MACMILLAN
CANCER SUPPORT

Understanding thyroid cancer (follicular and papillary)

About this booklet

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

The booklet explains what thyroid cancer is and how it is diagnosed and treated. It also talks about your feelings and has practical advice on dealing with work and finances.

There are other types of thyroid cancer, including medullary and anaplastic thyroid cancer and thyroid lymphoma. If you would like more information about these, visit **macmillan.org.uk** or call us free on **0808 808 00 00**.

We hope this booklet helps you deal with some of the questions or feelings you may have. 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 on page 3 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 120, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see pages 121).

Quotes

In this booklet, we have included quotes from people who have had thyroid cancer, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes David, who is on the cover of this booklet. 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, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

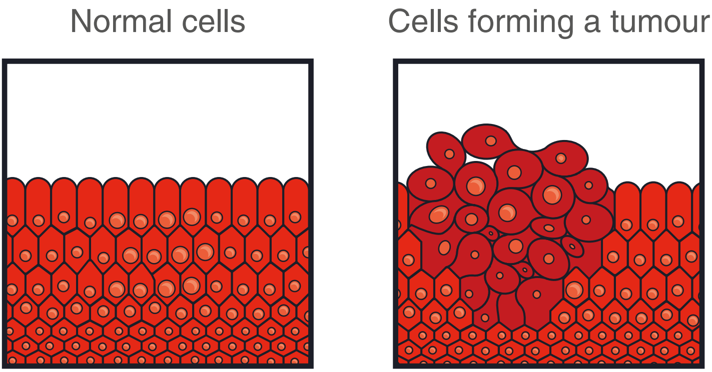
THE THYROID GLAND AND THYROID CANCER

What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

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 of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

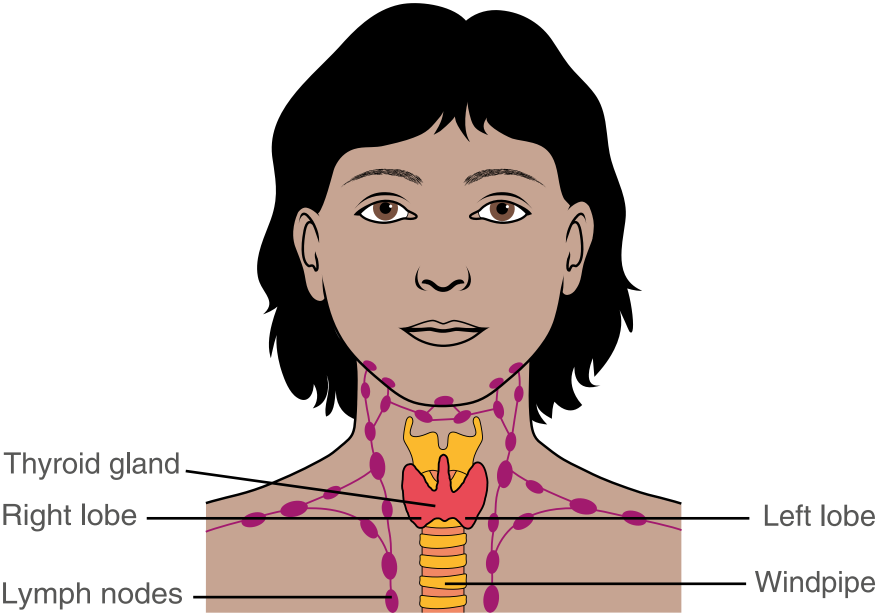
A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see pages 12 to 13). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The thyroid gland

The thyroid is a small gland in the front of your neck, just below your voicebox (larynx). 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



The thyroid gland is part of the endocrine system. This system makes hormones that help control the way your body functions. Your thyroid gland makes the following hormones:

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

T3 (triiodothyronine) and T4 (thyroxine)

