants, 33, 132–133, 310
muscles
  damaged in fibromyalgia patients, 54
  relaxation therapy for, 180–181
  stiffness, 23, 44, 48
  strengthening exercises, 208–211
  topical remedies for pain relief, 129
  trigger points, 80–81, 82, 142, 305
myofascial pain syndrome (MFS), 80–82, 142, 305
myths about fibromyalgia, 297–300

• N •

napping, 196
Naprosyn (naproxen sodium), 138, 310
narcotics, 134–136, 137, 138, 144
National Center for Complementary and Alternative Medicine (NCCAM), 162, 315
National Fibromyalgia Association, 316, 317, 319
National Fibromyalgia Partnership, 319
National Fibromyalgia Research Association, 317
National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), 316
National Organization of Social Security Claimants Representatives (NOSSCR), 242
nerve problems, 117
neurochemicals, 42, 47–50, 128
neurofeedback, 173
neurological exam, 117
neurologists, 93, 98
neuromodulation, 173
Neurontin (gabapentin), 143, 309
newsgroups, 256, 318–319
newsletters, fibromyalgia, 319
noise sensitivity, 51–52, 77
nonsteroidal anti-inflammatory drugs (NSAIDs), 86, 138–139, 145, 272, 310
Norflex (orphenadrine citrate), 133, 310
Norvasc (amlodipine), 90

• O •

obsessive-compulsive disorder (OCD), 220, 303
Office of Dietary Supplements site, 166
ointment, topical, 129–130
older women, 72–73, 74
oligoanalgesia, 24
Orencia (abatacept), 86
organic problems, 116, 117
organizations, fibromyalgia, 315–316
orthopedic surgeons, 99
osteoarthritis. *See* arthritis
overeating, 222, 291
overheating, 148–149
over-the-counter drugs. *See* medications

• P •

pacemakers, 156
pain
  acute, 58
  advantages and disadvantages, 58–59
  antidepressant benefits for, 226
  avoiding tasks during bouts of, 293–294
  in children, 269–270
  chronic, 24, 57, 58, 59, 61

  defined, 58
  diary, 63–64, 305
  documenting, 62–64
  endorphins relieving, 152, 157, 167
  exercise for relieving, 203–211
  in fibromyalgia sufferers versus others, 60–61
  flu-like, 1, 89, 92, 95, 127
  heat versus cold therapy for, 148
  hypnotherapy for reducing, 185
  ignoring, 287–288
  immune system weakened by, 59
  intensity of, 22, 59, 299
  lower back, 91
  management, 61–66, 98, 306
  in massage therapy, 154–155, 284
  mattress for relieving, 159
  migration of, 24
  muscle or morning stiffness, 23, 44, 48, 82, 270
  with myofascial pain syndrome, 80, 81
  need to understand, 57
  nonfibromyalgia causes of, 66
  nontreatment (oligoanalgesia), 24
  overview, 11–12
  proof of, 22–23
  quality of life harmed by, 59, 65
  regional, 80, 81
  remembering, 9–10
  self-test for dominance by, 65
  sensitivity to, 54, 60, 63, 70–71
  sleep disorders and increase in, 192
  source difficult to locate, 23–24
  stimuli for, 58
  strengthening defenses against, 60
  stress connection to, 178
  telling doctor about, 108–109
  tender points, 22, 110–113, 268, 305, 306
  from thyroid hormone imbalance, 50
  time required for treatments, 64–65
  varying severity, 1, 22
  weather sensitivity, 28, 49
  when to call doctor, 66
  women's sensitivity to, 63, 70–71
painkillers
  advantages and disadvantages, 134
  for arthritis, 33, 86
  controlled or scheduled, 134–135, 137
  defined, 306
  heartburn aggravated by, 35
  immune system aided by, 134
  for lupus, 86
  narcotic, 134–136, 137, 138, 144
  over-the-counter, 125–127, 313
  prescription, 133–138
  reluctance to prescribe, 134, 136–138
  side effects, 134, 137, 313
  tables summarizing, 311, 313
  varying needs for, 131–132
Pamelor (nortriptyline), 140, 309
panic. *See* anxiety
paresthesia, 25
partner. *See also* family and friends
  blaming, 290
  caring for children, 249
  making time for, 250–251
  massage from, 156
  snoring by, 198
  taking to support group, 254–255
  tips for living with sufferer, 265
Paxil (paroxetine), 140, 143, 226, 309
Payne, Larry *(Yoga For Dummies),* 188
pediatric rheumatologist, 271
pediatricians, 270–271
peppermint oil, 129
Percocet (oxycodone with acetaminophen), 35, 135, 311
Percodan (oxycodone with aspirin), 135, 311
perimenopause, 72
periodic limb movements in sleep (PLMS), 269
phobias, 116, 303. *See also* anxiety
phony remedies, 161–162, 184
phosphates, 51, 122, 125
physiatrist, 98–99
physical abuse, 38, 39–40, 278
physical exam
  asking questions, 110
  common mistakes during, 108
  communicating with doctor, 107–110
  diagnostic tests, 113–117
  medical history, 106
  neurological, 117
  tender points identification, 110–113
  ultrasound, 117
Plaquinil (hydroxychloroquine), 86
polymyalgia rheumatica (PMR), 82, 84–85

