23

Myeloma

Also known as multiple myeloma or myelomatosis.

JASCAP

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS
MUMBAI, INDIA

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JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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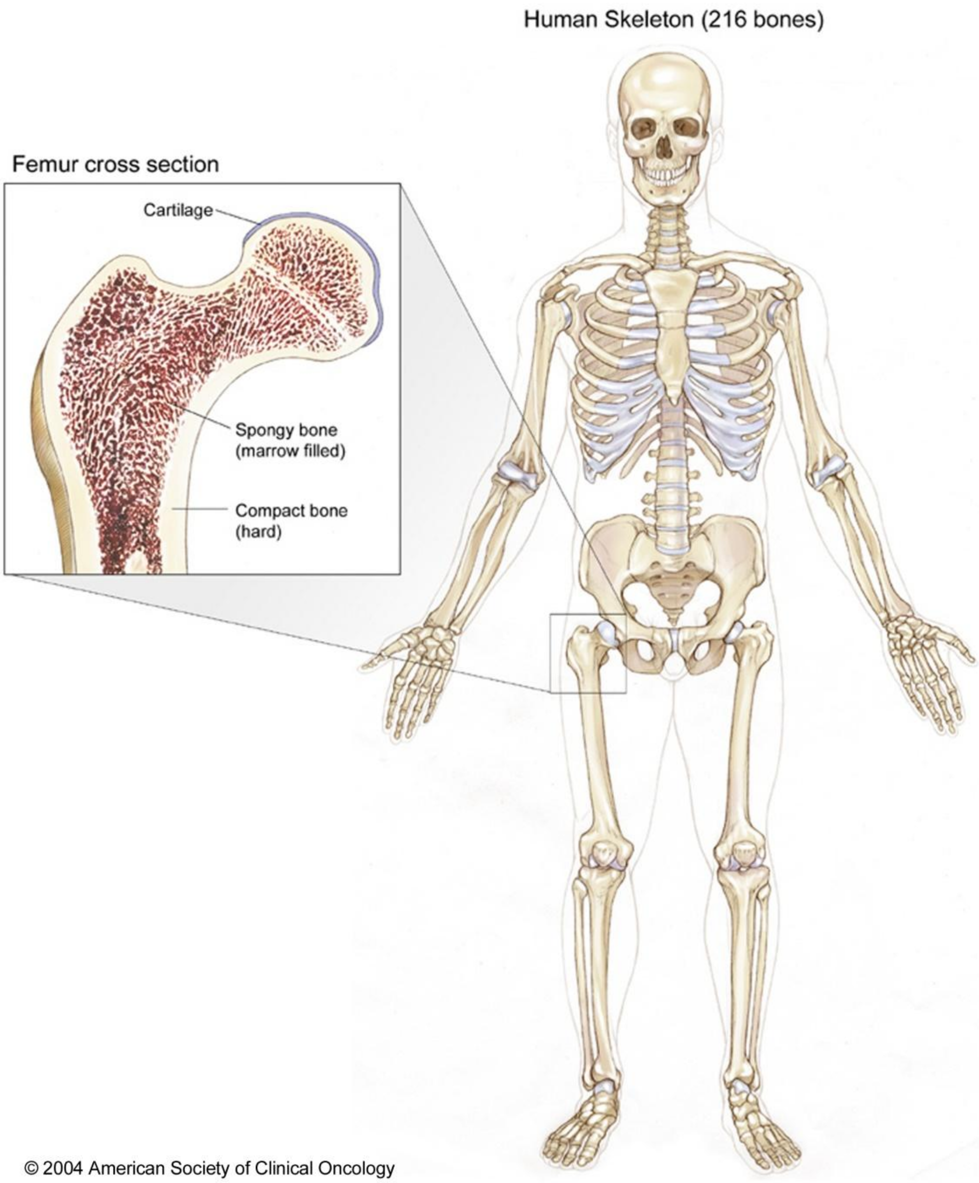

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Contents

About myeloma

- Bone marrow
- What is myeloma?
- What is cancer?
- Causes

Symptoms & diagnosis

- Symptoms
- Diagnosis
- Further tests
- Staging

Treating myeloma

- Treatment overview
- Controlling myeloma
- Maintenance treatment
- Relapse treatment
- Treatment of symptoms
- Research - clinical trials

Living with myeloma

- Follow up
- Rehabilitation & recovery
- Living with and after cancer

About myeloma

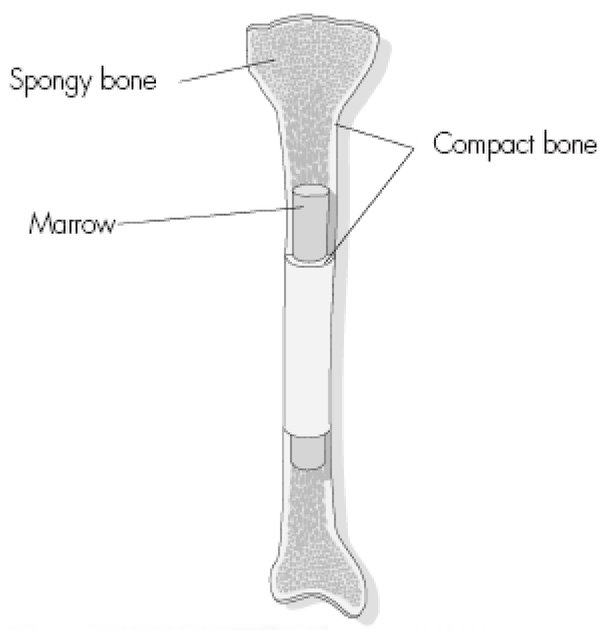
How myeloma is related to the bone marrow

Myeloma is a cancer of plasma cells, which are normally found in the bone marrow.

Bone marrow and blood cells

The bone marrow is a spongy material that fills the middle of some bones and produces cells called **stem cells**. These are immature cells that develop into the three different types of blood cells:

- **red blood cells**, which carry oxygen to all the cells in the body
- **white blood cells**, which are essential for fighting infection
- **platelets**, which help the blood to clot and so control bleeding.



Bone and bone marrow

Plasma cells

Plasma cells are one of several types of white blood cell, all of which work together to protect the body against infection. Plasma cells produce special proteins known as **antibodies** or **immunoglobulins**. These antibodies circulate in the blood ready to attack any viruses and bacteria that may be present in the body.

