Understanding thyroid cancer (follicular and papillary)

About this booklet

This booklet is about the most common types of thyroid cancer – follicular thyroid cancer and papillary thyroid cancer. It is for anyone who has been diagnosed with either of these types of cancer. There is also information for carers, family members and friends.

The booklet explains how these types of cancer may be treated. It also has information about emotional, practical and financial issues.

We hope it helps you deal with some of the questions or feelings you may have.

We have more information about medullary thyroid cancer and anaplastic thyroid cancer on our website. To find out more visit:

- macmillan.org.uk/medullary
- macmillan.org.uk/anaplastic

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 116 to 128, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had thyroid cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

We have some information in different languages and formats, including audio, easy read, Braille, large print, interactive PDFs and translations. To order these, visit macmillan.org.uk/otherformats or call 0808 808 00 00.

Contents

The thyroid gland and cancer

What is cancer?

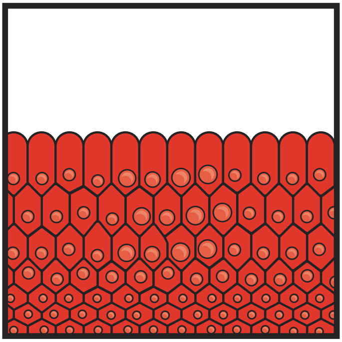
Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes are the instructions the cell needs to work properly.

The instructions send signals to cells to grow and divide and make new cells. This is how our bodies grow and heal. Over time, cells become old or damaged. When this happens, signals tell the cell to stop working and die.

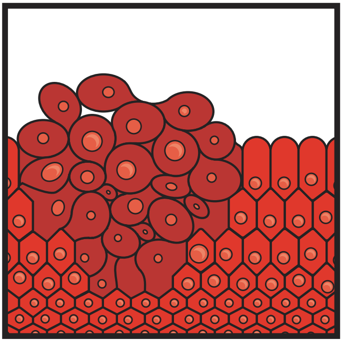
Sometimes genes in the cell can develop changes. If a gene is changed, it may not give the correct instructions anymore. A change in a gene is called a gene variant or mutation.

Gene variants in a cell may stop the cell working normally. Cancer may develop if cells like this multiply in an abnormal way and grow out of control. Over time, these cells can grow into a lump called a tumour.

Abnormal cells forming a tumour



Normal cells



Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample to look for cancer cells. This is called a biopsy.

Tumours that are not cancer are called benign. Benign tumours cannot spread anywhere else in the body. But they can cause problems if they grow and press on nearby organs.

Tumours that are cancer are called malignant. Malignant tumours can grow into nearby tissue and spread to other parts of the body. Cancer can spread from one place (the primary site) to another through the blood or lymphatic system. When cancer spreads and grows somewhere else, it is called a secondary cancer or metastasis.

Cancer can start in any type of cell. This includes tissue or skin cells and cells that form the lining of the organs. It can also start in stem cells in the bone marrow. Stem cells make blood cells.

What is the thyroid gland?

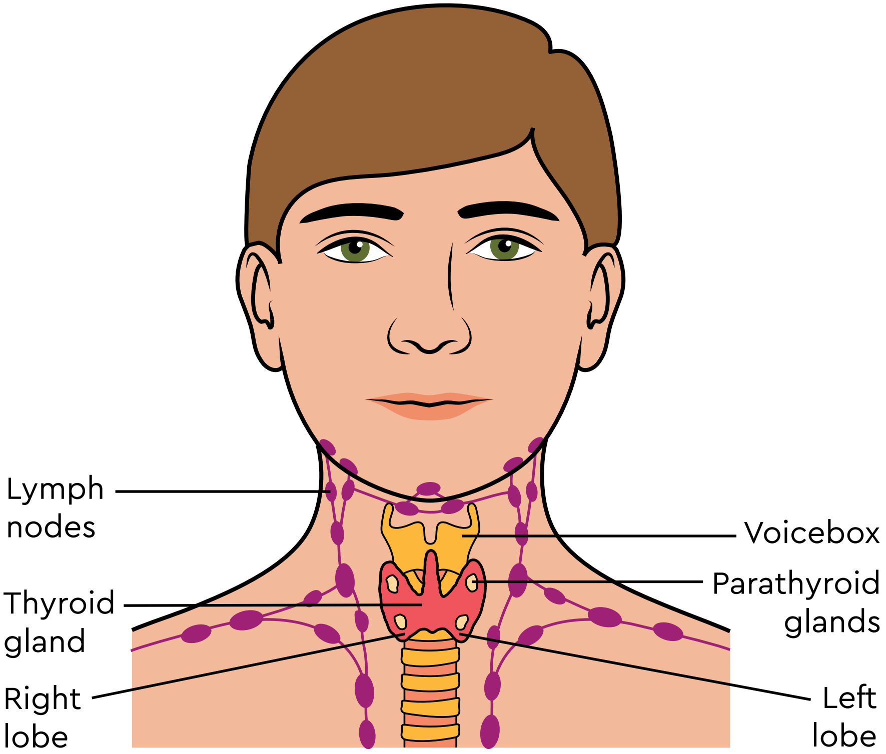
The thyroid is a small gland in the front of the neck, just below the voicebox (larynx) near the windpipe (trachea). It is made up of 2 parts called lobes. The lobes are connected by a thin bridge of thyroid tissue called the isthmus.

The thyroid gland is part of the endocrine system. This system makes hormones that help control the way your body functions. It sends these hormones into the blood so they can travel to different cells in the body and influence what these cells do.

Depending on what the body needs, the thyroid produces more hormones. For example, it produces more hormones when you are growing or during pregnancy.

The thyroid

Parathyroid glands



You have 4 small parathyroid glands are attached to your thyroid gland and situated just behind it.

The thyroid gland and the parathyroid glands have similar names, but they are different and do different things. We also have information about parathyroid cancer. It is a different type of cancer and is treated differently. Visit macmillan.org.uk/parathyroid

Iodine and the thyroid

The thyroid is made up mainly of small clusters of cells called follicles that make and store hormones.

They also absorb and use iodine. Iodine is important for making thyroid hormones. It is absorbed in our bowel from digested food and carried in the blood to the thyroid gland. Iodine is mainly found in fish, seafood and dairy products.

The thyroid gland needs a regular supply of iodine to produce thyroid hormones.

Thyroglobulin

The thyroid cells also make a protein called thyroglobulin, which stores iodine. Depending on your treatment, you might have your thyroglobulin levels measured regularly.

Thyroid hormones

Your thyroid gland makes the following hormones:

- triiodothyronine (T3)
- thyroxine (T4)
- calcitonin.

Thyroid hormones T3 and T4

The thyroid hormones T3 and T4 keep your body functioning at the right speed. This is called your metabolism. It provides the body with energy for essential things like breathing and digestion.

If these thyroid gland is not making enough hormone or too much it can cause different symptoms and the following conditions.

Hypothyroidism

If the thyroid gland does not make enough T3 and T4 hormones, your body's cells work slower than normal. This is called hypothyroidism, or an underactive thyroid. Symptoms usually include feeling tired and putting on weight more easily.

Hyperthyroidism

If the thyroid gland makes too many hormones, your body's cells work faster than normal. This is called hyperthyroidism, or an overactive thyroid. Symptoms usually include:

- weight loss
- feeling hungrier than normal
- feeling shaky and anxious.

Your heartbeat may be faster than normal or irregular. Most people with thyroid cancer have normal levels of T3 and T4.

If you have surgery to remove all of the thyroid gland, you will need to take thyroid hormone replacement tablets. This is to replace the hormones no longer being made by the thyroid.

Calcitonin

Another type of thyroid cells, called parafollicular cells, make the hormone calcitonin. Calcitonin helps to control the amount of calcium in the blood. It works with another hormone called parathyroid hormone (PTH) made in the parathyroid glands.