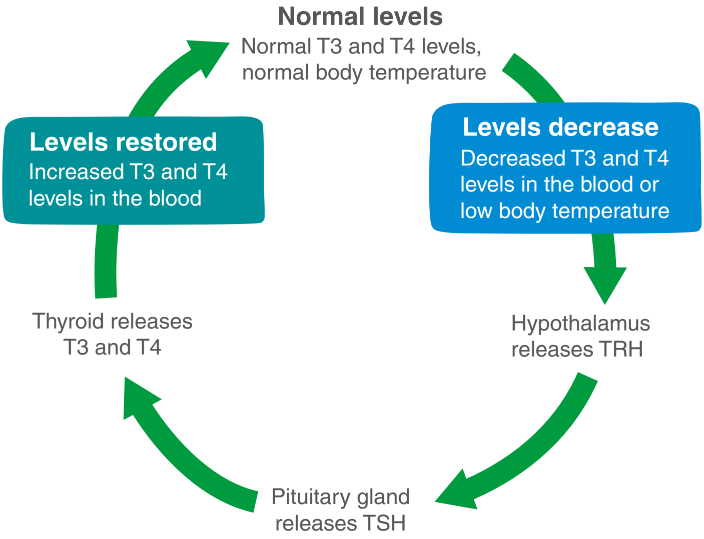
These hormones keep your body functioning at the right speed.

If your thyroid gland does not make enough hormones, your body's cells work slower than normal. You usually feel tired and put on weight more easily. This is called hypothyroidism, or an underactive thyroid.

If your thyroid gland makes too many hormones, your body's cells work faster than normal. This is called hyperthyroidism, or an overactive thyroid. You usually lose weight, feel hungrier than normal, and feel shaky and anxious. Your heartbeat may be faster than normal or irregular.

A part of your brain called the hypothalamus senses if the levels of T3 and T4 in your blood are too low. If they are, it sends thyroid-releasing hormones (TRH) into your blood. The rising level of TRH makes another gland in the brain (pituitary gland) release thyroid-stimulating hormone (TSH). TSH then stimulates the thyroid gland to produce more T3 and T4. If your brain senses that the levels of T3 and T4 are too high, it sends messages to lower the amount of TSH.

Thyroid hormones



Most people with thyroid cancer have normal levels of T3 and T4.

The thyroid gland needs a regular supply of iodine to produce thyroid hormones. We get iodine from our diet. It is mainly found in fish, seafood and dairy products. Some types of salt also contain iodine, but they are not commonly used in the UK.

