



# Thyroid cancer

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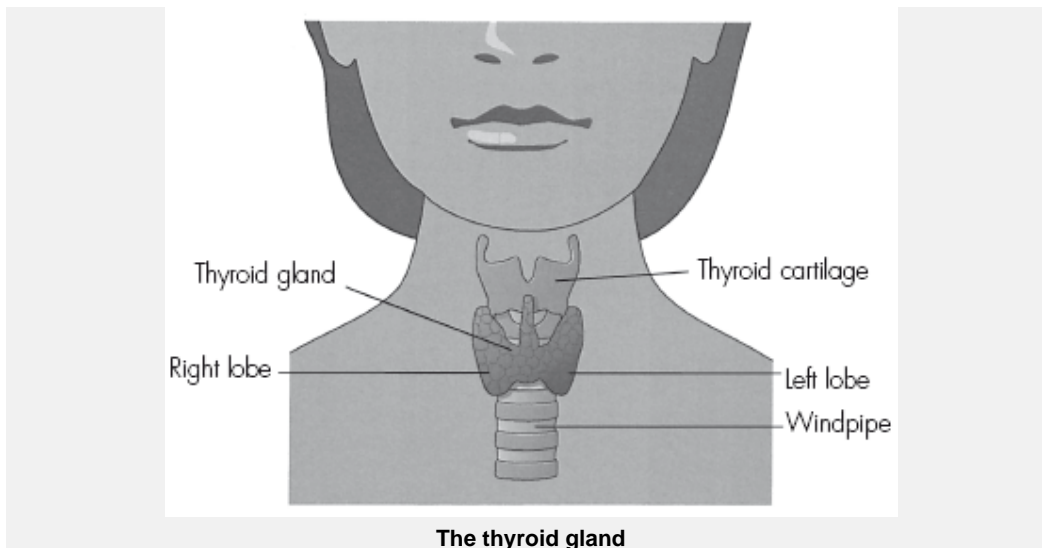
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# About thyroid cancer

## The thyroid gland

The thyroid is a small gland in the front of the neck just below the voice box (larynx), and is made up of two parts, or lobes. It is one of a network of glands throughout the body that make up the **endocrine system**. This system is responsible for producing the body's hormones that help to control and influence various functions.

The thyroid is sometimes known as the 'activity' gland because it produces the two main hormones, **thyroxine (T4)** and **triiodothyronine (T3)**, which are needed to keep the body functioning at its normal rate. In order to produce the thyroid hormones, the thyroid gland needs a regular supply of iodine (which is found in fish, seafood and dairy products).



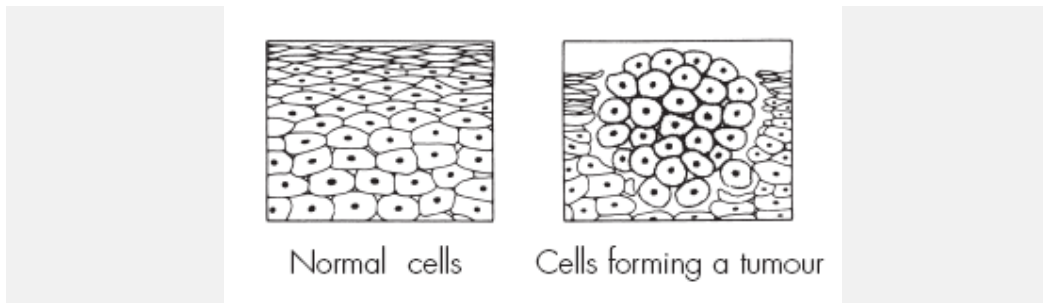
If the levels of T3 and T4 in the blood fall, the hypothalamus (a part of the brain) sends out thyroid-releasing hormone (TRH) into the blood. As the levels of TRH in the blood rise, the pituitary gland releases thyroid-stimulating hormone (TSH) which stimulates the thyroid to produce more thyroid hormones.

If the thyroid gland doesn't produce enough hormones you will feel tired and lethargic and put on weight easily. This is called **hypothyroidism**, or **myxoedema**. If the thyroid gland produces too much hormone you will lose weight, have an increased appetite, feel shaky and anxious, or have palpitations. This is known as **hyperthyroidism**, or **thyrotoxicosis**.

## 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**.



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

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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

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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

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

## Thyroid cancer

Each year, approximately 1500 people in the UK are diagnosed with thyroid cancer. It is a rare cancer that is most likely to affect people who are middle-aged or older. However, one type of thyroid cancer (papillary) can occur in people younger than this. Thyroid cancer is more common in women. It is very rare in children.

By examining cells from the cancer, your doctor will be able to tell which type you have, and the best type of treatment for you. There are four main types of cancer of the thyroid:

- **Papillary** This is the most common type of thyroid cancer.
- **Follicular** This is a less common type of cancer, usually found in older people.

These two types are sometimes called differentiated thyroid cancer and they are often treated in the same way.

- **Medullary** This is a rare type of thyroid cancer that can run in families. For this reason, members of your family may be checked at regular intervals to ensure they are not showing any signs of the cancer.
- **Anaplastic** This is also a rare type of thyroid cancer. It occurs more commonly in older people and grows quickly. Unlike other types of thyroid cancer, it can be difficult to treat.

It is also possible to have a lymphoma of the thyroid gland. This is another rare type of thyroid cancer, which starts in the lymph tissue of the thyroid. The lymph tissue is part of the body's lymphatic system. Usually thyroid lymphomas are a type of non-Hodgkin lymphoma (NHL).