If an infection occurs, more plasma cells are produced, creating more antibodies to attack whatever is causing the infection.

What is myeloma?

Myeloma is also known as **multiple myeloma** or **myelomatosis**.

Blood cells look and work differently, but they all repair and reproduce themselves in the same way. Normally, new cells are produced to replace old, worn-out cells in an orderly, controlled way. However, in myeloma the process gets out of control and large numbers of abnormal plasma cells – myeloma cells – are produced. These fill up the bone marrow and interfere with production of normal white cells, red cells and platelets.

The myeloma cells usually produce a large amount of one type of abnormal antibody. This is known as a **paraprotein** or **M protein**. This paraprotein cannot fight infection effectively and often reduces the production of normal antibodies.

Myeloma cells have the ability to spread throughout the bone marrow and into the hard outer casing of the bone. Some, or many, areas of bone may be affected. Myeloma can cause thinning of the outer bone and bone pain.

Myeloma usually occurs in middle-aged and older people. It is unusual before the age of 50 and very rare in people younger than 40.

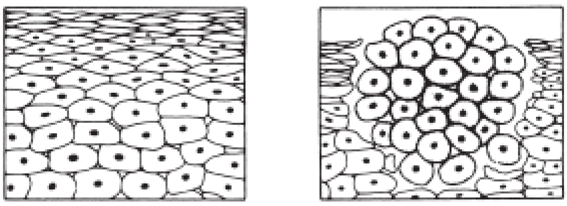
Myeloma is one type of disorder of the plasma cells. Some other conditions of the plasma cells can develop into myeloma but may not necessarily do so. The two most common of these are monoclonal gammopathy of uncertain significance (MGUS) and **smouldering myeloma** (also known as indolent or asymptomatic myeloma). If you are diagnosed with either of these conditions, you will be monitored with blood tests, but may not need to have any treatment unless the condition progresses.

Sometimes abnormal plasma cells are found in a bone in only one area of the body. This condition is known as a **solitary plasmacytoma**. It is treated with radiotherapy. Some people with solitary plasmacytoma may go on to develop multiple myeloma, so you will be regularly monitored with blood tests.

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a **tumour**.



Normal cells

Cells forming a tumour

Tumours can be either **benign** or **malignant**. Cancer is the name given to a malignant tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a **biopsy**.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. However, if they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

The lymphatic system is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs, such as bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or **metastasis**.

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Types of cancer

Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

- squamous cells - that line different parts of the body, such as the mouth, gullet (oesophagus), and the airways
- adeno cells - form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
- transitional cells - are only found in the lining of the bladder and parts of the urinary system

- basal cells - that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

- bone sarcomas - that are found in the bones
- soft tissue sarcomas - that develop in the other supportive tissues of the body.

Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

Causes of myeloma

Each year, approximately 3700 people in the UK are diagnosed with myeloma.

Although the causes of myeloma are unknown, research is going on all the time into the possible causes of the disease. Myeloma, like other cancers, is not infectious and cannot be passed on to other people.

Symptoms & diagnosis

Symptoms of myeloma

Myeloma commonly affects the bones of the spine (vertebrae), so its most common symptom is back pain. Some people also become shorter. Other bones may also be affected such as the ribs, skull or pelvis. Other symptoms may include any of the following:

- Excessive tiredness and lethargy due to a lack of red blood cells (anaemia).
- Kidney problems caused by the paraproteins produced by the myeloma cells. Kidney damage can cause tiredness and anaemia.

- Repeated colds, coughs and other infections (particularly chest infections) because of a shortage of normal antibodies.
- Weakening of the bones by the myeloma cells, which may increase the risk of fractures.
- Loss of appetite, feeling sick, constipation, depression and drowsiness caused by too much calcium in the blood (hypercalcaemia). The excess calcium is released into the blood from the damaged bones.
- Unexplained bruising and abnormal bleeding (for example, nosebleeds or bleeding gums) because the number of platelets in the blood has decreased.
- Pins and needles, numbness, tingling or weakness in the feet or legs; or difficulty passing urine or opening the bowels. Any of these symptoms could mean that a myeloma tumour is pressing on the spinal cord (known as cord compression). Contact your doctor immediately if you think that this may be happening to you.

If you have any of the symptoms in this list, it is important to see your doctor as soon as possible. But remember, many of these symptoms can occur in other conditions. Most people with the above symptoms will not have myeloma.

Occasionally myeloma will be found by a blood test done for another reason, when the person has no symptoms.

How myeloma is diagnosed

Usually you begin by seeing your family doctor (GP), who will examine you and arrange for you to have any tests or x-rays that may be necessary. Your GP will refer you to hospital for these tests and for specialist advice and treatment.

At the hospital

At the hospital, the specialist will ask you about your general health and any previous medical problems, before examining you.

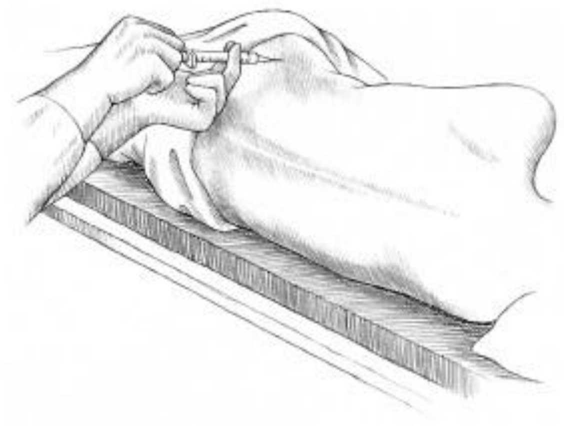
Samples of your blood and urine will be taken and examined to check your general health and how well your kidneys are working. These tests will also show whether there are any paraproteins (the abnormal proteins that are produced by myeloma cells) in your blood and urine.

If the blood test shows that a paraprotein is present, your doctor will want to take a bone marrow sample and do some further tests. These are done so that the doctor can plan the best treatment for your situation.

Bone marrow sample

A sample of bone marrow is usually taken from the back of your hipbone (pelvis) or, sometimes, the breast bone. It will be examined to see if it contains any myeloma cells.

The bone marrow sample is taken under a local anaesthetic. You will be given a small injection to numb the area and the doctor will gently pass a needle through the skin into the bone. The doctor will draw a small sample of liquid marrow into a syringe to be looked at later under the microscope (bone marrow aspirate). The doctor will then take a small core of marrow from the bone (a trephine biopsy).