Calcitonin

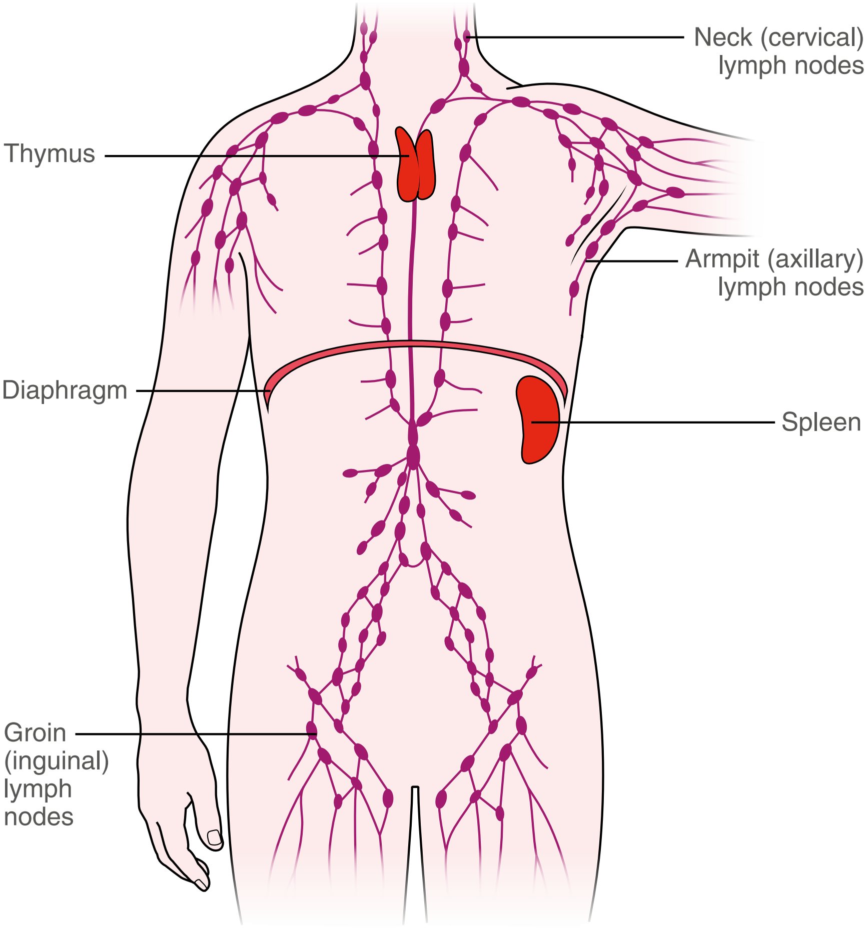
Calcitonin helps to control the amount of calcium in the blood. It works together with another hormone called parathyroid hormone (PTH), which is made in the parathyroid glands. These are 4 very small glands behind the thyroid gland. Calcium helps:

- your muscles and nerves work
- to build strong bones
- your blood to clot.

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.

The lymphatic system



Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph 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.

Thyroid cancer

Thyroid cancer is not common. Around 3,500 people in the UK are diagnosed with thyroid cancer each year. Thyroid cancer can happen at any age. It is more common in women and people assigned female at birth.

Types of thyroid cancer

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). 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. It is usually slow-growing. Papillary thyroid can affect anyone. It is more common in younger people and women.

Follicular

This is a less common type of thyroid cancer. It is mostly found in middle-aged people.

Other types of thyroid cancer

There are other types of thyroid cancer This booklet describes them below, but it does not go into more detail about these types of thyroid cancer.

Medullary

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

Anaplastic

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

Thyroid lymphoma

Thyroid lymphomas start 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 non-Hodgkin lymphoma.

More information

We have information about medullary thyroid cancer and anaplastic thyroid cancer at **macmillan.org.uk** You can also contact our cancer support line on **0808 808 00 00** (7 days a week, 8am to 8pm).

Risk factors and causes

We do not know what causes thyroid cancer in most people. But there are some things that may increase your risk of developing it. These are called risk factors. Having one or more risk factors does not mean you will get thyroid cancer. And if you do not have any risk factors, it does not mean you will not get cancer.

Benign thyroid disease

Having an overactive or underactive thyroid (hyperthyroidism or hypothyroidism) does not increase your risk of developing thyroid cancer.

But if you have certain types of non-cancerous (benign) thyroid disease, you are slightly more likely to develop thyroid cancer. These include:

- an enlarged thyroid (goitre)
- thyroid nodules (adenomas)
- inflammation of the thyroid (thyroiditis) – including Hashimoto’s thyroiditis.

Benign thyroid disease can run in families. You are more at risk of getting thyroid cancer if you have family members with benign thyroid disease. The risk is higher if more than one family member is affected.

Exposure to radiation

If you have had radiotherapy treatment (see pages 70 to 71) to the neck area, you have a higher risk of developing thyroid cancer many years later. This risk is higher if you were a child or young adult at the time.

Being exposed to high levels of radiation in the environment can also increase your risk. For example, accidental exposure after a nuclear accident like Chernobyl. This is very rare.

It is important to remember that only a small number of thyroid cancers are caused by any kind of radiation exposure.

Family history

Your risk of developing thyroid cancer is higher if you have a close family member (relative) with thyroid cancer. A close relative is:

- a parent
- a brother or sister (sibling)
- your child.