Apart from the anaplastic type and lymphoma, cancer of the thyroid tends to develop very slowly, and it may be some years before it starts to cause any problems. With treatment, the outlook for most people with cancer of the thyroid is very good and many people are completely cured, even if the cancer has spread beyond the thyroid.

## Risk factors and causes of thyroid cancer

**The exact causes of thyroid cancer in most people are not known, but research is going on all the time to try to find the cause. There are a number of risk factors that can increase your chance of developing thyroid cancer.**

**These are:**

- Benign thyroid disease

- Diet
- Low iodine levels
- Inherited faulty gene
- Exposure to radiation

## Benign thyroid disease

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People who have certain non-cancerous (benign) thyroid diseases are more likely to develop thyroid cancer. These include:

- an enlarged thyroid (goitre)
- thyroid nodules (adenomas)
- inflammation of the thyroid (thyroiditis).

The more common thyroid conditions of an over- or under-active thyroid (hyperthyroidism and hypothyroidism) do not increase your risk of developing thyroid cancer.

## Diet

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A poor diet that contains large amounts of butter, cheese and meat may increase your risk of developing thyroid cancer. Large amounts of fresh fruit and vegetables may help to reduce your risk.

## Low iodine levels

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People who eat very little iodine in their diet are more likely to develop thyroid cancer. You are more likely to have a low iodine level if you are also exposed to radiation or if you have a history of benign thyroid disease.

Iodine is found in the soil and if you live in an area where the levels of iodine are low, the levels in your drinking water, and any locally grown vegetables or reared animals will also be low.

## Inherited faulty gene

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In a very small number of people, medullary thyroid cancer may be due to an inherited faulty gene. The affected gene is the RET gene. There are two main types of inherited condition in which this occurs:

- **Familial medullary thyroid cancer (FMTC)**, affecting many family members.
- **Multiple endocrine neoplasia (MEN) syndrome types 2A and 2B**; with this syndrome, family members are at risk of developing a number of different endocrine tumours including medullary thyroid cancer. We have further information about the MEN 2 syndromes.

Family members of someone with medullary thyroid cancer can be tested to see if they have inherited an abnormal RET gene. If someone is found to have the abnormal gene they may be advised to have their thyroid gland removed to prevent cancer developing. This is known as a prophylactic thyroidectomy.

There is also an increased risk of developing thyroid cancer if you have the inherited bowel condition called familial adenomatous polyposis (FAP).

## Exposure to radiation

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This may be due to radiotherapy given in childhood, or to unusually high levels of radiation in the environment; for example, in the areas surrounding Chernobyl in the Ukraine, following the nuclear power explosion of 1986. Thyroid cancer can develop many years after exposure. However, only a small number of thyroid cancers are caused by radiation exposure.

## Symptoms & diagnosis

### Symptoms of thyroid cancer

In most people cancer of the thyroid develops very slowly. The first sign is usually a painless lump in the neck which gradually gets bigger. Occasionally, a thyroid tumour may press on the gullet (oesophagus) or windpipe (trachea) and cause difficulty in swallowing or breathing.

Very rarely, the first symptoms may be caused by secondary tumours in the bones or lungs after the cancer has spread beyond the thyroid.

It is unusual for cancer of the thyroid to affect the production of thyroid hormones, so symptoms of an over- or under-active thyroid are rare.

If you notice a lump in your neck, or any of the above symptoms, you should see your doctor as soon as possible. However, most thyroid swellings (or **goitres**) are benign (non-cancerous).

## How thyroid cancer is diagnosed

If you have symptoms that may be due to a thyroid cancer, you will usually begin by seeing your GP. They will do an examination and arrange any tests which may be necessary. If your GP thinks that cancer may be present, or is not sure what the problem is, they will refer you to a hospital for specialist advice and treatment.

The doctor at the hospital will ask you about your general health and any previous medical problems, before examining you.

### Blood tests

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Samples of blood will be taken to check your thyroid hormone and TSH levels. Your blood will also be tested to check your general health.

### Fine-needle aspiration or biopsy

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For a fine-needle aspiration or biopsy, a small needle is passed gently into the swelling in your neck. Sometimes the doctor will use an ultrasound scanner to help guide the needle to the right area. They will then take a sample of cells and examine this under a microscope to check whether there are cancer cells present.

## Further tests for thyroid cancer

**The specialist will want to do some further tests. These may include any of the following:**

- Surgical biopsy
- Ultrasound thyroid scan
- Thyroid radioisotope scan
- CT scan
- MRI scan
- PET scan

### Surgical biopsy

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Sometimes it may be necessary to do a surgical biopsy, which is done under either a local or general anaesthetic. The doctor will make a small cut in the skin close to the thyroid, and remove a small sample of the thyroid gland. You may have a surgical biopsy if:

- it is not possible to do a needle aspiration or biopsy
- the needle aspiration does not collect enough cells
- the doctor who looks at the cells under the microscope (a pathologist) is not able to be sure about whether cancer cells are present from the needle aspiration or biopsy sample.

## Ultrasound thyroid scan

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Sound waves are used to make up a picture of the inside of the neck and the thyroid.

Once you are lying comfortably on your back, a gel is spread over your neck. A small device like a microphone, which produces sound waves, is then rubbed over the area. The sound waves are changed into a picture by a computer and may show whether the lump is solid or just fluid in a cyst.

## Thyroid radioisotope scan

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For this test a small amount of a slightly radioactive liquid (technetium or iodine) is injected into a vein in your arm. After about 20 minutes you will be asked to lie on a couch and a machine called a gamma camera will be positioned over your neck.