The test can be done on the ward or in the outpatients department. The whole procedure takes about 15–20 minutes. It may feel uncomfortable while the marrow is drawn into the syringe but this should only last for a few seconds. You may be offered a short-acting sedative to reduce any pain or discomfort during the test. You may feel bruised after the test and have an ache for a few days. This can be eased with mild painkillers.

Cytogenetics

Each cell in the body contains **chromosomes**, which are made up of **genes**. The genes control all activities of the cell. In myeloma there may be changes in the structure of the chromosomes within the myeloma cells, but not the normal cells of the body. The tests on the blood and bone marrow samples will often include a chromosome analysis to look for any particular changes in the chromosomes. These tests, known as **cytogenetic tests**, may help to decide on the best treatment and predict how well the myeloma may respond to that treatment.

X-rays

These will be taken to check for any damage that may have been done to your bones by the myeloma cells. You will usually have x-rays taken of your whole body, which is known as a **skeletal survey**.

Blood and urine tests

If the tests show that you have myeloma, your doctor will want to do regular blood tests to measure the level of paraprotein in your blood, to check for anaemia and hypercalcaemia (a raised level of calcium in the blood), and to make sure that your kidneys are working properly.

Samples of your urine will be taken to test for a particular paraprotein known as the Bence Jones protein. This may involve taking a container home and collecting your urine for 24 hours.

In a few people with myeloma, standard blood and urine tests are unable to measure the level of paraprotein. A new test which detects very small amounts of paraprotein, called the **Freelite test**, may be used.

Further tests for myeloma

Your doctors may suggest that you have further tests which can give more detailed information about the bones and organs of the body.

- MRI scan
- CT scan
- Ultrasound scan
- PET scan
- Waiting for your test results

MRI scan

An MRI (magnetic resonance imaging) scan uses magnetic fields to build up a series of cross-sectional pictures of the body. During the test you will be asked to lie very still on a couch inside a metal cylinder that is open at both ends. The whole test may take up to an hour and is painless – although the machine is very noisy. You will be given earplugs or headphones to wear.

Before going into the room you should remove all metal belongings. You should also tell your doctor if you have ever worked with metal or in the metal industry, or if you have any metal inside your body (for example, a cardiac monitor, pacemaker, surgical clips, or bone pins).

You may feel claustrophobic inside the cylinder, but you may be able to take someone with you into the room to keep you company. It may also help to mention to the staff beforehand if you do not like enclosed spaces. They can then offer extra support during your test.

CT scan

A CT (computerised tomography) scan takes a series of x-rays which builds up a three-dimensional picture of the inside of the body. Sometimes CT scans can be better at showing bone damage than an ordinary x-ray. The scan is painless but takes longer than an ordinary x-ray (it will last approximately 30 minutes).

Ultrasound scan

An ultrasound scan uses sound waves to look at internal organs. It may be done to see if your kidneys have been damaged by the myeloma.

PET scan

PET (Positron Emission Tomography) scans are a new type of scan and you may have to travel to a specialist centre to have one. They are not always necessary but you can discuss with your doctor whether one would be useful in your case.

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and show up on the scan.

Waiting for your test results

It will probably take several days for the results of your tests to be ready and this waiting period will obviously be an anxious time for you. It may help if you can find a relative or close friend you can talk things over with. You may wish to ring our cancer support speclialists or another support organisation for emotional support.

Staging of myeloma

The stage of a cancer is a term used to describe its extent and how much it is affecting the body. Knowing the extent of the myeloma helps doctors to decide on the most appropriate treatment.

Generally, myeloma is divided into three stages, which indicate the effect the disease is having on the body and how quickly or slowly it may develop. A commonly used staging system for myeloma, known as the **Durie-Salmon system**, is described below.

This staging system is based upon how the disease is affecting the:

- red blood cells (haemoglobin, Hb)
- calcium level in the blood
- amount of paraproteins
- bones.

Stage 1 The myeloma is at an early stage. The number of red blood cells is either normal or only slightly reduced. The amount of calcium in the blood is normal. There are low levels of paraproteins in the blood or urine. The bones either appear normal or there is a single plasmacytoma. There may be no symptoms.

Stage 2 The myeloma is at an intermediate stage, between stage 1 and stage 3.

Stage 3 The myeloma is at a more advanced stage. It has caused one or more of the following:

- the haemoglobin has dropped to quite a low level and anaemia is quite severe
- the level of calcium in the bloodstream has risen greatly
- three or more bones are affected and fractures may occur
- there are high levels of paraproteins in the blood or urine.

Stages 2 and 3 are also further divided depending upon how well the kidneys are working. As well as a number, the different stages are given a letter, either A or B. For example, you may have stage 2A or 3B.

A Kidney function is normal, or little affected by the myeloma.

B Kidney function is abnormal.

A second staging system for myeloma, that has recently been developed, looks at the levels of particular blood proteins: **beta-2 microglobulin** and **albumin**. This newer staging system, known as the **International Staging System**, also contains three stages. It can help doctors to stage the myeloma more accurately.

Stage I The beta-2 microglobulin is less than 3.5mg/L and the albumin level is greater than or equal to 3.5g/dL.

Stage II Both the beta-2 microglobulin level and the albumin levels are less than 3.5, or the beta-2 microglobulin level is between 3.5 and 5.5mg/L.

Stage III The beta-2 microglobulin level is greater than or equal to 5.5 mg/L.

If myeloma comes back after initial treatment it is known as **relapsed** or **recurrent** myeloma.

Treating myeloma

Treatment for myeloma

Once the doctors know the stage of the myeloma they will be able to plan the most appropriate treatment.

- When treatment is given
- Why treatment is given
- What treatments are used
- Multidisciplinary team
- Second opinion
- Giving your consent
- Benefits and disadvantages of treatment

When treatment is given

Myeloma is rarely curable, but it is treatable. Treatment can be very effective at controlling symptoms and stopping the development of the disease. Myeloma can develop very slowly and so some people with myeloma who have no symptoms will not initially need any treatment. Usually they will see the doctor and have blood and urine samples every few months. This is known as **active monitoring**. Treatment will be started if the myeloma begins to get worse or if symptoms occur.