How thyroid hormones are released

The hypothalamus and the pituitary gland are parts of the brain. They help to control the thyroid gland. We have more information and diagrams of the brain on our website. Visit macmillan.org.uk/the-brain

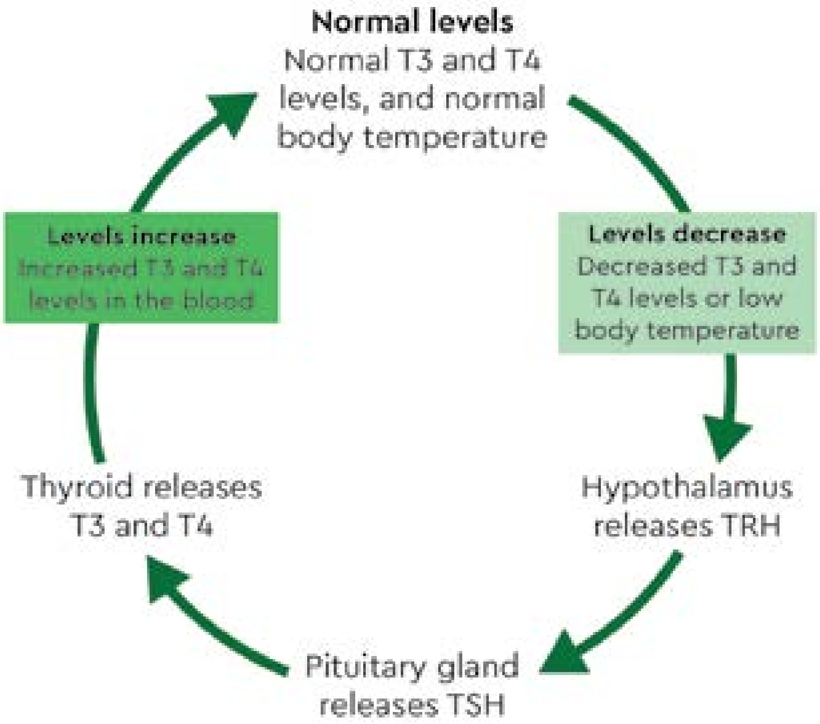
If levels of T3 and T4 are low

The hypothalamus sends thyroid-releasing hormones (TRH) into your blood. The rising level of TRH makes the pituitary gland release thyroid-stimulating hormone (TSH). TSH encourages the thyroid gland to produce more T3 and T4.

If levels of T3 and T4 are too high

The hypothalamus sends messages to lower the amount of thyroid-stimulating hormone (TSH).

Thyroid hormones



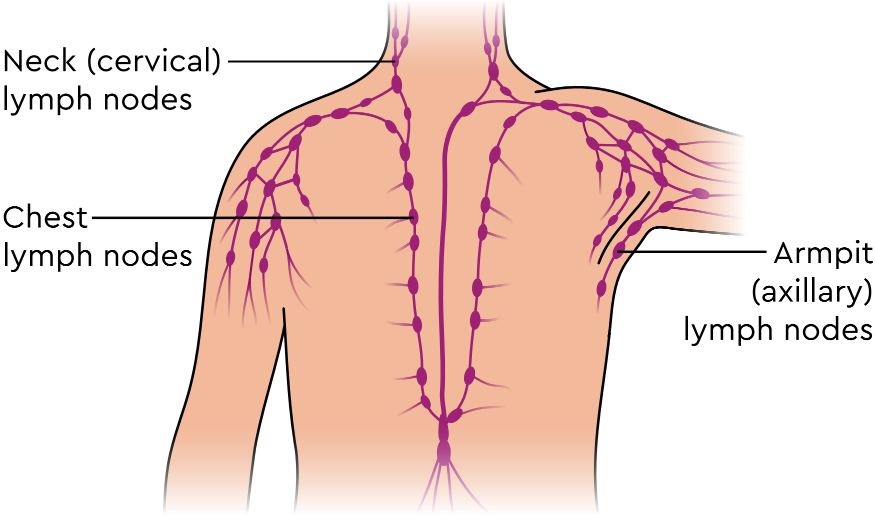
The lymphatic system

The lymphatic system helps to protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

Thyroid cancer cells can sometimes spread to the lymph nodes in the neck and chest.

Lymph nodes in the body



Types of thyroid cancer

Thyroid cancer is not common. Around 4,000 people in the UK are diagnosed with thyroid cancer each year. Thyroid cancer is much more common in younger and middle aged women and people assigned female at birth. In men it is usually diagnosed when they are older.

There are different types of thyroid cancer. This information is about papillary and follicular thyroid cancer. These types of thyroid cancer together are called differentiated thyroid cancer (DTC). Differentiated means the thyroid cancer cells look like normal thyroid cells.

About 9 in 10 thyroid cancers (90%) are DTC. They are often treated in the same way. Most people with DTC can be cured.

Papillary

This is the most common type of thyroid cancer and is more common in younger people. About 8 in 10 thyroid cancers (80%) are papillary. It starts in the follicular cells of the thyroid gland and usually grows slowly. It spreads it usually spreads to the lymph nodes (glands) in the neck.

Follicular

This is a less common type of thyroid cancer that also starts in the follicular cells of the thyroid. It is mostly found in middle aged people. About 1 in 10 thyroid cancers (10%) are follicular.

Hurthle cell

Hurthle cell thyroid cancer is similar to follicular thyroid cancer. It is treated in the same way.

Other types of thyroid cancer

There are other types of thyroid cancer.

Medullary

Medullary thyroid cancer (MTC) is a rare type of thyroid cancer. It can sometimes run in families.

We have more information about medullary thyroid cancer on our website. Visit macmillan.org.uk/medullary

Anaplastic

Anaplastic thyroid cancer is a very rare type of thyroid cancer that is fast-growing.

We have more information about anaplastic thyroid cancer on our website. Visit macmillan.org.uk/anaplastic

Thyroid lymphoma

Thyroid lymphoma starts in the lymph tissue of the thyroid. The lymph tissue is part of the body's lymphatic system. Most thyroid lymphomas are a type of non-Hodgkin lymphoma (NHL) and are treated with treatments for NHL.

We have more information about lymphoma our booklet Understanding non Hodgkin lymphoma. Or on our website, visit macmillan.org.uk/lymphoma

Thyroid sarcoma

Thyroid sarcoma is very rare. Most soft tissue sarcomas start in the arms or legs. But they can develop anywhere in the body, including the thyroid.

We have more information in our booklet Understanding soft tissue sarcoma. Or on our website, visit macmillan.org.uk/soft-tissue-sarcoma

More information

You can contact the Macmillan Support Line on 0808 808 00 00, 7 days a week, 8am to 8pm.

Planning your treatment

Finding out you have thyroid cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis may have been unexpected. Sometimes a thyroid lump shows up on a scan you may be having for another reason. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with thyroid cancer. We have more information about:

- causes and risk factors
- symptoms
- tests to diagnose thyroid cancer.

You can find this at macmillan.org.uk/papillary-follicular

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment you will have. You might choose to spend some time reading about the cancer. Or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on 0808 808 00 00. You can talk to them about what has happened and they can help answer any questions you have.

Staging

The stage of a cancer describes its size and whether it has spread from where it started. Staging is based on the results of the tests you have had. It helps doctors plan the best treatment for you.

Different types of cancer are staged differently. The stages we describe here are for papillary and follicular thyroid cancer. We also have information about staging medullary and anaplastic thyroid cancer on our website. Visit:

- macmillan.org.uk/medullary
- macmillan.org.uk/anaplastic

The most common staging system is the TNM system.

TNM staging system

T is for tumour, N is for nodes and M is for metastasis.

- T describes the size of the tumour and whether it has spread into nearby tissues around the thyroid gland.
- N describes whether the cancer has spread to the lymph nodes close to the thyroid gland.
- M describes whether the cancer has spread to other parts of the body, such as the lungs or the bones (metastatic or secondary cancer).

Tumour

Doctors put a number next to the T to describe the size and spread of the cancer.

T1

T1 means the tumour is 2cm or less and has not grown outside the thyroid gland:

- T1a means the tumour is 1cm or smaller.
- T1b means the tumour is between 1cm and 2cm.

T2

T2 means the tumour is between 2cm and 4cm. It has not grown outside the thyroid gland.

T3

T3 means the tumour is bigger than 4cm, or it has grown slightly outside the thyroid gland:

- T3a means the tumour is bigger than 4cm and has not grown outside the thyroid gland.
- T3b means the tumour is of any size and has grown slightly outside the thyroid gland into nearby muscles.

T4

T4 means the tumour has grown outside the thyroid gland and into nearby structures:

- T4a means the tumour has started to grow into nearby structures, such as the voicebox (larynx), windpipe (trachea), gullet (oesophagus) or the nerves going to the voicebox.
- T4b means the tumour has grown into the area close to the spine, or into a major blood vessel in the neck or upper chest.

Nodes

The N may have a number written next to it. This gives information about the nodes that were examined:

- N0 means the lymph nodes are not affected.
- N1 means the cancer has spread to lymph nodes close to the thyroid gland or in the neck or chest area.
- N1a means the cancer has spread to lymph nodes in the middle of the neck, close to the thyroid gland.
- N1b means the cancer has spread to lymph nodes in one or both sides of the neck, or the upper part of the chest.