The risk is still small because thyroid cancer is rare.

Having an inherited altered gene called familial adenomatous polyposis (FAP) can also slightly increase your risk of thyroid cancer. Family members of a person with FAP can have tests to see if they have the same altered gene.

People with PTEN Hamartoma tumour syndrome have a higher risk of thyroid cancer. This is a group of rare conditions which include Cowden's syndrome.

Sex

Thyroid cancer is more common in women. There may be a link to female hormones.

Weight

Being overweight may increase the risk of getting thyroid cancer. A healthy diet and regular exercise may reduce the risk.

Symptoms of thyroid cancer

In most people, thyroid cancer develops very slowly. The most common symptom of thyroid cancer is a painless lump in the neck. The lump usually gets slowly bigger. Most thyroid lumps are not cancerous (benign) but it is important to get any lump checked.

Other symptoms include:

- a hoarse voice that has no obvious cause and does not go away after a few weeks
- difficulty swallowing – caused by a thyroid tumour pressing on the gullet (oesophagus)
- difficulty breathing – caused by a thyroid tumour pressing on the windpipe (trachea)
- pain in the front of the neck.

You should see your doctor as soon as possible if:

- you notice a lump in your neck whether it is painful or not
- you notice any of the other symptoms above.

These symptoms can be caused by conditions other than cancer.

DIAGNOSING THYROID CANCER

> ‘When I got the diagnosis, I found the Macmillan online information really helpful. I thought it was so good I attached the link to an email I sent out telling people I was undergoing cancer treatment.’
>
> **David, diagnosed with papillary thyroid cancer**

How thyroid cancer is diagnosed

You usually start by seeing your GP, who will examine you. They will refer you to a hospital for specialist advice and treatment if they:

- are unsure what the problem is
- think your symptoms could be caused by cancer.

You should be seen at the hospital within 2 weeks.

At the hospital

The doctor will ask you about your general health, family history and any previous medical problems you have had. They will also examine you. You may have some of the following tests.

Blood tests

It is not possible to diagnose thyroid cancer through blood tests. But you usually have blood tests to check your general health and your thyroid hormone levels. These levels show how well your thyroid is working.

Ultrasound scan

An ultrasound scan uses sound waves to build up a picture of the inside of the neck and the thyroid gland. Your doctor will also check the lymph nodes in your neck to see if any of them are abnormal. This is because thyroid cancer can spread to the lymph nodes.

You lie on your back for the scan. When you are lying comfortably, the person doing the scan spreads a gel over your neck. They move a small hand-held device, like a microphone, around the skin on your neck area. A picture of the inside of your neck shows up on a screen. An ultrasound scan only takes a few minutes and is painless.

The results of the ultrasound scan help the doctors to decide whether a fine needle aspiration biopsy (FNA) is needed.

Fine needle aspiration (FNA)

A doctor gently passes a small needle into the lump or swelling in your neck. Sometimes the doctor uses an ultrasound scan to help guide the needle to the right area. They take a small sample of cells and examine it under a microscope, to check for any abnormal cells.

If an FNA does not collect enough cells, it may need to be done again.

Core biopsy

Sometimes you may need to have a core biopsy. You have a local anaesthetic to numb the area. Your doctor uses a needle to take a sample of tissue. The needle is slightly bigger than the one used for the FNA. They may use an ultrasound scan to guide the needle to the right area. You may have a core biopsy if:

- the FNA does not collect enough cells
- the results from the FNA are not clear enough to make a diagnosis.

Further tests

If the tests show you have thyroid cancer, your specialist may want to do some further tests. These are to find out the size and position of the cancer, and if it has spread to other parts of the body. This is called staging (see pages 30 to 34). Knowing the stage of the cancer helps you and your doctor decide on the best treatment for you. You may have these tests after surgery.

Tests may include the following.