Cancer cells do not usually absorb the radioactive liquid as well as normal thyroid cells, so the camera may be able to show any areas of cancer in the thyroid. These are called **cold areas** or **cold nodules**.

The scan itself is painless and the radioactive injection has no harmful side effects.

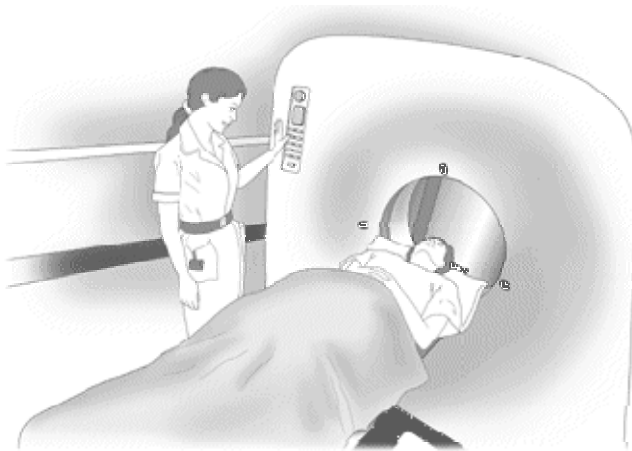
## CT scan

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A CT (computerised tomography) scan is a series of x-rays, which build up a three-dimensional picture of the inside of the body. This type of scan is sometimes used to help the doctors know exactly how the cancer is affecting you and can be good at detecting thyroid cancer if it has spread to the lungs. The scan is painless but takes 10–30 minutes.

CT scans expose you to a small amount of radiation, which will be very unlikely to harm you and will not harm anyone you come into contact with.

It is important that you aren't given an injection of a dye during the CT scan. The dye allows particular areas to be seen more clearly and it is fairly common for injections to be given during this type of scan. However, the dye contains iodine and can affect the way that radioactive iodine works.



## MRI scan

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An MRI (magnetic resonance imaging) scan is similar to a CT scan, but uses magnetic fields instead of x-rays to build up a series of cross-sectional pictures of the body. MRI scans can be useful for seeing if the cancer has spread in the neck.

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.

The cylinder is a very powerful magnet, so 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 not be able to have an MRI because of the magnetic fields.

Some people are given an injection of dye into a vein in the arm, but this usually does not cause any discomfort.

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.



## PET scan

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PET (positron emission tomography) scans are a specialist type of scan and you may have to travel to another centre to have one. They are not always necessary but you can discuss with your doctor whether one would be useful in your case. They are sometimes used if other investigations are negative or if the thyroid cancer comes back.

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.

## Staging of thyroid cancer

**The stage of a cancer is a term used to describe its size and whether it has spread beyond its original site. Knowing the particular type and the stage of the thyroid cancer helps the doctors to decide on the most appropriate treatment.**

Generally cancers are divided into four stages: small and localised (stage one); spread into surrounding structures (stages two or three); or spread into other parts of the body (stage four). If the cancer has spread to distant parts of the body this is known as **secondary cancer** (or **metastatic cancer**). Thyroid cancer is also staged according to the different types and the age of the person. The different staging systems are described below.

### Papillary & follicular thyroid cancer in people under 45

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**Stage 1** The tumour can be of any size and nearby lymph nodes may also be affected, but there is no spread of the cancer to other parts of the body.

**Stage 2** A tumour of any size that has spread to other parts of the body, such as the bones or lungs.

There is no stage 3 or 4 for these patients.

### Papillary or follicular thyroid cancer in people aged 45 & over, & medullary cancer

- **Stage 1** The tumour is no bigger than 2cm in size and is contained within the thyroid gland. There has been no spread to either the lymph nodes or other parts of the body.



- **Stage 2** The tumour is contained within the thyroid gland and is between 2 and 4cm in size. There has still been no spread of the cancer to lymph nodes or other parts of the body.
- **Stage 3** The tumour is bigger than 4cm in size and is contained within the thyroid gland. Or, the tumour is of any size and has spread just outside the gland or to nearby lymph nodes in the neck.
- **Stage 4A** The tumour may be any size and has spread into surrounding parts of the neck (such as the muscles, nerves or blood vessels) and/or to lymph nodes in the neck or the upper chest.
- **Stage 4B** The tumour may be of any size and has spread to neck tissues near the backbone or around the upper neck or chest. The cancer may also have spread to lymph nodes.
- **Stage 4C** The cancer has spread to other parts of the body, such as the lung or bone.

## Anaplastic thyroid cancer

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Everyone with anaplastic thyroid cancer is considered to have stage 4 disease. This stage is divided into three, depending upon how far the cancer has spread.

- **Stage 4A** The tumour is of any size and contained within the thyroid gland. Lymph nodes may also be affected, but the cancer has not spread to other parts of the body.
- **Stage 4B** The tumour is of any size and it has begun to spread into the soft tissues of the neck. Lymph nodes may also be affected, but the cancer has not spread to other parts of the body.
- **Stage 4C** The cancer has spread to other parts of the body, such as the lung or bones.

## TNM staging

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Your doctors may also describe your thyroid cancer using the TNM staging system.

**T** describes the size of the **tumour**. There are four main stages ranging from T1 – T4.

**N** describes whether the cancer has spread to the lymph nodes close to the thyroid gland. There are two stages: in **N0** there is no sign of cancer in the lymph glands; in **N1** there are cancer cells in the lymph glands.