Metastases

The M may have a number written next to it. This gives information about whether the cancer has spread:

- M0 means the cancer has not spread to other parts of the body.
- M1 means the cancer has spread to another part of the body.

Number staging system

Doctors often use the information from the TNM system to make an overall number stage, from 1 to 4.

Unlike most cancers, papillary and follicular thyroid cancers are also staged based on your age. This is because younger people with these types of thyroid cancer have a better outcome than older people.

Papillary or follicular thyroid cancer in people aged under 55

Stage 1

The tumour can be any size and the cancer may or may not have spread to nearby lymph nodes. It has not spread to other parts of the body.

Stage 2

The tumour can be any size and the cancer may or may not have spread to nearby lymph nodes. It has spread to other parts of the body, such as the bones or lungs.

There is no stage 3 or 4 thyroid cancer for people in this age group.

Papillary or follicular thyroid cancer in people aged 55 and over

Stage 1

The tumour is no bigger than 4cm and has not grown outside the thyroid. The cancer has not spread to the lymph nodes or to other parts of the body.

Stage 2

The tumour is 4cm or less. It may have spread to the lymph nodes in the neck or upper chest, but not to other parts of the body.

Or, the tumour is more than 4cm and has not spread outside from the thyroid gland. It may or may not have spread to nearby lymph nodes, but it has not spread to other parts of the body.

Or it may bea tumour of any size, that has spread to nearby muscles in the neck. It may or may not have spread to nearby lymph nodes, but it has not spread to the rest of the body.

Stage 3

The tumour is any size and has grown into nearby structures, such as the voicebox, windpipe or gullet. It may or may not have spread to nearby lymph nodes, but it has not spread to other parts of the body.

Stage 4A

The tumour is any size and has grown into:

- the area close to the spine
- a main blood vessel in the neck or upper chest.

It may or may not have spread to nearby lymph nodes, but it has not spread to other parts of the body.

Stage 4B

The tumour is any size and the cancer may or may not have spread to the lymph nodes. It has spread to other parts of the body, such as the lung, bones or liver.

The staging of thyroid cancer is complicated. If you would like more information, ask your doctor or specialist nurse to explain it in more detail.

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Treatment overview

The treatment you have for follicular or papillary thyroid cancer depends on:

- the stage of the cancer
- the risk of it coming back
- the results of tests on the thyroid cancer cells
- your general health and your preferences.

Your cancer team will talk to you about the aims of your treatment and tell you what your treatment options are. You can make decisions together with your team. This is called shared decision making. Most people with follicular and papillary thyroid cancers are cured with treatment.

Surgery

Surgery is usually the main treatment for thyroid cancer. Your surgeon may advise you to have:

- all the thyroid removed – this is called a total thyroidectomy part of the thyroid removed – this is called a lobectomy or partial thyroidectomy.

Sometimes the surgeon will also remove the lymph nodes and tissue around the thyroid.

If you have all your thyroid removed, you will need to take thyroid hormone replacement therapy. This is to replace the hormones that the thyroid gland normally makes. If you only have part of your thyroid removed, your hormone levels will be monitored to see if you need thyroid hormone tablets.

Thyroid hormone replacement therapy

Your doctor may advise you to take thyroxine (levothyroxine) tablets. Thyroxine is a type of thyroid hormone (T4). It is given to:

- replace the thyroid hormones you no longer make if the thyroid gland has been removed
- reduce the risk of the cancer coming back after treatment.

You will have regular tests to check your thyroid hormone levels to make sure you are getting the correct dose.

Radioactive iodine

If you have all your thyroid removed your doctor may suggest you have radioactive iodine after your surgery. You usually have it as a capsule and may need to stay in hospital for a few days. The thyroid cells, wherever they are in the body, absorb the radioactive iodine and get a very high dose of radiation. This destroys any remaining thyroid cancer cells and any normal thyroid tissue. There are certain restrictions you will need to follow while you are in hospital and for a few days after you leave. This is to avoid exposing other people to unnecessary radiation. Your radiotherapy team will explain all this to you.

External beam radiotherapy

Sometimes, external beam radiotherapy is used to treat follicular and papillary thyroid cancer. It might be given if surgery cannot remove all the cancer, the cancer has come back in that area or has spread to another part of the body, such as the bones.

Targeted therapies

Targeted therapies target something in or around the cancer cell that is helping it grow and survive. They might be used if papillary or follicular thyroid cancer:

- has spread to other parts of the body
- stopped responding to radioactive iodine treatment.
- has come back.

The 2 main targeted therapy drugs used to treat follicular or papillary thyroid cancer are:

- lenvatinib (Lenvima®)
- sorafenib (Nexavar®).

Other targeted therapy drugs may also be used to treat thyroid cancer. They only work if you have a certain gene change (mutation) in the thyroid cancer cells. If the cancer cells have a change in the RET gene your doctor might talk to you about having a drug called selpercatinib (Retsevmo®).

Chemotherapy

Chemotherapy is not usually used to treat follicular or papillary thyroid cancer. Your doctor may suggest it if your cancer comes back after other treatments.

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT looks at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- Surgeon – a doctor who does operations (surgery).
- Oncologist – a cancer doctor who specialises in radioactive iodine treatment, radiotherapy, chemotherapy and targeted therapy.
- Endocrinologist – a doctor who treats problems with the endocrine system and hormones.

- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Physicist – a radiation expert who helps plan your treatment and work out the amount of radiation you need and the best way of giving it.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

It may also include other healthcare professionals, such as a:

- speech and language therapist – someone who gives information and support to people who have problems talking and swallowing
- dietitian – someone who gives information and advice about food and food supplements
- physiotherapist – someone who gives advice about exercise and mobility
- psychologist or counsellor – someone who gives advice about managing feelings and behaviours.

Talking about your treatment plan

After the MDT meeting, you will usually meet with your cancer doctor and specialist nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your cancer doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you meet with for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit macmillan.org.uk/second-opinion


LLAN.

Treating thyroid cancer

Surgery

Surgery is usually the main treatment for follicular and papillary thyroid cancer. The type of operation you have depends on the stage of the cancer and your general health. Your surgeon and specialist nurse will explain this to you. They will tell you what to expect with the type of operation you will have.

Surgery to remove the thyroid

Your doctors will look at the results of your scans and biopsies to advise you on which operation is best for you. This might mean having either:

- all the thyroid removed – called a total thyroidectomy
- half of the thyroid removed – called a lobectomy or hemithyroidectomy.

If you were diagnosed with thyroid cancer during surgery for other thyroid problems, you may need further treatment.

Some thyroid doctors think that some very small, low risk thyroid cancers could be monitored with tests rather than removed with surgery straight away. You and your doctor can talk about the possible risks and advantages of this approach. Then you can decide if this is right for you.

Total thyroidectomy

This is when the surgeon removes the whole thyroid. If it is not possible to remove the whole thyroid, the surgeon will remove most of it. This is called a near-total thyroidectomy.

If the cancer has started to spread outside the thyroid, the surgeon may also need to remove some of the tissue around it. Your doctor will discuss this with you before the operation.

After a total thyroidectomy you will need to take thyroid hormone replacement therapy to replace the hormones your thyroid used to make.

Lobectomy (hemithyroidectomy)

You might have a lobectomy if:

- the cancer is small and has a low risk of coming back
- repeated tests on the thyroid cells do not clearly show if the cells are cancerous, but your doctor suspects cancer.

The surgeon removes the lobe of the thyroid containing cancer or where cancer is suspected. The isthmus, which is the tissue between the left and right lobe, may also be removed.

If cancer has not already been confirmed this operation can diagnose it. Doctors sometimes call this a diagnostic lobectomy. It also tells the doctor if you need more surgery to remove all the thyroid.

After a lobectomy you might not need to take thyroid hormones. The remaining thyroid may produce enough hormones.

Surgery to remove the lymph nodes

The most common place for thyroid cancer to spread is to the lymph nodes around and below or in front of the thyroid. Removing lymph nodes from the neck is called a neck dissection. If you have a small thyroid cancer you might not need to have any lymph nodes removed.

A neck dissection is done to:

- remove suspicious or cancerous lymph nodes
- reduce the risk of the cancer coming back – when the cancer has a high risk of the spreading to the lymph nodes.

Your surgeon may remove the lymph nodes from:

- the side of your neck
- the front of your neck (central neck).
- the side and the front of your neck.

Removing the lymph nodes also gives your doctor information to help them plan further treatment. Your surgeon or nurse will talk with you about the benefits and disadvantages of lymph node surgery before your operation.

Before your operation

You usually visit a pre-assessment clinic before your operation. You will have some tests to check your general health. These may include:

- blood tests
- a chest x-ray
- a recording of your heart (ECG).