CT scan

A CT scan makes detailed pictures of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

The scan takes 10 to 30 minutes and is painless. You may be asked not to eat or drink for a few hours before the scan.

You may have an injection of a dye called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

If your treatment for thyroid cancer is going to include radioactive iodine (see pages 58 to 69), a CT contrast may affect when you can have this treatment. Your doctor or specialist nurse will discuss this with you.

MRI (magnetic resonance imaging) scan

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner. They may give you an injection of a dye, called a contrast. It helps show certain areas of the body more clearly.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes 15 to 90 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body. It is sometimes given together with a CT scan. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on x-rays, CT scans or MRI scans. PET scans are not suitable for everyone. Your doctor or specialist nurse can tell you whether they might be helpful for you.

PET scans are not available at all hospitals, so you may have to travel to a specialist centre to have one. If you are pregnant or breastfeeding, you should phone the scanning department before the test for advice.

About an hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in the arm. This is called a tracer. While you wait to have the scan, you will be encouraged to drink. Drinking water helps move the tracer around your body. Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The person who works the scanner is called a radiographer. The scan takes about 30 to 60 minutes. You will lie on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner. You can usually go home after the scan. The amount of radioactive substance used is very small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan.

Vocal cord check

Your doctor will usually check your vocal cords before and after surgery to remove your thyroid gland. This is because the nerves that control your vocal cords are close to the thyroid gland. These nerves can be damaged during surgery. If they are, it may cause voice changes, such as hoarseness.

The doctor may use a local anaesthetic spray to numb your nose and throat. They then pass a thin, flexible tube with a small camera at the end (nasendoscope) through your nose. They use this to look at how your vocal cords move. This may be uncomfortable, but it should not be painful. The test only takes up to a few minutes.

You may be asked to avoid eating or drinking for a few hours after the test. This is until the local anaesthetic wears off.

Staging

The stage of a cancer describes its size and whether it has spread from where it started. Staging helps doctors plan the best treatment for you.

Different types of cancer are staged differently. The stages we describe here are for thyroid cancer. The most common staging system is the TNM system.

TNM staging

- 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).

T – 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 voicebox nerve (recurrent laryngeal nerve).
- 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.

N – 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.

M – 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

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 cancer are also staged based on your age.

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 is 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 gland. 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 spread to other parts of the body.

Or, the tumour is more than 4cm and not spread out with 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 a 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 by a cancer registry (page 120).

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.

TREATING THYROID CANCER

Treatment overview

The treatment you have depends on the stage of the cancer (see pages 30 to 34) and your general health. Most people with follicular and papillary thyroid cancers are cured with treatment.

Surgery

Surgery is usually the main treatment for thyroid cancer (see pages 46 to 53). Your surgeon may advise you to have:

- all of the thyroid gland removed (total thyroidectomy)
- part of the thyroid gland removed (lobectomy or partial thyroidectomy).

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

If you have all your thyroid removed, you will need to take thyroid hormone 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 drugs

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.

Radioactive iodine

If you have all your thyroid removed (total thyroidectomy), your doctor may suggest you have radioactive iodine (see pages 58 to 69) after your surgery.

External beam radiotherapy

Sometimes, external beam radiotherapy (see pages 70 to 71) is used to treat follicular and papillary thyroid cancer. This can be given before or after radioactive iodine treatment.

Targeted therapies

Targeted therapies are newer drugs that target the differences between cancer cells and normal cells (see pages 72 to 73). They are used when thyroid cancer has spread and is no longer responding to radioactive iodine treatment.

Chemotherapy

Chemotherapy (see pages 74) is not usually used to treat follicular or papillary thyroid cancer. Your doctor may suggest it if the 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 look 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.
- Nuclear medicine specialist – a doctor who analyses tests and scans that use radioactive substances, such as a thyroid scan.
- 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
- a dietitian – someone who gives information and advice about food and food supplements
- a physiotherapist – someone who gives advice about exercise and mobility
- a psychologist or counsellor – someone who gives advice about managing feelings and behaviours.