**M** describes whether the cancer has spread to another part of the body, such as the lungs or the bones (secondary or metastatic cancer). There are two stages: **M0** is where there are no metastases; **M1** is where there are metastases.

## Treating thyroid cancer

### Treatment for thyroid cancer

**Surgery, radioactive iodine and radiotherapy are given alone or in combination. Most types of thyroid cancer can usually be treated very successfully and many patients are cured.**

**Chemotherapy is sometimes used to treat advanced thyroid cancer, or if the cancer comes back after treatment.**

- How treatment is planned
- Second opinion
- Giving your consent
- Benefits and disadvantages
- Treatment decisions

## How treatment is planned

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In most hospitals a team of specialists will decide the treatment that is best for you. This **multidisciplinary team (MDT)** will include:

- a surgeon who specialises in thyroid cancers
- an oncologist (a cancer specialist)
- a radiologist (a doctor who advises on x-rays and scans)
- a pathologist (a doctor who specialises in how disease affects the body).

There may also be a number of other healthcare professionals such as a nurse specialist, dietitian, physiotherapist and psychologist or counsellor.

Together they will be able to advise you on the best course of action and plan your treatment, taking into account a number of factors. These include your age, general health, the tumour type and stage.

If two treatments are equally effective for your type and stage of cancer – for example, surgery or radiotherapy – 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 have, so that you can decide what is the right treatment for you.

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

## Second opinion

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Even though a number of cancer specialists work together as a team to decide 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 it will be helpful. The second opinion may cause a delay in the start of your treatment, so you and your doctor need to be confident that it will be useful.

If you 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 ready so that you can make sure your concerns are covered during the discussion.

## Giving your consent

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Before you have any treatment, your doctor will explain the aims of the treatment to you. They will usually ask you 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 possible 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 cancer treatments are complex, so it is not unusual for people to need repeated explanations.

It is often a good idea to have a friend or relative with you when the treatment is explained, to help you remember the discussion more fully. You may also find it useful to write down a list of questions before you go to your appointment.

People often feel that the 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. 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. The staff can explain what may happen if you do not have it. It is essential 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 is helpful to let the staff know your concerns so that they can give you the best advice.

## Benefits and disadvantages

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

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

### Early-stage thyroid cancer

Treatment can be given for different reasons and the potential benefits will vary depending upon the individual situation. Treatment will be able to cure thyroid cancer for many people.

### Advanced thyroid cancer

If the cancer is at an advanced stage, treatment may still be able to cure it, but it may only be able to control it, leading to an improvement in symptoms and a better quality of life. For some people, treatment may have no effect upon the cancer and they may get the side effects without any of the benefit.

## Treatment decisions

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If you have been offered treatment that aims to cure your cancer, deciding whether to accept the treatment may not be difficult.

However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to decide whether to go ahead. Making decisions about 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, you can still be given supportive (palliative) care, which uses medicines to control any symptoms.

## Surgery for thyroid cancer

**The first treatment for cancer of the thyroid is usually an operation. When the cancer is detected and removed early, most people have an excellent chance of being cured completely. Your surgeon will explain to you the type of surgery that you need.**

**If the cancer has spread beyond the thyroid gland, surgery alone may not cure the cancer and you will often need a combination of treatments. Your surgeon may still recommend that the thyroid gland is removed as this can help to control symptoms.**

- How surgery is carried out
- After your operation
- Thyroid hormone replacement
- Radioactive iodine scans and treatment
- Hoarse voice
- Change in calcium levels
- Tiredness
- Scar
- Appointment

## How surgery is carried out

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It is not always possible for the doctors to make a diagnosis of cancer before surgery. In this situation, the surgeon will remove the affected lobe of the thyroid gland so that it can be examined under a microscope. If the diagnosis of cancer is confirmed, the remaining lobe will often be removed as well, during a second operation.

In people who have stage 1 papillary or follicular thyroid cancer it may be possible to remove only the affected lobe of the thyroid (**partial or hemi-thyroidectomy**); however, it is far more common for the

surgeon to remove the whole gland (**total thyroidectomy**). The reason for this extra surgery is to make sure that as much of the cancer is removed as possible and to examine the thyroid very carefully in case cancer cells are present in other parts of the gland. It also means that treatment with radioactive iodine is then possible.

Sometimes the surgeon removes and examines some, or all, of the lymph nodes close to the thyroid gland, to see whether the cancer has spread into them. This can help to reduce the risk of the cancer coming back after surgery.

Occasionally, it may be necessary for the surgeon to remove some of the tissues in the area around the thyroid gland. This may be done if:

- the cancer has begun to spread outside of the gland (locally advanced cancer)
- you have anaplastic thyroid cancer, as this type often spreads more quickly.

Sometimes the surgeon will have to remove part of the tube through which you breathe (trachea) and make an opening in the throat to allow you to breathe (tracheostomy).

Sometimes surgery is the only treatment needed for thyroid cancer, however your doctor may also recommend radioactive iodine or external radiotherapy. Radiotherapy aims to destroy any cancer cells that may be left, or to treat any cancer that has spread to other parts of the body.

## After your operation

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You will be encouraged to start moving about as soon as possible after your operation. This is an essential part of your recovery and, even if you have to stay in bed, it is important to do regular leg movements and deep breathing exercises. The physiotherapist will help you with these.

To ensure that you can breathe easily after the operation, the nurses will make sure that you are lying in a semi-upright position.