post-traumatic stress disorder (PTSD), 41, 46, 220, 306
potassium deficiency, 115
prayer, 188
prednisone, 86
pregnancy, 41–42, 156, 165
prescriptions. *See* medications
primary-care doctor, 94–96
Procardia (nifedipine), 90
prolactin, 191, 192
The Promise of Sleep (Dement and Vaughan), 191
ProSom (estazolam), 202
proteinuria, 115
Prozac (fluoxetine), 140, 143, 202
psychiatrists, 35, 223, 272
psychologists, 223, 272
publications, fibromyalgia, 319
pulse rate, resting, 115–116

• Q •

quality of life, 59, 65

• R •

Raynaud's phenomenon, 90
rebound insomnia, 199
regional pain, 80
Relafen (nabumetone), 138, 310
relaxation
  activities aiding, 184
  hypnotherapy for, 184–186
  need for help with, 177
  not a cure for fibromyalgia, 299–300
  prayer for, 188
  as sleep aid, 197–198
  tai chi for, 172–174, 306
  therapy, 87, 180–181, 306
  yoga for, 187–188
REM sleep, 191, 192, 194
Remicade (inflixamab), 32, 86
ReN 1869 (antihistamine), 144
repetitive strain injury, 40
Requip (ropinirole), 144–145, 312
resentment, 248
restless legs, 25
Restoril (temazepam), 143, 202, 311
rheumatoid arthritis. *See* arthritis
rheumatologists, 32, 93, 98, 107, 113, 271
Rheumatrex (methotrexate), 32
Rituxan (rituximab), 86
Rozarem (ramelteon), 145, 311
Rubin, Alan L. *(Thyroid For Dummies),* 88, 305

• S •

salicylate, 129, 130
scams (phony remedies), 161–162, 184
schedule, calendar for, 295
scheduled medications, 134–135, 137
school
  peer problems at, 277–278
  working with child's teacher, 274–277
seizures, 156
self-blame, 268, 289, 295
self-hypnosis, 186
self-perception, 245–246, 289, 292
self-tests
  emotional problems, 221–222
  fibromyalgia, 13–16
  pain dominance, 65
  sleep disorder, 194–195
  stress, 178–180
sensitivity
  environmental, 50–51, 91–92
  hyper-arousability, 51–52
  to pain, 54, 60, 63, 70–71
  to weather, 28, 49
Septra (antibiotic), 139
Serax (oxazepam), 308
serotonin, 50
serotonin norepinephrine reuptake inhibitors (SNRIs), 140, 141
sex, 20, 142, 155, 249–251
sexual abuse, 38, 39–40
shame, 292
shared environment, 53
Shoquist, Jennifer *(Migraines For Dummies),* 34, 304
siblings, special time with, 274
significant other. *See* partner
Skelaxin (metaxalone), 133, 310
SLE (systemic lupus erythematosus), 33, 43, 82, 84, 114