You will meet with a member of the surgical team. You may also meet a specialist nurse. They will talk to you about your operation. You can ask them questions and talk about any concerns you have.

You will meet with the doctor who gives you your anaesthetic (anaesthetist) either at a clinic or when you are admitted to hospital.

If you smoke, it is important to try to stop or cut down before your operation. This will help reduce your risk of problems such as a chest infection. It will also help your wound heal after the operation. Your GP or practice nurse can give you advice. We have details of stop smoking services.

If you think you might need help when you go home after your operation, tell the nurses at the pre-assessment clinic. They can help you plan this in plenty of time.

You are usually admitted to hospital on the morning of your operation. The nurses will give you elastic stockings (TED stockings) to wear during and after the operation. These help to prevent blood clots forming in your legs.

After your operation

After your operation, the nurses on the ward will help you to lie in an upright position, supported by pillows. This helps to reduce swelling in your neck area. They will regularly check your:

- blood pressure
- pulse
- oxygen levels.

After surgery you will have a blood sample taken. This is to check your calcium levels. We have more information about blood tests to check calcitonin levels.

Sometimes surgery to the thyroid might damage the parathyroid glands. These glands help to control calcium levels. The damage might be temporary, but in some people it can be permanent. Your doctor will prescribe calcium tablets and a form of vitamin D for you to take.

Moving about

Your nurses will encourage you to start moving around as soon as possible. This is an important part of your recovery. If you need to stay in bed, they will encourage you to do regular leg movements and deep-breathing exercises. A physiotherapist or nurse will show you how to do these.

Drips

Operations to the neck area may cause swelling. This can make eating and drinking difficult and uncomfortable for a time. You will usually have a tube going into a vein in the arm. This is called an intravenous drip. The nurses give you fluids through this tube for a few days. It is removed when you can drink fluids again.

Drains

You may have 1 or 2 thin plastic drainage tubes coming from the operation area. The tubes collect fluid from the wound. Drains usually stay in place for 2 to 7 days. If you go home with a drain, the district nurse can check it. You usually come back to hospital to have it removed.

Your wound

The nurses will check your wound regularly for signs of any problems with:

- bleeding
- infection.

Bleeding inside the wound might cause a collection of blood to form. This is called a haematoma. It causes the neck to swell.

If you do not have dissolvable stitches, you usually have your stitches or staples removed about 7 days after surgery. Some wounds are sealed closed using a glue.

The nurses will give you advice on what to do when you go home and how to recognise any signs of infection. Contact the hospital straight away if there are signs of infection. These can include the following:

- If you have white skin, the skin around the wound may appear redder.
- If you have black or brown skin, the skin around the wound may appear darker than the surrounding areas.
- Any swelling or heat around the wound.
- Any discharge from the wound.
- District nurses can visit you at home and check your wound.

Pain and numbness in the area

You will probably have some pain or discomfort after your operation. Your doctor will give you painkillers to help. If you are still sore, tell your nurse so that they can change the type of painkillers you get.

The skin on your neck up to your jawline might feel numb after surgery. This is caused by the local anaesthetic used during surgery.

Neck stiffness

Your neck may feel stiff and uncomfortable after surgery. This usually gets better after a few weeks. But it may continue for longer if you had surgery to remove some lymph nodes.

If you had a neck dissection you will usually be given exercises to help strengthen your neck and shoulder muscles. You usually do these for up to 3 months after surgery. You can take painkillers 30 minutes before you start the exercises to make sure you are comfortable and do not have any pain. Your doctor may refer you to a physiotherapist if you have problems with neck stiffness.

Eating and drinking

You should be able to start drinking an hour or so after your operation. You may find it painful to swallow solid foods at first. You may need to start by eating soft foods.

Over the next 2 to 3 days, you should find it easier to swallow and can start eating solid foods. The nurses or a dietitian will discuss this with you before you go home. It is important to have a balanced diet. If you are finding it difficult to eat, nutritious drinks are a good way to supplement your diet.

Scarring

After your operation, you will have a scar on the front of your neck. The scar is usually in a natural skin fold. It is usually about 4 to 6cms. If you have white skin the scar will be red to begin with. If your skin is brown or black the scar will be darker than your usual skin tone. The colour of the scar fades as it heals so that eventually the scar should be much less noticeable.

If you have more surgery to remove lymph nodes you will still have one scar, but it will extend up the neck towards your ear.

Your nurse can show you how to gently massage your wound. This can help to help flatten the tissue. They might suggest creams or oils that might also help. We have more information on managing a scar in our booklet Body image and cancer.

> **"In the end, I had all of my thyroid and lots of lymph nodes in my neck removed. The surgery was extensive. It affected my neck and jaw . "**
>
> Matt, diagnosed with thyroid cancer

Hoarse voice

The thyroid gland is close to the nerves that control your vocal cords. Sometimes, these nerves can be bruised or damaged during surgery. This can make your voice sound hoarse and weak. Your doctor may check your vocal cords before and after your surgery.

A hoarse, weak voice is usually temporary, but may be permanent in a very small number of people. You may be referred to a speech and language therapist for specialist advice.

> **"Initially, I had a partial thyroidectomy. I then had to have a total thyroidectomy as the tumour was malignant. My vocal cords were damaged and I had just a whisper for a voice. But I had speech therapy regularly and my voice returned."**
>
> Kerry, diagnosed with thyroid cancer

Change in calcium levels

If your parathyroid glands are damaged, the level of calcium in your blood may become low. This is called hypoparathyroidism. It can cause:

- tingling in your hands or feet, or around your mouth
- unusual muscle movements, such as jerking, twitching, spasms or muscle cramps.

Your doctor or nurse will check the calcium level in your blood after your operation. If it is low, they will give you calcium either as a tablet or through a drip in your arm. They check your levels every day until they improve. You might need to take calcium tablets for a short time when you go home. After this your GP or hospital doctor will check your calcium levels regularly.

Lymphoedema

When lymph nodes are removed as part of your thyroid operation there is a risk that fluid might build up in the tissues of the neck. This is called lymphoedema.

It is common to get swelling (oedema) near the surgery scar in the first few days after the operation. This can take several weeks to go away completely. This type of swelling is not the same as lymphoedema.

Lymphoedema usually happens a few months or years later. Taking care of the skin in the area can help reduce the risk of lymphoedema.

If you are worried about any swelling, talk to your doctor or specialist nurse straight away.

We have more information in our booklet Understanding lymphoedema.

Recovering after surgery

How long you are in hospital will depend on the operation you had and your recovery. You might be ready to go home about 1 to 2 days after their operation. Recovery takes time and it is faster for some people than others. Eat healthily and try to pace yourself and do not do too much too soon. You can slowly build up your strength and fitness with light exercise, such as short walks.

Follow the advice your cancer team gives you. For example:

- Do not lift heavy items for a minimum of 4 weeks, to avoid any strain on your neck wound.
- Avoid putting your wound completely under water until at least 2 weeks after surgery, or until your surgeon says it is okay
- Do the neck exercises you have been shown and carry on with these for 3 months even if you full movement and strength back. Take painkillers about 30 minutes before you do them. You might be advised to keep on doing these exercises.
- Avoid direct sunlight to your wound and when the wound is healed always use a high sun protection factor (SPF) to protect the skin.

We have more information in our booklets Healthy eating and cancer and Physical activity and cancer.

Thyroid hormones

If you have all the thyroid removed, your body will no longer produce thyroid hormones. You will need to take tablets to replace these for the rest of your life.

If you had a lobectomy, you might still need to take thyroid hormones. Your doctor or specialist nurse will talk to you about this if you need them.

Physical activity

You can do some light physical activity, such as walking. You can gradually build up your activities and do them for longer. To protect your neck and wound you will need to avoid contact sports for a while. Your cancer team can tell you more about this.

Going back to work

Your surgeon or nurse will give you advice on this. You might be able to return to work within a few weeks of your operation, but this will depend on the type of work you do. You might need more time if your work involves:

- heavy lifting
- standing for long periods
- walking around a lot.

We have more information in our booklet Work and cancer.

Driving

Your doctor will tell you when it is safe for you to start driving after your surgery. You must be able to do an emergency stop and be able to turn your neck in all directions. Make sure you do not have any side effects from the painkillers, such as feeling drowsy. You may need to tell your insurance company that you have had thyroid surgery. Some policies give time limits for not driving after surgery.
We have more information on our website. Visit macmillan.org.uk/insurance-cancer

Thyroid cancer risk groups

Doctors look at the risk of thyroid cancer coming back (recurrence) during or after treatment ends. This is called dynamic risk stratification (DRS). It includes how the cancer responds to treatment, including radioactive iodine.