Why treatment is given

Treatment may be given:

- To control the myeloma so it goes into remission (remission is when treatment gets rid of the abnormal myeloma cells and they cannot be detected in the blood or bone marrow and normal bone marrow has developed again).
- As maintenance treatment once the myeloma is controlled, to prolong the remission.
- If the disease comes back (relapses).
- To control symptoms and any problems that the myeloma may be causing.

What treatments are used

Chemotherapy, usually combined with steroids, is the main treatment for myeloma. Some studies are using chemotherapy together with other drugs including bisphosphonates and thalidomide.

Some people may benefit from **high-dose chemotherapy**. For this treatment, some of the blood stem-cells are removed before the high-dose chemotherapy and are given back through a drip after the treatment. This is known as **high dose treatment with stem cell support** (stem-cell transplant) and can help some people to stay in remission, but it is an intensive treatment that is not suitable for everyone.

After chemotherapy, interferon or steroids may be used to help keep the myeloma in remission – this is known as **maintenance treatment**.

Thalidomide has recently been found to be effective in controlling myeloma that has come back after chemotherapy. Thalidomide is also being tested as an initial treatment and as maintenance treatment.

Other drugs that may be used to treat people whose myeloma has come back after initial treatment, are **bortezomib** (Velcade®) and **lenalidomide** (Revlimid®).

Drugs known as **bisphosphonates** are commonly used to reduce bone damage caused by the myeloma and to help bones to heal. They are also very helpful in lowering raised calcium levels in the blood. They can be given alongside chemotherapy or after chemotherapy has finished. They may also be given to help prevent bone damage from occurring.

Radiotherapy may be used to strengthen the bone and reduce pain in the affected areas.

Surgery may also occasionally be used to strengthen weakened bones, to prevent fractures or, rarely, to remove areas of myeloma that are pressing on parts of the body such as the spinal cord.

Other treatments may be needed, such as:

- painkillers to treat bone pain
- blood transfusions, if you are anaemic
- kidney dialysis, if your kidneys are not working properly.

The treatments used will vary from person to person. If you have any questions about your own treatment, don't be afraid to ask your doctor or nurse. It often helps to take a close friend or relative with you to appointments.

Multidisciplinary team

In most hospitals, a team of cancer specialists will discuss with you the treatment that they feel is best for your situation. This multidisciplinary team (MDT) will often include a doctor who specialises in treating blood disorders (haematologist), chemotherapy and radiotherapy specialists (oncologists) and may include a number of other healthcare professionals such as a:

- nurse specialist
- pathologist (a doctor who specialises in how disease affects the body)
- radiologist (a doctor who specialises in x-rays and scans)
- dietitian
- physiotherapist
- occupational therapist
- psychologist or counsellor.

Together the doctors will be able to advise you on the best course of action taking into account a number of factors. These include your age, general health, and how the myeloma is affecting you.

Occasionally your doctors may offer you a choice of treatments. Sometimes people find it very hard to make a decision. If you are asked to make a choice, make sure that you have enough information about the different treatment options, what is involved and the side effects you might experience, so that you can decide what is the right treatment for you.

Remember to ask questions about any aspects that you do not understand or feel worried about. You may find it helpful to discuss the benefits and disadvantages of each option with your cancer specialist, nurse specialist or with our cancer support specialists.

If you have any questions about your own treatment, don't be afraid to ask your doctor or nurse. It often helps to make a list of questions and to take a close friend or relative with you.

Second opinion

Even though a number of cancer specialists work as a team to decide on the most suitable treatment, you may want to have another medical opinion. Most doctors will be willing to refer you to another specialist for a second opinion if you feel that it will be helpful. The second opinion may take some time to organise and may cause a delay in the start of your treatment, so you and your doctor need to be confident that it will be helpful.

If you do go for a second opinion, it may be a good idea to take a friend or relative with you, and to have a list of questions so you can make sure your concerns are covered during the discussion.

Giving your consent

Before you have any treatment your doctor will explain its aims to you and you will usually be asked to sign a form saying that you give your permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should have been given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any other treatments that may be available
- any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straight away so that they can explain again. Some myeloma treatments are complex, so it is not unusual for people to need their treatment to be explained more than once.

Patients often feel that hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you and the staff should be willing to make time for you to ask questions.

You can always ask for more time to decide about the treatment, if you feel that you can't make a decision when it is first explained to you. You are also free to choose not to have the treatment, and the staff can explain what may happen if you do not have it.

Benefits and disadvantages of treatment

Many people are frightened of having cancer treatments, and of the side effects that may occur. Some people ask what would happen if they did not have any treatment.

Although many of the treatments can cause side effects, these can often be well controlled with medicines.

Treatment can be given for different reasons and the possible benefits will vary depending upon the individual situation. Myeloma is rarely curable and treatment is usually only able to control it, leading to an reduction of symptoms and a better quality of life.

The treatments for myeloma can vary, and some involve far more side effects and risks than others. For some people, the treatment will help to control the myeloma and the side effects of the treatment will be mild. However, for others treatment will have no effect upon the cancer and they will get the side effects with little benefit.

Making decisions about whether to have treatment in these circumstances is always difficult, and you may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to have treatment, you can still be given medicines to control any symptoms that you have. This is known as **supportive care** (or **palliative care**).

It is important to tell a doctor, or the nurse in charge, so that they can record your decision in your medical notes. You do not have to give a reason for not wanting to have treatment, but it can be helpful to let the staff know your concerns so that they can give you the best advice.

Treatment to control myeloma

- Chemotherapy
- Side effects of chemotherapy
- Stem cell transplants
- Side effects with stem cell treatment
- Thalidomide
- Side effects of thalidomide
- Steroid therapy
- Bisphosphonates

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs and is one of the main treatments used to control myeloma. Chemotherapy drugs circulate in the blood, and can reach myeloma cells all over the body.

One or more chemotherapy drugs are given for a few days every 3–4 weeks, followed by a rest period during which you will have regular blood tests to check the effect of the drugs. The dose of the drugs may be altered according to the results of your blood tests.

Chemotherapy may be given to you as an outpatient, but sometimes it may mean having to spend a few days in hospital.

Some drugs for myeloma are given as tablets or capsules (orally), others by injection into a vein (intravenously). The drugs melphalan and cyclophosphamide are commonly used to treat myeloma and are usually given as tablets or capsules, but can also be given into a vein. They are most often given with steroid tablets (prednisolone). When given as tablets, these drugs have fewer side effects. This makes them more suitable for people who are not able to have stronger treatments.