### Drips and drains

You will have a drip (intravenous infusion) to replace your body's fluids until you are able to eat and drink again – usually within 24 hours. One or two tubes (drains) will drain fluid from your wound. These are usually removed within 48 hours. If clips are used instead of stitches to close the wound, these will be removed before you go home.

### Pain and discomfort

You will probably have some pain or discomfort after your operation and your doctor will prescribe painkillers for you. If you find the painkillers are not helping, let your nurse know as soon as possible so that the drugs can be changed.

### Eating and drinking

You may find it painful to swallow for a short time and you may need to eat soft food. The nurses, or a dietitian, will discuss this with you before you go home. It is important to maintain a balanced diet. If you are finding it difficult to eat, nutritious drinks are a good way of supplementing your diet. Our eating well booklet has details of different nutritious drinks and supplements.

### Going home

Most people are ready to go home about 3–5 days after their operation. If you think that you might have problems when you go home (for example, if you live alone or have several flights of stairs to climb) let your nurse or the social worker know when you are admitted to the ward. They can arrange help before you leave hospital.

Some people take longer than others to recover from their operation. If you have any problems, you may find it helpful to talk to someone who is not directly involved with your illness. The nurses in our cancer support service can talk to you, and tell you how to contact a counsellor or local cancer support group.

## Thyroid hormone replacement

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You will need to take hormones to replace those normally produced by the thyroid gland.

## Radioactive iodine scans and treatment

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If you have an operation for papillary or follicular thyroid cancer, you are likely to have a scan or treatment using radioactive iodine in the weeks following the surgery. Your doctor may delay starting thyroid hormone replacement therapy until this has been done.

## Hoarse voice

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Occasionally, because of the position of the thyroid, the operation may affect the nerves supplying the voice box (larynx). This can make your voice sound hoarse and weak for some time after the operation. This is usually a temporary problem, but in a very small number of people may be permanent.

## Change in calcium levels

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With a thyroidectomy there may also be some damage to the parathyroid glands (tiny glands behind the thyroid). Their function is to control the level of calcium in the blood and, if damaged, this may become low. If necessary, your doctor will prescribe calcium supplements for you. Often these are only needed for a short time, but your doctor will let you know how long you need to take them for.

## Tiredness

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It is perfectly normal to feel a little tired for the first few weeks after removal of the thyroid gland, especially if you have to wait before starting thyroid hormone replacement therapy.

## Scar

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You will have a scar across the front of your neck just above the collar bones. The scar will look red or dark initially but it should fade with time.

## Appointment

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Before you leave hospital you will be given an appointment to attend an outpatient clinic for a post-operative check. This is a good time to discuss any concerns you may have.

## Whole-body radioisotope scanning for thyroid cancer

If you have either papillary or follicular thyroid cancer and have had the thyroid gland removed, you are likely to have further scans of the neck and body using radioactive iodine.

Whole-body radioisotope scanning is similar to the thyroid radioisotope scans that are used to diagnose thyroid cancer. The scans are done to see if there are any thyroid cancer cells left in the neck, or other parts of the body, after the operation.

If cancer cells are seen on the scan, you can be treated with stronger doses of radioactive iodine to destroy the cells. This is described in more detail in the section on internal radiotherapy. It may be possible to have a second operation to remove the cancer cells: for example if they are in a lymph node.

Whole-body radioisotope scanning is not possible if you still have some healthy thyroid gland left, as the healthy thyroid tissue would absorb all of the radioactive iodine.

## Thyroid hormone replacement after surgery for thyroid cancer

The thyroid gland produces hormones which are responsible for keeping the body functioning at its normal rate. Once your thyroid gland is removed and no longer producing these hormones, you will need to replace them by taking tablets for the rest of your life. Without these hormone tablets you would develop the signs and symptoms of **hypothyroidism**, eg weight gain, tiredness, dry skin and hair, and physical and mental slowness.

Following the operation, if you are likely to need radioactive iodine treatment or repeated radioisotope scans, you may be given the hormone tablet liothyronine sodium (T3, Triiodothyronine or Tertroxin®). This is given until you no longer need scans or have finished treatment. The usual long-term thyroid hormone replacement drug is thyroxine (T4) and this is normally started after radioactive iodine treatment. Most people only need to take thyroxine once a day.

As well as replacing the hormones you are missing, the thyroxine tablets may also help to stop papillary or follicular thyroid cancer coming back. The replacement hormones will stop the body from producing thyroid stimulating hormone (TSH). TSH normally stimulates the thyroid to produce more thyroid hormones, but can also encourage these types of thyroid cancer cells to grow. Some people who have only had part of their thyroid gland removed may be given thyroxine tablets for the same reason.

You will be carefully monitored in a specialist clinic to make sure that you are having the correct dose of thyroid hormone replacement. Regular blood tests will be needed to check the levels of thyroid hormones in your blood. It can sometimes take many months to find the right dose of thyroid hormones. You may find that you have a variety of symptoms, such as tiredness, during this time.

Once the right dose is found, there should be no side effects from taking these tablets, as they are simply replacing the hormones which the thyroid gland produces naturally.

It is important to remember to take the thyroid hormone tablets every day. It can help to take them at the same time daily to ensure you get into a routine.

## Internal radiotherapy for thyroid cancer

- Radioactive iodine
- Preparing for radioactive iodine treatment
- Diet
- Side effects
- Safety measures
- What will happen
- Fertility and breast feeding

### Radioactive iodine

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Small doses of radioactive iodine can be used to help diagnose cancer of the thyroid (thyroid radioisotope scan), and to see if any papillary or follicular thyroid cancer cells have been left behind after a thyroidectomy (whole-body radioisotope scanning). When given in larger doses, radioactive iodine can be used to treat any remaining cancer cells.