Doctors might also use a form of DRS after surgery when they know more about the cancer. Assessing the risk of the cancer coming back can help you and your doctor to make decisions about:

- how much treatment you need
- whether you need to take thyroid hormones.

Doctors decide on the risk group based on:

- the results of a neck ultrasound scan or radioactive iodine scan
- blood test for thyroglobulin 6 to 12 months after radioiodine treatment.

They group risk from 1 to 4. Group 1 is the lowest risk with group 4 having a higher risk of the cancer coming back.

Some thyroid cancers that are high risk can become low risk if they respond well to treatment with radioactive iodine.

Thyroid hormone replacement therapy

If you have all of your thyroid gland removed, you will need to take thyroid hormone replacement tablets every day for the rest of your life. This replaces the thyroxine which your thyroid gland is not making.

Thyroid hormone tablets do 2 very important things. They help to:

- keep your body functioning at the correct speed (metabolism)
- reduce the risk of thyroid cancer coming back.

If you had a low risk thyroid cancer and only had part of the thyroid removed you might not need replacement hormones.

But even if only part of the thyroid gland is removed, some people may need to take thyroid hormone replacement tablets. Sometimes you may not need to take them immediately. Instead, you will start to take them after a blood test.

Taking thyroid hormone tablets

You usually have a hormone drug called levothyroxine. It is a synthetic version of the thyroxine (T4). It replaces T4 after your thyroid is removed. Levothyroxine has different brand names. The dose you start taking depends on your weight. Your doctor might change this depending on the results of regular blood tests that measure your T4 and TSH levels.

Hormone replacement tablets help to prevent the signs and symptoms of hypothyroidism. These include:

- tiredness
- weight gain
- feeling slowed down both physically and mentally
- feeling cold
- dry skin and hair
- hair thinning
- constipation.

Finding the correct dose

You will have regular blood tests to check the levels of thyroid hormones. Your cancer team will monitor these to make sure you are having the correct dose. It might take a few months to find the right dose of thyroid hormones for you. During this time, you may have some symptoms such as tiredness.

Once the correct dose is found, you should not have any side effects from the tablets. This is because they are replacing the hormones your thyroid gland would have made naturally.

Pregnancy

If in the future you are planning on getting pregnant, talk to your thyroid doctor (endocrinologist) or your cancer doctor first.
They can explain:

- changes to your levothyroxine dose in pregnancy
- how often your thyroid hormone levels will be checked.

This helps look after your health, and the wellbeing of the baby.

How to take thyroid hormone tablets

Your doctor, nurse or pharmacist will talk to you about when to start taking your thyroid hormone replacement tablets. Always take them exactly as they explain. This helps makes sure they work as well as possible for you.

It is important to check with your pharmacist that the type of thyroid hormone tablets they give you are exactly as prescribed. This is to try and make sure you continue to take the same brand.

If you have any questions about your medication, speak to your doctor, specialist nurse or pharmacist.

Other things to remember about taking your thyroid hormone tablets:

- Take the tablets at the same time every day.
- Take them at least 30 minutes before breakfast or your first meal of the day without any other medications.

- Do not take levothyroxine together with calcium and zinc – wait for at least 4 hours before taking these supplements. This is because they might affect the way your body absorbs the thyroid hormone replacement tablets.
- Swallow the tablets with plenty of water.

Reducing the risk of thyroid cancer coming back

Thyroid hormone drugs like levothyroxine stop your body making thyroid-stimulating hormone (TSH). TSH helps the healthy thyroid to produce thyroid hormones. But if you had papillary or follicular thyroid cancer it can encourage thyroid cancer cells to grow.

After surgery you will be given levothyroxine at a slightly higher dose to keep TSH levels very low. Doing this helps to reduce the risk of the cancer coming back after surgery. This is called TSH suppression and is part of your ongoing treatment. It is most important in the first 2 years. After this time and if you are in a low risk group your cancer doctor may talk to you about allowing TSH levels to increase a little.

Radioactive iodine (RAI) treatment

Radioactive iodine (RAI) uses radiation to treat follicular and papillary thyroid cancer. The radiation comes from a radioactive substance called iodine-131. You usually take it as a capsule that you swallow.

How RAI treatment works

The radioactive iodine (RAI) circulates through your body in your bloodstream. The thyroid cells, wherever they are in the body, absorb the iodine and get a very high dose of radiation. This destroys any remaining thyroid cancer cells left in your body and any normal thyroid tissue, which is producing thyroglobulin.

RAI does not affect other tissue cells. This is because they do not absorb iodine in the same way.

You have RAI treatment in a special room at a hospital. After treatment there are certain restrictions you need to follow when you leave hospital. This is to avoid exposing other people to unnecessary radiation. Your body fluids will be slightly radioactive for a short time after the treatment.

When you have RAI treatment

You usually have RAI if you had a total thyroidectomy and there is a certain risk of thyroid cancer coming back. Not everyone needs treatment with RAI. It depends on the level of risk. Your cancer doctor or specialist nurse will talk to you about this.

You usually wait for up to 3 months after surgery to have RAI.

You usually have RAI to:

- destroy any remaining thyroid cancer cells in the body after surgery, and any normal thyroid cells
- reduce the risk of thyroid cancer coming back (recurrence)
- treat thyroid cancer that has come back after treatment.

RAI treatment can be given again if:

- tests show there are still some thyroid cells left after your first RAI treatment
- thyroid cancer has come back.

Doctors use dynamic risk stratification (DRS) to check if you need further treatment. You will not have RAI again until several months or up to one year after your first treatment. Your cancer team will tell you this at a follow-up appointment after your first treatment.

Preparing for RAI treatment

Before you have RAI treatment your doctor or nurse will talk to you about how to prepare. This usually means the following:

- You will need to eat a low iodine diet for 1 to 2 weeks.
- You will have injections into a muscle to increase the level of thyroid-stimulating hormone (TSH) in your blood. RAI needs a high level of TSH to work well. The injection is called Thyrogen® (thyrotropin alfa).
- If you cannot have the injections to increase your TSH levels, you will stop your thyroid hormones.

Iodine and low iodine diet

Usually, the thyroid gland takes iodine from our diet and uses it to make thyroid hormones. Before you have RAI, the amount of iodine in the body needs to be reduced. You do this by following a low iodine diet. This helps make sure the thyroid cancer cells take up the radioactive iodine. When there is less iodine in the body, the pituitary gland makes more thyroid-stimulating hormone (TSH). High TSH levels make the thyroid cancer cells take up the radioactive iodine.

Eating a low iodine diet

You will usually be asked to have a low iodine diet for 1 to 2 weeks before your treatment starts. Your cancer team will give you more information and tell you when to start.

If you eat a high iodine food by mistake do not worry. It is unlikely to affect your treatment. But it is important to follow the advice on diet your cancer team give you as best you can. After you have had the radioactive iodine treatment, you can go back to your normal diet.

The following tables show examples of:

- foods you can have on a low iodine diet
- foods to limit or avoid.

Low iodine foods to eat freely	
Fresh or frozen fruit and vegetables, including potatoes	Non-dairy spread such as Vitalite™, Pure™ or Flora™ non-dairy
Cooked green vegetables such as spinach and broccoli	Olive oil, vegetable oils and nut oils
Fresh or frozen meat	Water, soft or fizzy drinks, fruit juices and alcoholic drinks
Ordinary table salt and sea salt	Tea and coffee without milk
Rice and dried pasta	Dark or plain chocolate with a minimum of 70% cocoa
Fresh bread (including fresh sliced bread)	Crisps
Milk substitutes such as rice, coconut, almond or soya milk – please check labels for ingredients and avoid brands that contain carrageenan, a seaweed derivative	

Foods you should limit	
Milk – limit to a maximum of 25ml per day, which could be used in tea and coffee (about 5 to 7 teaspoons of milk per day)	Other dairy products such as yoghurt, dairy ice cream – limit to 1 portion per week
Butter – limit to a very thin layer (1 teaspoon or 5g) per day	Egg – limit to 1 per week
Cheese – 1 ounce or 25g once per week	Products containing egg such as mayonnaise, custard, fresh egg pasta, egg fried rice, pancakes, Yorkshire puddings etc.