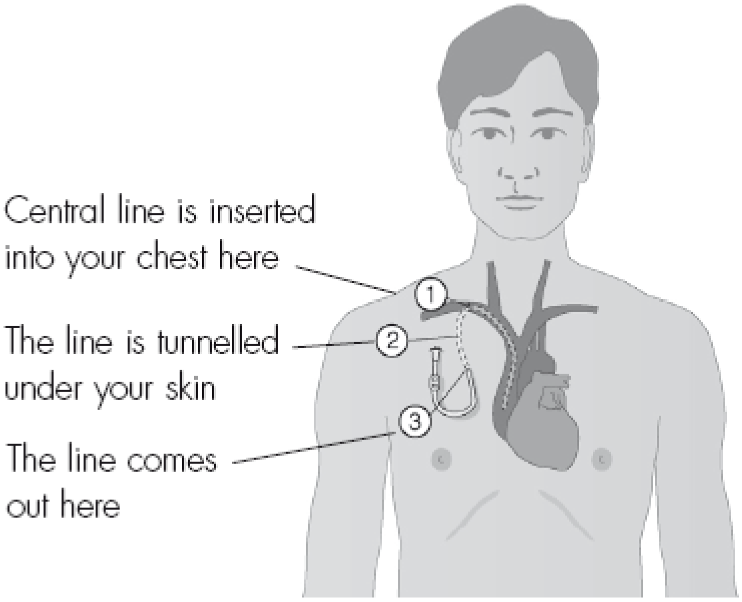
Some people may be offered a combination of chemotherapy drugs given by injection or infusion (drip) into a vein over a few days, again often with steroids. Two commonly used chemotherapy regimes are VAD and C-VAMP.

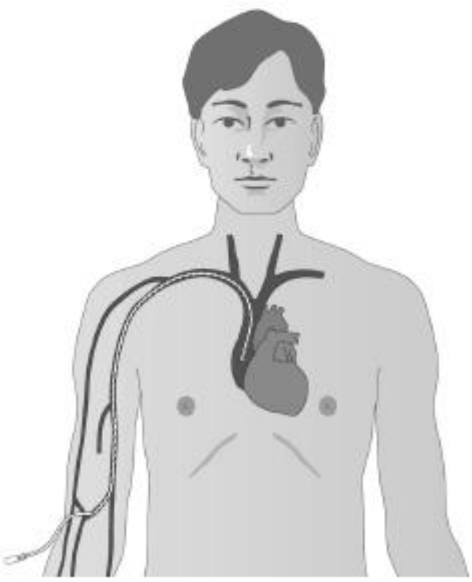
- VAD involves the drugs vincristine, doxorubicin and the steroid dexamethasone
- C-VAMP is a combination of the drugs cyclophosphamide, vincristine, doxorubicin and the steroid methylprednisolone

These treatments tend to have more side effects than tablets or capsules, and will often make your hair fall out. In view of this, they are usually given only to younger people who are fit enough.

A newer combination treatment for myeloma which is given as tablets is CTD. This is a combination of the chemotherapy drug cyclophosphamide, the drug thalidomide and the steroid, dexamethasone. This treatment may form part of a research trial.

If you are going to have your treatment by drip, your doctor may suggest that you have a plastic tube (such as a central line or PICC line) put into a vein in your chest or the crook of your arm.





The line can stay in place throughout your treatment. Your nurses will show you how to care for the line when you are at home. A tube with an injectable port just under the skin may sometimes be used. This is known as an implantable port.

The length of treatment will depend on the stage of the myeloma and how well it is responding to the drugs, but usually the course of treatment will take four–six months to complete. On average, two out of three patients will go into remission during treatment.

Side effects of chemotherapy

Everyone reacts to chemotherapy in different ways. Not all drugs cause the same side effects and some people may have very few side effects. Your doctor will tell you about any problems that your treatment may cause.

Chemotherapy tablets for myeloma may cause fewer side effects than chemotherapy by injection or infusion into a vein.

We have further information about individual drugs and their side effects. We also have detailed information about all of the side effects mentioned in this booklet.

Lowered resistance to infection

Chemotherapy can reduce the production of white blood cells by the bone marrow, making you more prone to infection. This effect can begin about seven days after treatment has been given and your resistance to infection usually reaches its lowest point 10–14 days after chemotherapy. Your blood cells will then increase steadily and will usually have returned to normal before your next course of chemotherapy is due.

Contact your doctor or the hospital straightaway if:

- your temperature goes above 38ºC (100.5ºF)
- you suddenly feel unwell (even with a normal temperature).

You will have a blood test before having more chemotherapy, to make sure that your cells have recovered. Occasionally it may be necessary to delay treatment if your blood count is still low.

Bruising or bleeding

The chemotherapy can also reduce the production of platelets, which help the blood to clot. Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, or bleeding gums.

Feeling sick

Chemotherapy tablets usually cause very mild feelings of sickness (nausea). With some of the injected drugs this may be more of a problem, and these may even cause vomiting. There are now very effective anti-sickness drugs to prevent or greatly reduce these effects. If nausea occurs, it may begin a few hours after the treatment is given and last for up to a day. If it is not controlled, or continues, tell your doctor. They can prescribe other drugs which may be more effective.

Sore mouth

Chemotherapy drugs can make your mouth sore, so regular mouthwashes are important; the nurse will show you how to do these properly. If you don't feel like eating at any time during your treatment, you could replace some meals with nutritious drinks or a soft diet. It might be helpful to speak to the hospital dietitian.

Anaemia (low number of red blood cells)

While having chemotherapy you may become anaemic. This may make you feel tired and breathless.

Hair loss

Hair loss is more common with chemotherapy given into a vein than it is with chemotherapy tablets. If your hair falls out, it usually grows back within three months after treatment.

Tiredness (fatigue)

Chemotherapy affects people in different ways. Some are able to lead a fairly normal life during their treatment, while others find they become very tired and have to take things more slowly. Just do as much as you feel like and try not to overdo it. For some people, the fatigue continues for quite some time after their treatment has ended.

Stem cell transplants

If they go into remission after the initial chemotherapy, some people can go on to have high-dose chemotherapy to try to destroy any remaining myeloma cells.

The high doses of chemotherapy will destroy the bone marrow as well as the myeloma, so the bone marrow will need to be replaced with a transplant of stem cells. The stem cells are collected before the treatment, stored and then given by drip into a vein afterwards. This is known as an **autologous** transplant.