sleep
  circadian rhythm, 190
  defined, 190
  dreaming, 190, 192, 194, 200
  exercise for aiding, 195
  hormones secreted during, 190, 191, 192
  importance of, 295
  stages of, 190–192
sleep disorders
  aggravating fibromyalgia, 49
  alcohol not aid for, 195
  anti-anxiety medications for, 202, 226
  antidepressant benefits for, 201–202, 226
  from antidepressants, 142
  antihistamines aiding, 128
  with arthritis, 87
  avoiding scary movies before bed, 196
  breathing technique for, 192
  in children, 269
  common with fibromyalgia, 28
  constant waking, 193–194
  defined, 306
  difficulty falling asleep, 193–194
  foods aiding sleep, 187
  with gastroesophageal reflux disease, 35
  herb therapy, 165
  hypnotherapy for, 185
  lack of deep sleep, 194
  lifestyle changes for, 197–198
  limiting use of bed, 198
  mattress choices aiding, 159
  medications, 17, 145–146, 199, 200–202, 311
  with myofascial pain syndrome, 81
  napping, 196
  number of sufferers, 196
  overview, 15, 28, 145, 189
  pain increase with, 192
  with post-traumatic stress disorder, 41
  relaxation aiding, 197–198
  self-test for, 194–195
  sleep apnea, 196, 198, 202
  snoring partner, 198
  stress-related, 179
  supplements for, 199–200
  symptoms, 145
  from thyroid hormone imbalance, 50
  types of, 193
  vicious cycle of, 29
slow-wave sleep, 192
smoking, 90, 108
snoring partner, 198
SNRIs (serotonin norepinephrine reuptake inhibitors), 140, 141
Social Security disability program, 239–242, 306
social workers, 223
Sohmer, Alec G. (attorney), 241
Soma (carisoprodol), 132, 133, 310
Soma Compound (carisoprodol with acetaminophen), 133
Sonata (zaleplon), 145, 201, 311
spastic colon. *See* irritable bowel syndrome (IBS)
specialists, 97–99, 100–101. *See also specific kinds*
spouse. *See* partner
St. Armand, Paul (endocrinologist), 122–123
Stafford, Diane *(Migraines For Dummies),* 34, 304
steroids, 86
stomachache. *See* gastrointestinal distress
strengthening exercises, 208–211
stress
  alcohol-dependent release, 179, 290
  biofeedback for reducing, 173, 181–184
  cortisol as aid to coping with, 50
  family's relationship to, 179
  hormone production inhibited by, 47
  hormones, 42
  hypnotherapy for reducing, 184–186
  IBS aggravated by, 30
  meditation for reducing, 187
  in middle-aged women, 72
  overview, 17
  pain connection to, 178
  prayer for reducing, 188
  PTSD, 41, 46, 220, 306
  Raynaud's phenomenon aggravated by, 90
  relaxation therapy for, 180–181
  self-assessment for, 178–180
  sleep disorders from, 179
  tai chi for reducing, 172
  work-related, 179, 180
  yoga for reducing, 187–188
stretching exercises, 209, 210, 211

Substance P (neurochemical), 48–50, 78, 306
sugar, 296
supplements
  defined, 306
  magnesium, 34, 164, 283
  online information about, 166
  risks, 110, 165–166
  for sleep disorders, 199–200
  telling doctor about, 109–110, 163–164
support groups
  advantages and disadvantages, 254
  attendance by family or friends, 264–265
  attending before joining, 253
  e-mail lists (listservs), 256, 317–318
  finding local, 316
  forums, online, 319
  newsgroups, 318–319
  online, 256, 316, 317–319
  professionally moderated, 253
  taking others to, 254–255
survivor's guilt, 264
suspicion, 248
swimming, 87
symptoms of fibromyalgia
  associated medical problems, 11, 13, 29–30, 75–76, 90
  in children, 268–270
  faking, myth of, 298
  fatigue, 25–26
  feeling well versus being well, 299
  fibro fog, 26–28
  hiding, 229–230, 292
  list of, 10–11
  looking well versus being well, 298–299
  in men, 73–74
  pain, 22–24, 91
  paresthesia, 25
  restless legs, 25
  shared by family members, 52–53
  sleep disorders, 29
  tinnitus, 25
  unusual, 25
  weather sensitivity, 28
  work suffering from, 229, 231
  worsening at work, 231
symptoms of related conditions
  anxiety disorders, 220, 222
  arthritis, 83
  chronic fatigue syndrome, 77–79
  depression, 218, 222
  heartburn, 35
  lupus, 84
  Lyme disease, 89
  MCSS, 91
  mononucleosis, 92
  myofascial pain syndrome, 80–81
  osteoarthritis, 83
  polymyalgia rheumatica, 84
  post-traumatic stress disorder, 41
  rheumatoid arthritis, 83
  sleep disorders, 145
syncope (fainting), 77, 116
systemic lupus erythematosus (SLE), 33, 43, 82, 84, 114