High-iodine foods you should avoid	
Fish, seafood, seaweed, kelp, laverbread	Cakes and biscuits containing butter and eggs
Raw green vegetables such as spinach or broccoli	Milk or white chocolate
Soy products, such as soy sauce, soy milk, tofu	Takeaway meals and fast foods, or restaurant foods – this is because the ingredients are unknown
Milk alternatives such as oat and almond milk that have iodine added	Any salt with added iodine – UK table salt or sea salt are okay as they do not have added iodine
Vitamins and mineral supplements, nutritional supplements and cough mixtures – unless you have been prescribed calcium and vitamin D supplements by your medical team	

Thyroid hormones

Radioactive iodine treatment needs a high level of thyroid-stimulating hormone (TSH) to be effective. There are 2 ways to increase the TSH level in your blood. The most common way is to have injections to raise the level of TSH in your body. The other is stopping your thyroid hormones.

Injections to raise your TSH levels

You may be given recombinant human thyroid-stimulating hormone (rhTSH). This is also called thyrotropin alfa (Thyrogen®) .

The drug works like the TSH produced in your body. It allows you to keep taking your hormone-replacement tablets. This means you avoid the symptoms of thyroid hormone withdrawal.

You have an injection 2 days before your RAI treatment. Your nurse will give you the injections into the buttock (intramuscularly). You usually have them as an outpatient.

The drug has very few side effects. Possible side effects include:

- feeling sick (nausea)
- being sick (vomiting)
- muscle aches
- headaches
- tummy pain
- tiredness (fatigue).

Only a small number of people will get these side effects. They are usually mild and only last for 1 to 2 days. You can take paracetamol to help with any aches or pains.

Stopping your thyroid hormones

If you are not able to have the injections, your doctor may advise you to stop taking your thyroid hormones (T3 or T4). This is because thyroid hormone replacement stops your body from making TSH.

You usually stop taking them a few weeks before and during your treatment. This allows your body to make its own TSH. Your doctor or nurse will tell you when to stop. It is important to follow their instructions exactly or the RAI may need to be delayed or may not work as well as it should.

While you are not taking your thyroid hormones, you will have the symptoms of thyroid hormone withdrawal. These are likely to include:

- tiredness (fatigue), weakness and a lack of energy
- hair thinning
- poor concentration
- constipation
- feeling cold
- a low mood.

These symptoms should stop when you start taking the thyroid hormone tablets again, but it can take a few weeks.

Pregnancy and breastfeeding

If you are pregnant or breastfeeding, you cannot have RAI treatment. It is important to tell your doctor if you are pregnant or think you might be. If you are at an age where you can still get pregnant, you will have a pregnancy test before the treatment.

If you are breastfeeding, you must stop at least 8 weeks before having RAI. This helps to lower the amount of radiation the breasts are exposed to. It is not safe to start breastfeeding again after your treatment. But it will be safe for you to do so if you have more children in the future.

Having radioactive iodine treatment

You are usually admitted to the ward on the day of your RAI treatment. RAI is usually taken as a capsule. Before and after the treatment, you can eat normally. Your nurse will encourage you to drink plenty of fluids.

Because the iodine is radioactive, you will be radioactive for a while after the treatment. The radioactivity will slowly leave your body in your:

- urine (pee)
- stools (poo)
- blood, if you are having a period
- saliva
- sweat.

Usually, you stay in a room on your own, in the hospital. This is for 1 to 3 days after treatment. A physicist is responsible for the radioactivity dose, and they measure the radiation level regularly. This helps them decide when you can go home.

Some people might have RAI treatment and go home on the same day.

You will have to follow certain safety measures and restrictions.
These include:

- having no contact with people aged under 16
- having no contact with anyone who is pregnant or breastfeeding
- restrictions on the length of time visitors and staff can spend with you.

Each hospital has different procedures for RAI treatment. Your healthcare team will explain these before your treatment.

You may find the safety measures and restrictions difficult, especially if you have young children.

Some people feel lonely staying in a single room. Talk to your specialist nurse before treatment and tell them if you have concerns. You may be able to visit the unit to find out more about what to expect.

The nurses will encourage you to shower daily. This helps to wash off any radioactivity from your skin. You will also be encouraged to drink lots of fluids. You will need to flush the toilet 2 times after you use it.

Side effects of radioactive iodine treatment

Many people do not have any side effects after RAI treatment. Side effects are usually temporary and might include some of the following:

- Soreness or tightness around your neck or in the surgical scar.
- Feeling a bit sick (mild nausea) which usually only lasts for a couple of days.
- A dry mouth. This is not common during treatment, but it may happen after you go home. It can help to drink plenty of fluids.
- Taste changes. This may not happen during treatment, but it can happen days or weeks later. It usually gets better within a few weeks.

It is important to tell your doctor or nurse if you have any of these symptoms. They can give you medicines to help.

Rarely, a dry mouth can become a long term side effect of RAI treatment. This usually only happens if you have had more than one treatment. It happens if the salivary glands take in the radioactive iodine. Tell your doctor or specialist nurse if you get a dry mouth or if it does not improve. They can help you to manage it. We have more information about coping with a dry mouth on our website. Visit macmillan.org.uk/dry-mouth

Pregnancy and fertility

After RAI treatment, it is important to use contraception to prevent pregnancy. You should not:

- get pregnant for at least 6 months
- make someone pregnant for at least 4 months.

RAI treatment does not normally affect being able to get pregnant or make someone pregnant (fertility). If you need more than 1 RAI treatment there is a very small risk that it might affect sperm quality. You might be offered the option of storing sperm so it can be used to make someone pregnant in the future. This is called sperm banking.

The first year after you have RAI treatment you have a slightly higher risk of having a miscarriage.

Your doctor or nurse can give you more information and support about this.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm. ☎

Going home

When you go home, you will need to continue taking certain precautions for a few days. These can include:

- avoiding close contact with children, babies, and anyone who is pregnant
- limiting close and prolonged contact with people – for example you may not be able to share a bed or have sex for a few days
- avoiding long journeys on public transport, or anywhere where you could be sitting or standing next to the same person for a long time.

How long you need to take these precautions for depends on how quickly the radioactivity leaves the body. Before you go home, the radiotherapy team will measure the level of radioactivity. They will give you more detailed information about your situation. This will include written information about the treatment and safety measures you should take. You should carry this document with you for 7 days after treatment.

Travelling after radioactive iodine treatment

For up to 3 to 6 months after RAI treatment, you may set off security radiation alarms at airports. It is a good idea to take the written information from the hospital, or a letter from your doctor, explaining the treatment you have had. Keep it with your passport.

External beam radiotherapy

This type of treatment is used much less often for treating follicular and papillary thyroid cancer. It may be used if:

- it is not possible to remove all of the tumour
- the cancer has come back in the neck area
- the cancer has spread to other parts of your body, for example the bones.

External beam radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given. It does not make you radioactive. It is safe for you to be with other people, including children, throughout your treatment.

Planning your treatment

Before you start your treatment, it needs to be carefully planned. You will have a hospital appointment to plan your treatment.

Planning makes sure that the radiotherapy is aimed precisely at the cancer. This means it causes the least possible damage to the surrounding healthy tissue.

If your neck area is being treated, you will need to have a mould or mask made before your treatment is planned. This is to keep your head still while you have treatment. You will also have a CT scan to help with planning. We have more information about radiotherapy masks on our website. Visit macmillan.org.uk/radiotherapy-masks

Having external beam radiotherapy

You normally have external radiotherapy as a series of short, daily treatments in a hospital radiotherapy department. A radiotherapy machine aims high-energy rays at the area of the body being treated.

You usually have radiotherapy as an outpatient. How many treatment sessions you have depends on the aim of your treatment. You then have a rest with no treatment at the weekend.

The person who operates the machine is called a radiographer. They give you information and support during your treatment.

At the beginning of each session, the radiographers will make sure you are in the correct position and carefully fit your mask if you have one. They will tell you how long your treatment will take. When everything is ready, they leave the room and the treatment starts. The treatment itself is not painful. It does not make you radioactive. You will not be a risk to anyone during the course of your treatment.

The radiographers can see and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to during your treatment.

Side effects of external beam radiotherapy

Radiotherapy to the neck can cause side effects. This will depend on how much treatment you are having, and the area being treated.

Most side effects will usually improve about 6 weeks after radiotherapy has ended. Your cancer doctor, specialist nurse or radiographer will discuss possible side effects with you before you start your treatment.

Always tell your radiotherapy team about any side effects. There are usually things they can do to help improve them. They will give you advice on what you can do to manage side effects. For example, they can give you advice on how to:

- care for the skin in the treated area
- take care of your mouth
- check for any signs of infection, such as oral thrush.

The side effects will depend on the part of the body being treated and how much treatment you are having. If you have radiotherapy to improve symptoms the side effects are often mild. You may need only a few treatments.