As this is a very intensive treatment with a lot of side effects, it is usually only suitable for people under 65–70, although your general health rather than your age is the main deciding factor.

It may also be possible to have a stem cell transplant as part of a research trial, using donated stem cells, either from your brother or sister, or from an unknown donor. When the stem cells are donated by a brother or sister, this is called an **allogeneic** transplant. The risks of this treatment are greater than if you use your own stem cells and, as a result, it is usually only available to people under 50.

A matched unrelated donor (MUD) transplant, where the donor is not related to the patient, has more side effects than one using cells from a relative. MUD transplants are rarely used to treat people with myeloma.

Our booklet stem cell and bone marrow transplants explains this treatment in more detail.

Other treatments involving the use of stem cells are being researched in some hospitals. These include mini-transplants (which involve less intense chemotherapy), and tandem transplants (in which a second transplant is given straight after the first). It is not yet known how effective these methods will be.

Side effects with stem cell treatment

If high doses of chemotherapy with stem cell (or bone marrow) support are used, the side effects of the chemotherapy can be more severe and you will need to stay in hospital for about four weeks. This is because the treatment will make the number of blood cells and platelets in your blood drop to very low levels for a few weeks. During this time, people often need to be given antibiotics to prevent infections, as well as blood transfusions and transfusions of platelets to prevent any bleeding.

Thalidomide

Thalidomide is a drug that has been shown to be effective in treating myeloma. It may be given to treat myeloma that has relapsed (come back). Research trials are also looking into its use as a maintenance treatment for myeloma, especially after high dose treatment, and also its use as an initial treatment given with chemotherapy.

It is thought that thalidomide can stop cancers from developing new blood vessels, and may be able to stop the cancer getting a supply of oxygen and nutrients. It is hoped that this will stop the cancer growing or make it shrink.

Thalidomide is taken daily, usually in the evening, as a tablet.

Side effects of thalidomide

These include constipation; drowsiness; an increased risk of developing blood clots in the veins in the legs (known as deep vein thrombosis or DVT); and damage to particular nerves, which can cause tingling in the hands and feet (peripheral neuropathy). You may be given medicines to thin your blood because of the risk of blood clots.

Peripheral neuropathy is a common side effect of thalidomide. It usually starts with tingling and numbness in the feet which then spreads to the hands. It's important to tell your doctor if you have any symptoms so they can adjust the dose if appropriate. The degree of neuropathy may depend on the dose and how long you take thalidomide for. People who have had chemotherapy which causes peripheral neuropathy may be more at risk.

Thalidomide can cause birth defects, so its use is strictly controlled. It should not be given to pregnant women, and people taking thalidomide who are sexually active should use a barrier form of contraception.

Occasionally the side effects outweigh any benefit, and the dose of thalidomide will be reduced or stopped.

Steroid therapy

Steroids are drugs which are often used in the treatment of myeloma. They may be taken on their own or with chemotherapy. The steroids are usually taken as tablets.

Steroids for myeloma are usually taken only for a few days at a time. Depending on the dose prescribed, they may have some side effects. These can include feeling irritable, increased appetite, feeling more energetic, heartburn, indigestion and difficulty sleeping.

If you are taking steroids for some time, you may have other temporary side effects including water-retention, high blood pressure and a slightly greater risk of getting infections. You may also develop an increased level of sugar in the blood. If this happens to you, your doctor will prescribe daily tablets or injections to bring your blood sugar level back to normal.

You may need to do a simple daily test to check for sugar in your urine. Your nurses will show you how to do this.

It is unusual for people with myeloma to have to take steroids for a long time but if you do you, may notice that you put on weight, especially on your face, waist and shoulders.

These side effects may seem hard to bear at the time, but it is important to remember that they are all temporary and will disappear as the steroid dose is reduced.

Bisphosphonates

Bisphosphonate drugs can be given to reduce the symptoms of myeloma. They may be used to reduce the amount of excess calcium in the blood and to help strengthen weakened bones. They are also be given to people in remission, as they have been shown to help delay bone damage, and to prevent bone pain, raised calcium levels and fractures.

Research has suggested that bisphosphonates may help treat myeloma. Trials are investigating this further.

Bisphosphonates can be given in two ways. They can be given as a drip (infusion) into a vein once a month. This takes between 15 minutes and four hours, depending upon which drug is used. Bisphosphonates are also available as tablets.

Side effects are generally mild and include indigestion and nausea. A very rare side effect of bisphosphonates is osteonecrosis of the jaw. This condition involves damage and decay of the jaw bone. It is more likely if a person has had dental treatment just before or during treatment with bisphosphonates. It is important that your dentist knows if you are on bisphosphonates and that your doctors know if you need dental treatment.

Maintenance treatment for myeloma

Maintenance treatment may be used to try to keep people with myeloma in remission for as long as possible. The drugs which may be used are interferon, steroids and thalidomide. Research is looking at maintenance treatment for myeloma.

New drugs such as bortezomib and lenalidomide are also being looked at to see if they help keep people in remission.

Interferon

This is a protein that is normally produced by the body during viral infections, such as flu. It is given as a cancer treatment to stimulate a person's immune system to attack the myeloma cells. Interferon may be used as a maintenance treatment, to try to keep the myeloma in remission after chemotherapy. It can help to control the disease, but sometimes the side effects can outweigh the benefits.

Interferon is given three times a week, or occasionally daily, as a small injection under the skin (subcutaneously) using a very fine needle. The injections are slightly uncomfortable. You will be taught how to give yourself these injections.

In the first week or two of treatment, interferon can cause symptoms similar to those of flu; especially chills, a high temperature, headache, and aching in the back, joints and muscles. Your doctor may recommend that you take paracetamol, about half an hour before the injection, to prevent these symptoms.

The side effects often disappear within a few weeks of starting treatment, but for some people they continue. Interferon can also make you feel very tired.

Treatment if myeloma comes back

If your myeloma comes back, it may be possible to repeat the treatment that you originally had to control the disease, depending on what the treatment was and how long your remission lasted. If this isn't possible, there are usually other treatment options. Your doctor will discuss all the possible treatment options with you.

Treatments that may be considered are: chemotherapy, high-dose treatment with a stem cell transplant, thalidomide, bortezomib (Velcade®) and steroids.