Radioactive iodine is only useful for the detection and treatment of any cancer cells that may remain, if all of the healthy thyroid tissue has been removed. It is common for an operation for papillary or follicular thyroid cancer to be followed by a treatment with radioactive iodine, known as **thyroid ablation**, to destroy the tiny amounts of normal tissue which are often left behind.

The radioactive substance used for treatment is the same as that used for radioisotope scanning, but given in much larger doses. It is mainly taken as capsules, but can be taken as a drink or injected into a vein in your arm (intravenously). It is a way of giving radiotherapy internally, rather than externally as high-energy rays.

The thyroid cancer cells absorb the iodine and receive a very high dose of radiation, which will help to destroy them. Radioactive iodine has very little effect on other parts of the body since other cells do not absorb iodine as much as the thyroid cells. Radioactive iodine treatment can be repeated if further tests show that cancer cells are still present.

### Preparing for radioactive iodine treatment

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If you are taking thyroid hormones (T3 or T4) these are usually stopped for 2–4 weeks before this treatment. Most people find that stopping the hormone replacement therapy makes them feel very tired, but it is important that you do this or the radioactive iodine treatment will not work.

To help overcome the potential problems of stopping your hormone replacement therapy, it may be

possible to be treated with recombinant human thyroid stimulating hormone (rhTSH). This drug, also known as thyrotropin alfa (Thyrogen®), is given as two injections into a muscle, usually in the buttock. It allows you to carry on taking your hormone replacement tablets and avoid the symptoms of thyroid hormone withdrawal.

## Diet

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Before treatment you may be asked to start eating a low iodine diet, as too much iodine in your body will make the treatment less effective. You will be given advice about which foods to avoid, but you should not have:

- fish and seafood
- table salt that has had iodine added
- cough medicines
- foods that contain the pink food colouring E127, such as salami, glace cherries and tinned strawberries
- vitamin supplements that contain iodine.

You should also try to cut down on the amount of dairy products that you eat, as these also contain some iodine. This includes foods such as:

- milk and milk products
- eggs
- cheese.

## Side effects

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Unfortunately, unlike external radiotherapy, this treatment makes you slightly radioactive for about 4–5 days. During this time the radioactivity will be gradually lost from your body in your urine, blood, saliva and sweat. This means that for a few days you will need to be looked after in hospital until the radioactivity has reduced to a safe level.

Very rarely, you may have pain, tiredness and/or breathlessness after having radioactive iodine treatment. If these side effects occur, let your nurse or doctor know, as medicines can be prescribed to help.

## Safety measures

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Because of the possibility of unnecessary radiation exposure to the hospital staff and your friends and relatives, certain safety measures are taken while the radioactive iodine is still in your body.

The staff looking after you will explain these restrictions to you in detail before you start your treatment. Each hospital has different routines, and it is worth visiting beforehand to discuss the procedure with the nursing and medical staff.

You may be admitted to the ward the day before your treatment so that the staff can go over the procedure with you. This is a good time to ask questions and it may help to make a list of them beforehand.

## What will happen

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- You will probably be in a side room, away from the main ward.
- You may have the room to yourself or be with someone else having similar treatment.
- Lead screens may be put on either side of your bed or in the doorway to block any radiation that is given out.
- Visitors will be restricted, and only allowed to stay in the room or sit at the end of the bed for a short time, if at all. Visitors will be able to talk to you from outside the room through an intercom.
- Children under 18 and women who are pregnant will not be allowed to visit.
- Staff and visitors will be asked to stand away from your bed to reduce their exposure to the rays.

- An instrument called a Geiger counter will be used to monitor the level of radiation in the room. The nurses may wear a small counter.
- You will probably be in the single room for a short time, sometimes only one or two days. You can bring books and magazines into your room, watch TV or listen to the radio.

These safety measures and visiting restrictions can make you feel very isolated, frightened and depressed at a time when you want people around you. If you have these feelings it is important to let the staff looking after you know. People are different in the way they handle their fears; some find it easier to know everything about their treatment, while others prefer to know as little as possible. If you want any explanations, the staff on the ward will be happy to help you. It often helps to bring your fears or worries into the open by talking to the staff or to family and friends.

## Fertility and breast feeding

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It is advisable not to become pregnant, or father a child, while being treated for thyroid cancer, and for a year afterwards. If you are pregnant you cannot be given radioactive iodine treatment. For this reason, you should tell your doctor if you are, or think you might be, pregnant.

Your fertility should not be affected by radioactive iodine treatment, although there is a small risk if you need to have repeated treatments. Your doctor or nurse can give you more information and support about this.

If you are breastfeeding, you should stop a couple of days before you are treated with radioactive iodine. Although it is not safe to start breastfeeding again after your treatment, it will be safe for you to do so after future pregnancies.

## External radiotherapy for thyroid cancer

**Radiotherapy treats cancer by using high-energy rays that destroy the cancer cells, and is given in a way to cause as little harm as possible to normal cells.**

- When is it given?
- Planning your treatment
- Treatment sessions
- Side effects

### When is it given?

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This type of treatment is used less commonly than internal radiotherapy for treating thyroid cancer. It is more commonly used to treat medullary or anaplastic thyroid cancer, as they respond less well to radioactive iodine treatment. Sometimes, both radioactive iodine and external radiotherapy will be used.