We have more information about managing side effects of radiotherapy to the neck on our website and link to macmillan.org.uk/head-and-neck-side-effects

If you are having radiotherapy to the neck, side effects can include the following:

- Tiredness – this can continue for some weeks or longer after treatment finishes. Balance rest with some physical activity. Even going for short walks will help you to feel less tired.
- Discomfort or pain when swallowing.
- Skin changes in the area being treated – the skin in the treated area may become sore or itchy. If you have white skin, the skin may redden. If you have black or brown skin, the skin may become darker than the surrounding skin.
- A dry throat, and sometimes mouth – sip water regularly and avoid eating dry foods. Ask your team about artificial saliva products they can prescribe for you.
- Thick, sticky saliva – using a sodium bicarbonate mouthwash may help clear thick saliva. Ask your radiotherapy team for advice about the type of mouthwash that is best for you, and how to prepare it.
- Taste changes – this can take some weeks or longer after treatment finishes to improve. Try different foods to find out what tastes best to you.

Radiotherapy to the neck may also cause late effects. These are side effects that do not go away, or that develop months or years after treatment. Your doctor can tell you about any possible late effects and what you can do to help reduce the risk of these. We have more information in our booklet Managing the late effects of head and neck cancer treatment.

They can also give you information to help you cope with any side effects.

We have more information about radiotherapy in our booklet Understanding radiotherapy.


SIEMENS
Healthineers

Targeted therapy

Targeted therapies are drugs that target something in or around the cancer cell that is helping it grow and survive. They might be used if papillary or follicular thyroid cancer has:

- stopped responding to radioactive iodine treatment.
- spread to other parts of the body
- come back.

The 2 main targeted therapy drugs used to treat follicular or papillary thyroid cancer are:

- lenvatinib (Lenvima®)
- sorafenib (Nexavar®).

Lenvatinib and sorafenib are a type of targeted therapy drug called tyrosine kinase inhibitors (TKIs). They block (inhibit) signals in the cancer cells that make them grow and divide. They can help to shrink the cancer and to control it, sometimes for a long time.

You take lenvatinib as capsules, once a day. Sorafenib is taken as tablets 2 times a day. The side effects may include:

- a skin rash
- tiredness (fatigue)
- sore hands and feet
- feeling sick and being sick
- diarrhoea
- loss of appetite
- a sore mouth
- joint and muscle pain
- hair thinning
- high blood pressure.

We have more information about these drugs on our website. Visit macmillan.org.uk/treatments-and-drugs

Other targeted therapy drugs

There are other targeted therapy drugs that are used to treat thyroid cancer. These types of drugs only work if you have a certain gene change (mutation) in the cancer cells. For example, they may work if the cancer cells have changes in the NTRK, RET or BRAF gene. Your cancer doctor may test cancer cells taken from your biopsy or thyroid surgery to look for these gene changes. This is called molecular testing.

If the cancer cells have a change in the RET gene your doctor might talk to you about having a drug called selpercatinib (Retsevmo®). You might have selpercatinib either:

- if lenvatinib or sorafenib are not controlling the cancer
- as your first targeted therapy drug if radioactive iodine has not gotten rid of all the cancer.

You take selpercatinib as capsules, 2 times a day. The side effects may include:

- bruising or bleeding easily
- anaemia (low number of red blood cells)
- high blood pressure
- a sore or dry mouth
- a skin rash
- feeling sick
- diarrhoea or constipation
- tummy pain or indigestion
- loss of appetite.

Side effects

Your cancer doctor or specialist nurse will discuss with you if any of these drugs are suitable and available for you. They will give you more information about the drugs and the possible side effects.

They will give you advice about how these can be managed. Always tell them about any side effects you have and follow the advice they give you.

When you first start, you usually visit the hospital every 2 weeks. This is to check how you are managing the side effects. After this, the visits will be less often.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is rarely used to treat thyroid cancer. But it is sometimes used if the cancer comes back or has spread to other parts of the body and other treatments are not suitable.

We have more information about chemotherapy in our booklet Understanding chemotherapy.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.


UNDERSTANDING BREAST CANCER IN WOMEN
UNDERSTANDING BREAST CANCER IN MEN
UNDERSTANDING CANCER RESEARCH TRIALS (CLINICAL TRIALS)
Breast
Genetics
UNDERSTANDING CERVICAL CANCER
Gynaecology
Side Effects
UNDERSTANDING LYMPHOEDEMA
UNDERSTANDING RECTAL CANCER
Essential

After treatment

Your follow-up

Your follow-up care you have depends on different things, including the treatment you had.

In the first year, you usually have check-ups every few months. Eventually they are reduced to every 6 months or yearly. Some follow-up appointments might be with a specialist nurse or by phone.

At your face-to-face appointments, your doctor will examine you and you will have blood tests. They will explain if you need any other tests.

Your appointments are a good time to talk to your doctor or specialist nurse about any concerns you have.

You can ask about any symptoms you should be aware of, and what you can do to help with your recovery. If you notice any new symptoms between appointments, contact your doctor or specialist nurse for advice.

Follow-up tests

Thyroglobulin blood test

When your thyroid gland has been removed and you have had radioactive iodine, your body should no longer make thyroglobulin. There will be thyroglobulin in your blood if:

- a small amount of thyroid tissue is left
- there are still some thyroid cancer cells in your body.

The thyroglobulin blood test is a useful way to find any remaining papillary or follicular cancer cells. You will have this blood test regularly as part of your follow-up care.

Stimulated thyroglobulin test or sensitive thyroglobulin test

This test is done 9 to 12 months after your thyroid gland has been removed and you have had radioactive iodine treatment. It is used to see if you need further treatment.

Sometimes you may need to stop taking your thyroid hormone replacement some weeks before the blood test. You will not need to stop taking them if you are given recombinant human thyroid-stimulating hormone (rhTSH) before your blood test.

Your doctor or specialist nurse can give you information about this.

Ultrasound scan of the neck

You may have an ultrasound scan of your neck. This is usually done 9 to 12 months after radioactive iodine (RAI) treatment or after surgery if you have not had RAI. Your cancer team will talk to you about how often you will have scans.

Radioactive iodine (RAI) scan

If you had treatment with radioactive iodine you might have an RAI scan 6 to 12 months after treatment. This will depend on the risk of the thyroid cancer coming back. The scan checks for any remaining thyroid cancer cells in the body. Your doctors can tell you if you need his scan.

This test uses radioactive iodine, which you take as capsules you swallow or as an injection into a vein in the arm. After about 20 minutes, you lie on a couch and a machine called a gamma camera is placed over your neck. The scan is painless.

To make the scan as accurate as possible, you may be given a drug called recombinant human thyroid-stimulating hormone (rhTSH). Or you may be asked to stop taking your thyroid replacement tablets. You also need to have a low iodine diet for a few weeks before your scan.

Your doctor or nurse can give you more information about this test if you need it.

Other scans

If your thyroglobulin level is high, or if your scan shows any abnormal areas, you may have further tests. These may include:

- a CT scan
- an MRI scan
- a PET-CT scan.

Wellbeing and recovery

Most people with follicular and papillary thyroid cancer can be cured with treatment. But it can take some time after treatment before you feel fit and well again. Some people have treatment side effects that slowly improve over time, while others may have ongoing side effects. Instead of having specific treatment side effects, you may have a range of other effects, such as:

- trouble sleeping
- weight gain
- feeling weaker and more tired than usual.

It is important not to put yourself under any pressure. Recovery can take time and you need to do things at a pace that feels right for you. Taking good care of yourself and making even some small lifestyle changes can help.

Eat well and keep to a healthy weight

Having a healthy, balanced diet is one of the best choices you can make for your overall health. It can also help to keep you to a healthy weight.

It can also help reduce the risk of new cancers and other diseases, such as heart disease, diabetes and strokes.

A well-balanced diet should include:

- lots of fruit and vegetables – at least 5 portions a day
- plenty of starchy foods (carbohydrates) – choose wholegrain types such as wholemeal bread, rice, pasta, noodles, couscous and potatoes
- some protein-rich foods, such as lean meat, poultry, fish, tofu, nuts, eggs and pulses (beans and lentils)
- some milk and dairy foods, such as cheese and yoghurt.
- plenty of water, or other non-alcoholic fluids.

Try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

Before making major changes to your diet, it is a good idea to talk to your specialist nurse or a dietitian at the hospital.

If you are thinking of taking any food supplements or over the counter vitamins, it is important to talk to your cancer doctor or specialist nurse first. This is because some of these may affect your thyroid blood test results.

We have more information in our booklet Healthy eating and cancer.

Stop smoking

If you smoke, speak to your doctor or call a stop smoking helpline for further advice. They can tell you where your local stop-smoking service is.