Bortezomib (Velcade®)

Bortezomib is a new type of anti-cancer drug called a **proteosome inhibitor**. It is given to people who have previously been treated with chemotherapy, but whose myeloma has come back or continued to develop despite treatment, and who have already had, or are unsuitable for, a bone marrow transplant.

Proteosomes are a group of enzymes found in all cells in the body. They have an important role in controlling cell function and growth. By interfering with the function of proteosomes, bortezomib may cause cancer cells to die and may stop the cancer from growing. You will be given bortezomib as an injection into a vein. You will usually have four doses over a three-week period. You may also be given a steroid.

Side effects of bortezomib include tiredness, nausea, diarrhoea, numbness or tingling in the hands and feet (peripheral neuropathy) and a tendency to bruise or bleed more easily (caused by a low platelet count).

The National Institute for Health and Clinical Excellence (NICE) is an independent body that was set up by the government. NICE assesses medicines and treatments and gives guidance to doctors on how they should be used in the NHS in England and Wales. The equivalent body in Scotland is the Scottish Medicines Consortium (SMC).

NICE has approved the use of bortezomib for people when:

- the myeloma has come back and
- they have had one only one previous course of treatment and
- they have either had or are unsuitable for a bone marrow transplant.

The SMC approved the use of bortezomib in Scotland for people:

- who have had at least two different courses of treatment and
- the myeloma is getting worse and
- no other treatment is working.

Lenalidomide (Revlimid®)

Other drugs, known as immunomodulatory drugs (IMiDs™) that work in a similar way to thalidomide are currently being developed. The drug lenalidomide (Revlimid®) has been shown to help to control myeloma. It is licensed to be used with the steroid dexamethasone, for people who have already had at least one course of treatment. Lenalidomide is a capsule taken once a day for three weeks, followed by a week off.

The main side effects of lenalidomide are being more at risk of infection (due to having a lowered white blood cell count), anaemia, possible bruising or bleeding (due to low platelet count), and rarely, constipation, a rash and sleepiness. When taken with dexamethasone, there is an increased risk of blood clots in the legs. You may be given blood thinning machines to reduce this risk.

Lenalidomide has not yet been assessed by NICE or the SMC.

Treating the symptoms of myeloma

There are several ways of easing the symptoms of myeloma, so it is important to let your doctor know if you are having any problems.

- Radiotherapy
- Anaemia
- Infection
- Pain
- Excess calcium in the blood
- Weakened bones
- Pressure on the spine
- Kidney problems
- Hyperviscosity syndrome

Radiotherapy

Radiotherapy may be used in a variety of ways. It uses high-energy x-rays, which destroy the myeloma cells while doing as little harm as possible to normal cells.

Radiotherapy is usually given by a machine, similar to an x-ray machine, that produces a beam of rays. The rays can be directed at specific bones where the myeloma cells have created a weak area. This treatment can be very effective at relieving the pain in bones weakened by myeloma and allowing the bones to repair themselves. You may only need one or two treatments. Your pain should reduce within 2–3 weeks.

In advanced myeloma, if chemotherapy is no longer being effective, radiotherapy can be given to the whole body, half at a time, in two sessions several weeks apart. This, known as hemi-body irradiation, may help to reduce symptoms and control the disease for some time.

Radiotherapy may also sometimes be used as part of the preparation for a stem cell transplant.

Radiotherapy is given in the hospital radiotherapy department. How the treatment is given can vary a lot, depending on your particular needs. If you only need one or two treatments, you may not need a lengthy first appointment to plan the treatment. If you are having a longer course of treatment you will need to go to the hospital before your treatment starts so that the area to be treated, and the dose to be given, can be accurately worked out. Normally a course of treatment is given daily for two to four weeks, from Monday to Friday, with a rest at the weekend.

Radiotherapy for myeloma only occasionally causes side effects such as nausea and vomiting. If these do occur they can easily be treated – just let your doctor or nurse know. Any side effects should disappear once your course of treatment is over, but tell your doctor if they continue.

Radiotherapy can make you feel very tired, so try to get as much rest as you can, especially if you have to travel a long way each day for your treatment.

Anaemia

A shortage of red blood cells (anaemia) is common in people with myeloma and may be due to several causes. Anaemia may make you feel tired and breathless. It is quite common to have anaemia when myeloma is diagnosed but this will normally get better when treatment begins to control the myeloma.

Sometimes anaemia can develop because of the chemotherapy itself. If this happens your doctor may suggest that you have a blood transfusion. The blood will be given to you through your central line or PICC line, if you have one, or into a vein in your arm.

Infection

At the first sign of any infection or fever it is important to contact your doctor immediately so that they can prescribe antibiotics to help your body fight the infection. It will also help if you rest and drink plenty of fluids.

Pain

Radiotherapy and chemotherapy can help to reduce pain, but let your doctor know if it is becoming troublesome while you are waiting for these treatments to take effect, .They can prescribe effective painkillers to relieve your pain. You can try different types until you find one that works best for you. Our booklet, controlling cancer pain, gives information about the different methods of pain control.

Painkillers often work better if you take them regularly, rather than waiting for the pain to come back before taking them.

Many painkillers can cause constipation, so make sure you eat a diet high in fibre and drink plenty of fluids. Your doctor can prescribe a laxative with your painkillers to prevent constipation if this is needed. Gentle exercise can also help.

Excess calcium in the blood

The myeloma cells in the bones can sometimes start to break down some of the bone cells, which release calcium into the blood. This condition is called **hypercalcaemia** and can cause symptoms such as tiredness, nausea, constipation, thirst, irritability and confusion. However, in some people hypercalcaemia is discovered during a blood test before any symptoms develop.

Your doctor may ask you to start drinking plenty of water and will put a drip of fluids into a vein in your arm (intravenous infusion). This will encourage the kidneys to extract the calcium and flush it from the body in your urine.

You may also be given a drug known as a bisphosphonate, to reduce the calcium levels in your blood. Bisphosphonates prevent damage to the bone and will quickly reduce high calcium levels. The drug is given into a vein over a few hours and brings the calcium level down over the next 2–3 days. You may need a further dose if your calcium level starts to rise again.

Bisphosphonates are also available as tablets. These are not as effective as injections but they may help to increase the effect of the injections if necessary.

Weakened bones

Surgery is sometimes needed to repair a bone in the back, arm or leg that has been damaged or weakened by the myeloma cells. The operation will be done under a general anaesthetic and the damaged bone is strengthened with a metal pin or plate, which, once in place, cannot be felt or seen.