External radiotherapy may be given to treat medullary and anaplastic thyroid cancer:

- after surgery to destroy any cancer cells in the neck that were not removed by the operation
- if an operation to remove the thyroid cannot be done
- if the cancer comes back after treatment.

This treatment is given in the hospital radiotherapy department. The course is usually given in daily sessions from Monday to Friday, with a rest at the weekend. The length of your treatment will depend on the type and size of the cancer. Your doctor will discuss your treatment with you in more detail beforehand.

### Planning your treatment

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To ensure that the radiotherapy is as effective as possible, it has to be carefully planned by a clinical oncologist. This is a very precise treatment and it is important that you are able to lie still, in exactly the same position, for each treatment.



To help you do this, you may need to wear a see-through Perspex or plastic device ('mould', 'mask' or 'shell') that helps to keep your head and neck as still as possible. The mould allows you to see and breathe normally, but it may make some people feel claustrophobic. You will only have the mould on for a few minutes at a time, and most people soon get used to wearing it.

Your mould will be made on one of your first visits to the radiotherapy department. The radiographer (the person who gives the treatment) will explain the whole process to you before starting.

Treatment planning is a very important part of radiotherapy and several visits may be needed. On your first visit to the radiotherapy department, you will have a CT (computerised tomography) scan taken of the area to be treated. A CT scan takes a series of x-rays which build up a three dimensional picture of the area. At the same time therapy radiographers will take measurements from you which are needed for treatment planning. This session will usually take about 45–60 minutes and you will need to wear your radiotherapy mould. Sometimes you may also need to go to the hospital's scanning department to have an MRI scan. This uses powerful magnetic fields to give a detailed picture of part of your body, which can give additional useful information.

The radiographer's measurements and the information from the scans are fed into the radiotherapy planning computer to help your doctors plan your treatment more precisely.

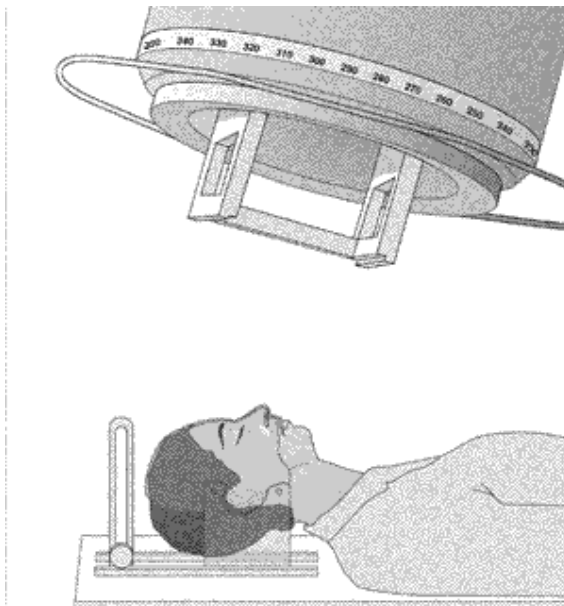
If you are not going to wear a mould for treatment, marks may be drawn on your skin to help the radiographer to position you accurately and to show where the rays are to be directed. These marks must remain visible throughout your treatment but they can be washed off once your treatment is over. Sometimes, tiny permanent marks will be made on your skin. This will only be done with your permission. At the beginning of your radiotherapy you will be given instructions on how to look after the skin in the area being treated.

## Treatment sessions

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The radiographer will position you carefully on the couch and make sure you are comfortable before each session of radiotherapy. During your treatment, which only takes a few minutes, you will be left alone in the room, but you will be able to talk via an intercom to the radiographer who will be watching you from the next room.

Radiotherapy is not painful but you do have to lie still while your treatment is being given.



## Side effects

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Radiotherapy can cause general side effects such as tiredness. Radiotherapy to the neck can also cause specific side effects such as pain on swallowing, a dry mouth and darker, or red, sore skin. These side effects vary depending on the dose of the radiotherapy and the length of your treatment. Your doctor or radiotherapist will discuss any possible side effects with you before you start your treatment.

If your throat is sore and you find it painful to eat your normal diet, you can replace meals with nutritious, high-calorie drinks, which are available from most chemists. Our booklet on diet and cancer has some helpful hints on how to eat when you are feeling ill or when you find swallowing difficult.

Your radiographer will give you advice on how to care for the skin on your neck, if it becomes sore. It is best to avoid perfumed soaps or creams on this area and to keep the skin as dry as possible during your course of treatment. Use water to wash the skin and then gently pat it dry.

Try to get as much rest as you can, especially if you have to travel a long way for treatment everyday. We have a booklet on coping with cancer-related tiredness.

The side effects should disappear gradually about two to three weeks after your treatment is over. It is important to let your doctor know if they continue for longer than this. External radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, throughout your treatment.

Your ability to become pregnant or father children is not affected by external radiotherapy treatment for thyroid cancer, but you will probably be advised to wait for at least a year. Women who become pregnant will have their hormone levels carefully monitored throughout the pregnancy.

## Chemotherapy for thyroid cancer

Chemotherapy is the use of special anti-cancer (cytotoxic) drugs to destroy cancer cells. It is rarely used to treat cancer of the thyroid but may be used if the cancer returns or has spread to other parts of the body.

We have a booklet on chemotherapy which discusses this treatment and how to cope with any side effects.

## Research - clinical trials for thyroid cancer

Cancer research trials are carried out to try to find new and better treatments for cancer. 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 therapy 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
- find out how cancer treatments work
- see which treatments are the most cost-effective.