• T •

tai chi (exercise), 172–174, 306
T'ai Chi For Dummies (Iknoian and Fuentes), 174
talk therapy. *See* cognitive behavioral therapy (CBT)
"Tax Highlights for Persons with Disabilities" (IRS publication), 239
Taylor, Nadine *(Arthritis For Dummies),* 86, 303
teacher, working with child's, 274–277
teasing of child, 277–278
telecommuting, 232
tender points
  defined, 22, 306
  fewer in children, 268
  in fibromyalgia diagnosis, 110–113
  illustrated, 112
  locating, 111–113
  number with pain, 113
  touching by doctor, 111
  trigger points with MFS versus, 81, 305
TENS (transcutaneous electrical nerve stimulation), 157–158, 285
tension headaches, 34, 304
therapy. *See also* alternative medicine; treating
  aromatherapy, 284
  for arthritis, 87
  biofeedback, 173, 181–184
  for children, 272–273
  chiropractic, 159–160

  cognitive behavioral, 36, 181, 219, 223, 272–273, 300
  cold (cryotherapy), 87, 149–150, 305
  for depression, 36
  finding a mental-health professional, 223–224
  giving up on, avoiding, 288–289
  heat, 87, 147–149, 151, 305
  hypnotherapy, 184–186
  massage, 87, 151–155, 159, 283–284, 305
  mud baths, 284
  relaxation, 180–181, 306
  self-hypnosis, 186
  TENS, 157–158, 285
  transcranial magnetic stimulation, 155–156
thyroid disease, 26, 87–88, 114, 306
Thyroid For Dummies (Rubin), 88, 305
thyroid hormones, 48, 50, 88, 114
thyroid-stimulating hormone (TSH), 88
tilt-table testing, 116
tinnitus, 25, 126
"Tips for the Savvy Supplement User" (FDA publication), 166
tissue problems, 117
Topamax (topiramate), 143, 309
topical remedies, 129–130
touching
  hugging, 260
  tender points, by doctor, 111
transcranial magnetic stimulation (TMS), 155–156
transcutaneous electrical nerve stimulation (TENS), 157–158, 285
traumas or injuries, 24, 37–42
treating. *See also* therapy
  anxiety disorders, 220
  arthritis, 33, 86–87
  bladder infection, 31
  checking doctor's success record, 102
  children with fibromyalgia, 271–273
  chronic fatigue syndrome, 79–80
  depression, 36, 218–219
  gastroesophageal reflux disease, 35
  giving up on, avoiding, 288–289
  good versus bad doctor's approach, 94–96, 288
  headaches, 34
  hypothyroidism, 88
  interstitial cystitis, 31
  irritable bowel syndrome, 30
  lifestyle changes, 17–18
  Lyme disease, 89–90
  myofascial pain syndrome, 82, 142
  overview, 17
treatment plan, 17, 62
trigger point injections, 142
trigger points, 80–81, 82, 142, 305
tryptophan, 197
TSH (thyroid-stimulating hormone), 88
turkey, 197
Tylenol (acetaminophen)
  with antihistamines (Tylenol PM), 128
  with codeine (Tylenol 3), 135, 311
  regular, 125–126, 313

• U •

ulcer, 133
Ultracet (tramadol with acetaminophen), 137, 311
Ultram (tramadol), 128, 136, 137, 202, 311
ultrasound, 117
unemployment benefits, 240, 241
university medical centers, 101
University of Florida Fibromyalgia Research Information, 317
urologists, 31

• V •

valerian, 165, 199, 282, 306
Valium (diazepam), 135, 143, 225, 308
Vaughan, Christopher *(The Promise of Sleep),* 191
veterans, 45–47
Vicodin (hydrocodone), 34, 135, 311
Vioxx (rofecoxib), 139
viral infection, 42–43, 46
Vistoril (hydroxyzine), 308
vitamin deficiency, 115
vitamins. *See* supplements

• W •

walking, 204, 205–207
war veterans, 45–47
water, drinking, 216
water aerobics, 207–208
weather sensitivity, 28, 49
Web resources. *See* Internet resources
weight gain, 142, 222, 291
weight loss
  benefits of, 203, 211
  dieting for, 214
  with emotional problems, 222
  goals, 212
  ideal weight, 212–214
  medications for, 214–215
  as side effect, 142
weightlifting, avoiding, 208
Wellbutrin (bupropion), 226, 309
wet heat, 148, 151
Wheeler, Christine *(IBS For Dummies),* 31, 305
white blood cell count, 115
women
  age and fibromyalgia risk, 71–73, 74
  conditions more common in, 28, 30, 83, 85
  fibromyalgia symptoms disparaged in, 95
  interstitial cystitis in, 31
  metabolic syndrome risk for, 72
  middle-aged, 71–72
  myofascial pain syndrome in, 80
  older, 72–73, 74
  pain studies, 63
  post-traumatic stress disorder in, 46
  pregnancy, 41–42, 156, 165
  sensitivity to pain, 63, 70–71
  stress in middle age, 72
  young, 71–72
work
  alternative arrangements, 232
  challenges with fibromyalgia, 229, 231
  deciding about staying at job, 232–233
  disability benefits, 237–242
  explaining fibromyalgia at, 229–231
  at home, 229
  injury at, 40–41
  laziness, 297–298
  making an ally, 294
  stress from, 179, 180
  telecommuting, 232
  unpaid leave, 233
  worker's compensation, 41, 238, 240, 241
  worsening symptoms at, 231
worker's compensation, 41, 238, 240, 241