Stopping smoking has many health benefits and reduces your risk of other diseases such as heart disease and stroke. We have more information about stop smoking services. We also have more information in our website. Visit macmillan.org.uk/stop-smoking

Get physically active

You can start gently and build up the amount of physical activity you do. There are different types of exercise you can try, such as:

- walking
- hiking
- cycling
- swimming.

We have more information in our booklet Physical activity and cancer.

Do not drink too much alcohol

NHS guidelines suggest you should:

- not regularly drink more than 14 units of alcohol in a week
- spread these units over 3 or more days in a week
- try to have several alcohol-free days every week.

Reduce stress

There are different ways to reduce stress. Different people find different things helpful, but you could try the following:

- Be more physically active.
- Make time to do things you enjoy.
- Complementary therapies, such as meditation or yoga.
- Talk to someone about your feelings or have counselling.
- Painting or drawing.
- Write a journal or online blog.

We have more information in our booklets Cancer and complementary therapies and How are you feeling? The emotional effects of cancer.

Get involved in your healthcare

Being involved in your healthcare means:

- taking any medicines as instructed
- going to your follow-up appointments
- being aware of the symptoms of the cancer coming back
- telling your doctor or specialist nurse what is important to you.

Getting help and support

It is important that you feel you have enough support. There are different people who can help you during and after your treatment, depending on your needs.

Emotional help

It is common to have different, and sometimes difficult, feelings after cancer treatment. These usually get easier to deal with as you recover and get back to your everyday life. Talking to family and friends often helps.

Talk to your doctor or specialist nurse if you think you may be depressed, or feel helpless or anxious a lot of the time. They can refer you to a psychologist or counsellor who specialises in the emotional problems people with cancer often have. Our cancer support specialists can tell you more about counselling and let you know about services in your area. Call us on 0808 808 00 00. We have more information in our booklet How are you feeling? The emotional effects of cancer.

Complementary therapies

Some people find that complementary therapies help them relax or cope with treatment or side effects. Some hospitals, hospices, GP surgeries or cancer support groups offer therapies such as:

- relaxation
- massage
- acupuncture
- aromatherapy.

Some complementary therapies are free through the NHS and some large cancer charities. Some cancer support groups offer therapies free of charge, or at a reduced cost.

Before making any decisions, make sure you have the information you need about the complementary therapy you are interested in. Talk about it with your cancer doctor or specialist nurse. We have more information in our booklet Cancer and complementary therapies.

Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through. Call us on 0808 808 00 00 or visit macmillan.org.uk/supportgroups for information about support groups.

Online support

Many people get support on the internet. There is a lot of support for people affected by cancer, including:

- online support groups
- social networking sites
- forums
- chat rooms
- blogs.

You can use these to:

- share your experience
- ask questions
- get advice
- read about other people's experiences.

Our Online Community is a social networking site where you can talk to people in our chat rooms, write blogs, make friends and join support groups. For more information, visit macmillan.org.uk/community

> **"My Macmillan nurse Celia was really positive and made me feel so much better. She answered all my questions. I talked about my dad and children, and said I didn't know how to tell my kids. She advised me on how to talk to them and gave me tools to do so."**

Kellie, diagnosed with thyroid cancer

Your feelings and relationships

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet How are you feeling? The emotional effects of cancer.

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships online and in our booklets Talking about cancer and Cancer and relationships: support for partners, families and friends.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet Talking with someone who has cancer.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet Looking after someone with cancer.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.

Work and financial support

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has expert money advisers who can talk to you about your money worries, provide information about benefits and recommend other useful organisations that can help. You can speak to them by calling the Macmillan Support Line on 0808 808 00 00. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line on 0808 808 00 00.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on travel insurance may also be helpful. Visit macmillan.org.uk/community

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, sometimes with reduced hours or other changes to their job.

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. You can also find out more about your employment rights in our booklet Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work

Further information

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit orders.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at informationproductionteam@macmillan.org.uk or call us on 0808 808 00 00.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on 0808 808 00 00. Or visit macmillan.org.uk/support-line to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at macmillan.org.uk/informationcentres or call us on 0808 808 00 00.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide information to help you manage cancer at work. Visit macmillan.org.uk/work

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Thyroid cancer support organisations

British Thyroid Foundation

Tel **0142 381 0093**
www.btf-thyroid.org
Produces a newsletter and online booklets about the thyroid gland and thyroid cancer. Also runs a network of local support groups.

Butterfly Thyroid Cancer Trust

Tel **0739 956 4463**
www.butterfly.org.uk
Offers information, support and encouragement for people with thyroid cancer. You can talk to others with thyroid cancer through their helpline, by email and telephone, or by arranging for a buddy to help you through the treatment process.

Parathyroid UK

Helpline **0134 231 6315**
www.parathyroiduk.org
Has information a self-help group for people with hypoparathyroidism – a condition that may develop as a result of thyroid surgery.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Drinkaware

www.drinkaware.co.uk
Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Northern Health and Social Care Trust

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health-related and illness-related websites.

Stop smoking services

NHS Smokefree Helpline (England)

Tel **0300 123 1044**
www.nhs.uk/better-health/quit-smoking
Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Quit Your Way (Scotland)

Tel **0800 84 84 84**
www.nhsinform.scot/quit-your-way-scotland
Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

Help Me Quit (Wales)

Tel **0808 278 6119**
Text 'HMQ' to **80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info
Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'Therapist directory' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email jo@samaritans.org
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales
www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Civil Legal Advice

Helpline **0345 345 4345**
Textphone **0345 609 6677**
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Law Centres Network

www.lawcentres.org.uk
Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland). You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NI Direct

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

NI Direct Make the Call

Make the Call helpline **0800 232 1271**
Text ADVICE to **0798 440 5248**
www.nidirect.gov.uk/make-the-call
Service to check if you or someone you care for may be entitled to extra benefits.

Northern Ireland Housing Executive

Tel **0344 892 0902**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity

Tel **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for young people

Young Lives vs Cancer

Tel **0300 330 0803**
www.younglivesvscancer.org.uk
Provides clinical, practical, financial and emotional support to children with cancer and their families in the UK.

Teenage Cancer Trust

Tel **0207 612 0370**
www.teenagecancertrust.org
A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

Youth Access

Tel **0208 772 9900**
www.youthaccess.org.uk
A UK-wide organisation providing counselling and information for young people. Find your local service by visiting youthaccess.org.uk/find-your-local-service

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for LGBTQ+ people

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage.
Also produces resources about LGBT cancer experiences.
OUTpatients runs a peer support group with Maggie's Barts.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

publichealthscotland.scot/population-health/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
qub.ac.uk/research-centres/nicr/

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Professor Nick Reed, Consultant Clinical Oncologist.

With thanks to: Lesley Dempsey, Macmillan Clinical Nurse Specialist Head and Neck; Sonja Hoy, Lead Nurse Thyroid, Head & Neck Oncology; Dr Daniel Morganstein, Consultant Endocrinologist; Amanda Naylor, Macmillan Head and Neck Advanced Nurse Practitioner; Professor Christopher Nutting, Consultant Clinical Oncologist; and Professor Jonathan Wadlsey, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact informationproductionteam@macmillan.org.uk

Sources

Below is a sample of the sources used in our thyroid cancer information. If you would like more information about the sources we use, please contact us at informationproductionteam@macmillan.org.uk

Datta, R. British Medical Journal Best Practice Guidelines, Thyroid cancer. 2023. British Medical Journal. Available from: www.bestpractice.bmj.com/topics/en-gb/263 [accessed January 2024].

European Society Medical Oncology (ESMO): Thyroid cancer, Clinical Practice Guidelines for Diagnosis, Treatment and Follow-up. 2019. Available from: www.annalsofoncology.org/article/S0923-7534(20)32555–2/fulltext [accessed January 2024].

National Institute for Health and Care Excellence (NICE). [NG230]. Thyroid cancer: assessment and management. Published: 19 December 2022. Available from: www.nice.org.uk/guidance/ [accessed January 2024].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, money advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number
☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Valid from
☐☐ ☐☐

Expiry date
☐☐ ☐☐

Issue no
☐☐☐

Security number
☐☐☐

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to macmillan.org.uk/donate

Registered with
FUNDRAISING
REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

This booklet is about the most common types of thyroid cancer – follicular thyroid cancer and papillary thyroid cancer. It is for anyone who has been diagnosed with these types of cancer. There is also information for carers, family members and friends.

The booklet explains how these types of thyroid cancer may be treated. It also has information about emotional, practical and financial issues.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call our support line.

Trusted Information Creator
Patient Information Forum