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

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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 develop new treatments. You will also be carefully monitored during and after the study. Usually, several hospitals around the country take part in these trials. It is important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments, or to have side effects that outweigh the benefits.

### Blood and tumour samples

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Many blood samples and bone marrow or tumour biopsies may be taken to 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 take place 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.

## Current research

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If you have papillary or follicular thyroid cancer you may be asked to take part in a trial called **HiLo**. The trial is trying to find out if low-dose radioactive iodine is as effective as the standard high-dose. The trial is also looking at how the drug recombinant human thyroid stimulating hormone affects the way the radioactive iodine works. Some of those taking part in the trial will be given rhTSH and others won't. Your doctor can give you more information about this trial.

Another trial, for people with advanced thyroid cancer, is investigating a newer way of giving radiotherapy called **intensity-modulated radiotherapy**, or **IMRT**. This is a way of giving radiotherapy so that the treatment beams are shaped to the cancer and allows the dose of radiotherapy to be altered over the whole treatment area, avoiding treating healthy tissue. Higher doses of radiotherapy can be given but with potentially fewer side effects. The trial is trying to find the best and safest dose of IMRT.

## Living with thyroid cancer

### Follow-up after treatment for thyroid cancer

**Once your treatment is completed, you will have regular check-ups and tests. These will probably continue for several years. If you have any problems, or notice any new symptoms between appointments, let your doctor know as soon as possible.**

**If your treatment is over apart from regular check-ups, our booklet on life after cancer gives useful advice on how to keep healthy and adjust to life after cancer.**

- Thyroglobulin
- Recombinant human thyroid stimulating hormone (rhTSH)
- Scanning

## Thyroglobulin

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Thyroglobulin is a protein that is normally made only by the healthy thyroid gland, but it can also be produced by papillary or follicular thyroid cancer cells. Levels of thyroglobulin can be detected in the blood.

When the thyroid gland has been removed and radioactive iodine given to destroy any remaining cancer cells, thyroglobulin should no longer be produced unless there are still cancer cells left in your body. This makes the thyroglobulin blood test a useful way of detecting any remaining papillary or follicular cancer cells. The blood test is often repeated every 6–12 months.

You may also have radioactive iodine scans (the same as the thyroid radioisotope scan) from time to time, to check whether there are any thyroid cancer cells in your body.

Before a thyroglobulin blood test or a radioactive iodine scan you will need to stop taking your thyroid hormone replacement tablets. If you are taking thyroxine (T4), you will need to stop taking it 4–6 weeks before the scan. Triiodothyronine (T3) tablets will need to be stopped 2–3 weeks before. This is done so that the body will produce enough thyroid-stimulating hormone (TSH) to make the tests as accurate as possible. TSH makes any thyroid cells, or thyroid cancer cells, that may be left in your body produce thyroglobulin and absorb radioactive iodine.

Stopping the hormone replacement tablets will mean that your levels of thyroid hormones will get lower. As a result you will begin to develop the symptoms of hypothyroidism, such as depression, weight gain, forgetfulness, decreased concentration and tiredness. This may affect your ability to drive or operate machinery. You can start taking your tablets again once the tests are finished. The symptoms should begin to reduce as the level of thyroid hormones in your bloodstream increase.

## Recombinant human thyroid stimulating hormone (rhTSH)

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It may be possible to be treated with recombinant human TSH (or rhTSH) to overcome the problems of stopping your hormone replacement treatment. This man-made drug (also known as thyrotropin alfa or Thyrogen®) is similar to the TSH produced in your body. If you are given rhTSH you do not need to stop taking your thyroid hormone replacement tablets, and will not develop the symptoms of hypothyroidism.

The drug rhTSH is given as an injection, usually into the muscle in your buttock. You will be given two injections, 24 hours apart. You can be given the radioactive iodine the next day if you are having a scan. The scan will then be done 48–72 hours later. The thyroglobulin blood test is done 72 hours after your second injection of rhTSH.

There are very few side effects to rhTSH. Some people feel sick (nausea); are sick (vomit); have headaches; or feel weak. rhTSH is not suitable for everyone, and your doctor can tell you if you are able to have this treatment.

## Scanning

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Sometimes it is possible for thyroglobulin to be detected in the blood after treatment for thyroid cancer. This suggests that there may still be some cancer cells, however thyroid cells may not be found when a radioactive iodine scan is done. In this situation, a PET/CT scan may be used to help detect any cells that may be there.

A small amount of a radioactive substance is injected in the same way as a standard PET scan, and then the CT scan takes a series of x-rays. The scanner combines the information from the two scans and allows your doctor to measure any changes in the activity of cells and to know exactly where in the body the changes are.

## Work after treatment for thyroid cancer

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and your decision if and when to go back is likely to depend mainly on the type of your work and whether your income is affected. It is important to do what is right for you.

Getting back into your normal routine can be very helpful and you may want to go back to work as soon as possible. Many people find that going back to work, as soon as they feel strong enough, gives them a chance to forget some of their worries as they become involved with their job and colleagues again. It can be helpful to talk to your employer about the situation - it may be possible for you to work part-time or job share.

On the other hand it can take a long time to recover fully from treatment for cancer, and it may be many months before you feel ready to return to work. Don't feel pressurised into taking on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work. If you have a disability caused by the thyroid cancer, your employer can get specialist help to enable you to work.

## Living with and after cancer

### Emotional effects

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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

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

## How we can help

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Find out about the ways in which Macmillan can offer you information and support.

***Note: JASCAP has booklets on the above subjects.***