• X •

Xanax (alprazolam), 135, 143, 144, 226, 308
Xenical (orlistat), 215

• Y •

Yazdany, Jinoos *(Arthritis For Dummies),* 86, 303
yeast infection, 171
yoga, 187–188
Yoga For Dummies (Feuerstein and Payne), 188
young women, 71–72

• Z •

Zanaflex (tizanadine HCl), 133, 310
Zoloft (sertraline), 140, 225, 309

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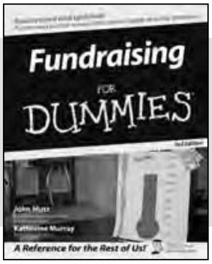

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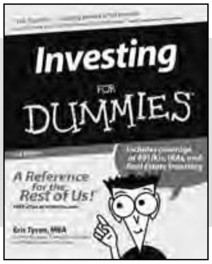

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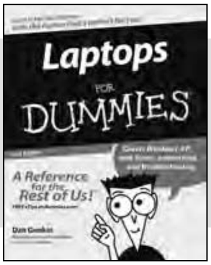

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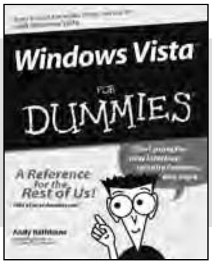

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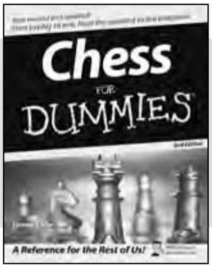

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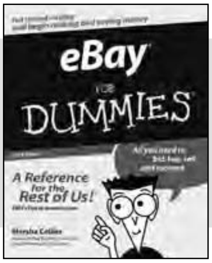

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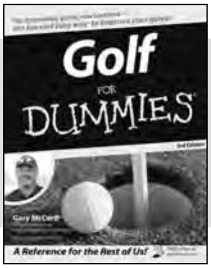

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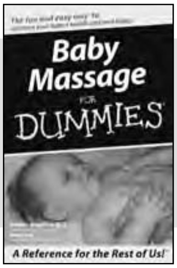

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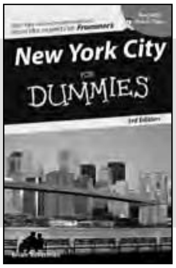

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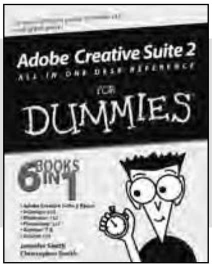

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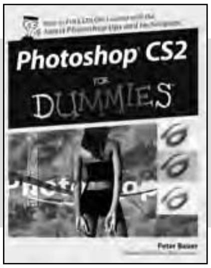

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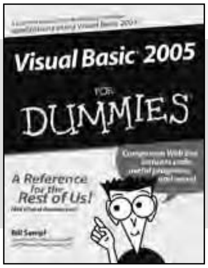

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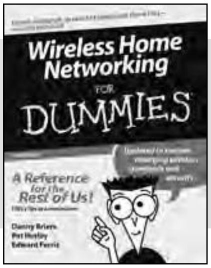

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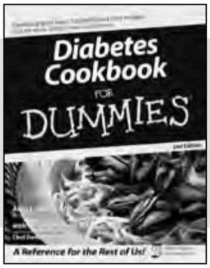

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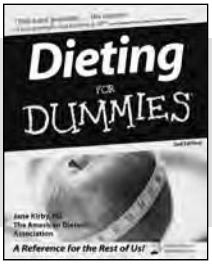

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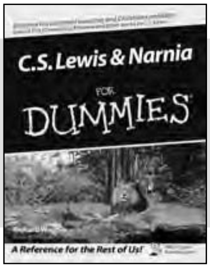

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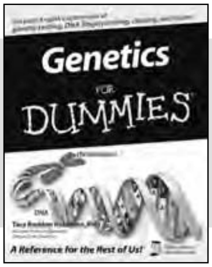

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