If the operation is on a limb, you will be able to start gently using it again the day after the operation, with the help of your physiotherapist. If the operation is on your back, you may need to rest for a few days before you start to move around again. You may also need some radiotherapy to the broken or weakened bone to destroy the myeloma cells in this bone and help it to heal.

If the bones of the spine (vertebrae) are weakened by the myeloma, they may collapse (known as a compression fracture). This can cause problems of pain, difficulty moving around and loss of height. This is often treated with painkillers, bed rest and by wearing a spinal brace.

Percutaneous vertebroplasty It may be possible to repair the compression fracture by injecting a special cement into the vertebrae which can help to stabilise the bone and relieve pain. This will only be carried out in specialist centres. Side effects are uncommon but possible effects include infection or damage to the nerves in the spine.

Balloon kyphoplasty This is a second technique that may be used to improve the strength of the bones of the spine, which may relieve pain and help people move around more easily. It involves inserting a balloon-like device, called an inflatable bone tamp, into the vertebrae and then slowly inflating it. Once the bone returns to its normal height, it can be injected with bone cement (as above). This is a newer technique, which will only be carried out in specialist centres. Possible side effects are similar to those caused by a percutaneous vertebroplasty. The long-term risks and benefits are not known.

Your doctor or specialist nurse will explain more about percutaneous vertebroplasty or balloon kyphoplasty if they feel that either treatment is appropriate for you.

Bisphosphonates are also sometimes used over a long period of time to help strengthen weakened areas of bone and prevent fractures and pain.

If your doctor prescribes bisphosphonates as tablets, you will take them every day. You and your doctor may find it more convenient for you to be given the drug into a vein once a month, particularly if this fits in with your trip to the hospital for chemotherapy.

Bisphosphonates usually cause few side effects but some people have indigestion, feel sick or are sick. If you develop these problems, discuss them with your doctor.

If you are working and your job involves heavy lifting, or if you take part in any sports that may put a strain on your back, you should ask your doctor's advice before going back to these activities.

Pressure on the spine

Myeloma can develop in the bones of the spine. Sometimes in this situation, the tumour can cause pressure on the spinal cord. The bone may become weakened and put pressure on the cord. This is called spinal cord compression and causes symptoms such as pain and tingling down the legs, weakness of the legs, or problems with passing urine or opening the bowels.

If you have any of these symptoms, you should let your doctor know as soon as possible. Spinal cord compression is usually treated with radiotherapy. Steroids are also given to help reduce the pressure on the spinal cord. Early treatment is very important for spinal cord compression to prevent paralysis of the legs. Sometimes surgery is needed to repair or remove the affected bone.

Kidney problems

The myeloma proteins may prevent your kidneys from filtering waste products from your blood properly, so it is essential to drink plenty of fluids each day – three litres or more if you can. This will help to flush your kidneys, allowing them to work more efficiently.

If kidney damage is severe, the kidneys can stop working altogether. In kidney failure, no urine is produced and excess fluid begins to build up in the body. If this happens, you will be given **kidney dialysis** to artificially filter your blood. There are different ways of giving dialysis. You can contact our cancer support specialists if you would like to discuss this treatment.

Hyperviscosity syndrome

Rarely, if myeloma makes the level of paraproteins in the blood very high, the blood can become thicker than normal. This can cause symptoms such as headaches, dizziness, sight problems and abnormal bleeding. To help correct this problem it is sometimes possible to have plasma exchange (plasmapheresis), a procedure which removes the excess paraproteins from the blood.

Our controlling the symptoms of cancer booklet may be helpful.

Research - clinical trials for myeloma

Research into new ways of treating myeloma and controlling symptoms is going on all the time. Trials that are carried out on patients are known as clinical trials. Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs, gene therapies or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, in order to make them more effective or to reduce side effects
- compare the effectiveness of drugs used for symptom control
- see which treatments are the most cost-effective
- find out how cancer treatments work.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and the development of new treatments. You will also be carefully monitored during and after the study. Usually, several hospitals around the country take part in trials.

The process of clinical trials is described in more detail in our booklet on cancer research trials.

Blood and tumour samples

Many blood samples and bone marrow or tumour biopsies may be taken help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you are taking part in a trial you may also be asked to give other samples which may be frozen and stored for future use when new research techniques become available. These samples will have your name removed from them (anonymised) so you can't be identified.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will, hopefully, improve the outlook for future patients.

Living with myeloma

Follow-up after treatment for myeloma

After your treatment has finished, your doctor will probably want you to have regular check-ups and x-rays. You will have regular blood and urine samples taken, to check the level of paraproteins. If you have any problems, or notice any new symptoms between appointments, let your doctor know as soon as possible.

Many people find that they get very anxious for a while before the appointments. This is natural and it may help to get support from family, friends or a support organisation during this time.

Our booklet, adjusting to life after cancer treatment, gives useful advice on how to keep healthy and adjust to life after treatment.

Rehabilitation and recovery after treatment for myeloma

Myeloma affects people in different ways. You may find that you can make a quick return to normal life after treatment, but don't worry if at first you are not as fit as you used to be and you cannot easily do all the things you once took for granted. It can take some time to get back into normal routines if you have been in hospital or have had to rest at home for long periods.

While you are in hospital, the physiotherapists will start to get you back on your feet by helping you to do muscle-strengthening exercises and helping you to walk.

The occupational therapists at the hospital will get you back in the practice of doing your normal activities around the home. They can visit your home with you to see whether you will need special adaptations, such as bath rails or a higher chair to help you cope more easily.

Many social workers attached to hospitals are also trained counsellors, and can offer valuable support and practical advice to you and your family, both in hospital and at home. If you would like to talk to a social worker, ask your doctor or senior nurse to arrange it for you.

Living with and after cancer

Cancer can affect many areas of your life such as your finances, work, your emotions and relationships. Find information and advice about what the effects might be, how to deal with them and how we can help.

Emotional effects

Information on the emotions you might experience as a result of your cancer diagnosis, ways that you might manage them and other sources of support.

Relationships and communication

Advice on how to talk to other people, talking to children, relationships and sexuality.

Note: JASCAP has booklets on each of the above topics.

Questions you might like to ask your doctor or surgeon

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. ____

Answer ____

____

2. ____

Answer ____

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3. ____

Answer ____

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4. ____

Answer ____

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5. ____

Answer ____

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JASCAP : We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of “JASCAP”.

Note for Reader

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

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