After the team have met, your doctor will discuss your treatment options with you. You can ask questions about anything you do not understand or are worried about. You will usually also be given the number for a nurse specialist or key worker, who you can contact if you have questions when you get home. You can also talk to our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

The benefits and disadvantages of treatment

Many people are worried about having cancer treatments. This is often because of the possible side effects. But these can usually be controlled with medicines.

Treatment can be given for different reasons and the potential benefits vary depending on your individual situation. Most people with follicular or papillary thyroid cancer will be cured. Sometimes treatment is given to reduce the risk of the cancer coming back.

If you have been offered treatment that aims to cure your thyroid cancer, it may be easy to accept treatment. But it may be more difficult to decide if the treatment is aimed at controlling the cancer, or reducing the risk of it coming back.

If curing the cancer is not possible, you are usually offered treatment to help control the cancer for a period of time. You will also be given advice and medicines to help control any symptoms.

Your doctor and specialist nurse will discuss with you the benefits and disadvantages of treatment for your situation. They will tell you about any possible side effects. It is important to ask them if you have any questions about your treatment.

> ‘I was encouraged by how treatable thyroid cancer is and I was well supported by family, friends and work. But it was still hard coming to terms with “the C word”.’

Duncan, diagnosed
with thyroid cancer

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 specialist 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 specialist 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 see 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 at **macmillan.org.uk**

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 (verbal) 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.

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.

Surgery to remove the thyroid gland

How much surgery you need depends on the stage of the cancer (see pages 30 to 34). Your doctors will look at the results of scans and biopsies you have had. These results and your preferences help them decide which operation you need.

Total thyroidectomy

The surgeon removes the whole thyroid gland. It is the most common surgery for thyroid cancer.

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

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

Lobectomy

The surgeon removes the lobe of the thyroid gland (see pages 8 to 11) that contains the cancer. The isthmus (bridge of tissue between the left and right lobe) may also be removed.

Surgery to the lymph nodes

Your surgeon may remove lymph nodes in the front, or the front and side, of your neck. This is called a neck dissection. How much surgery you need depends on the stage of the cancer. It is done to:

- remove suspicious or cancerous lymph nodes
- help reduce the risk of the cancer coming back.

Removing the lymph nodes also gives your doctor information to help them plan further treatment.

Some people with a small thyroid cancer may not need to have any lymph nodes removed. Your surgeon will discuss the benefits and disadvantages of this treatment before your surgery (see page 42).

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 see a member of the surgical team. In some hospitals you may also see a specialist nurse. They will talk to you about your operation. This is a good time to ask questions and talk about any concerns you have.

You will see the doctor who gives you your anaesthetic (the 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.

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.

Between 6 and 24 hours after your operation, they will take a blood sample to check your calcium levels.

The nurses will encourage you to start moving about as soon as possible. You should have a nurse with you the first time you get out of bed, as you may feel drowsy and dizzy. 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 explain these exercises.

Drips and drains

While you are unable to drink, you may have a drip (intravenous infusion) into your arm to give you fluids. This can be removed when you are drinking enough.

You may have 1 or 2 tubes (drains) to remove fluid from your wound. These are usually taken out within 24 to 48 hours.

Your surgeon will use stitches to close your wound. Sometimes they use dissolvable stitches. If you have stitches that need to be removed, the nurses will tell you when and where this will happen.

Pain and discomfort

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.

Your neck will feel stiff after surgery. Your nurse, surgeon or physiotherapist will show you some neck exercises to help with this. The physiotherapist may give you some exercises to continue at home.

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 you 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.

Going home

Most people are ready to go home about 1 to 2 days after their operation. If you think you might have problems when you go home, tell your nurse or the social worker when you are admitted to the ward. For example, you might have problems if you live alone or you have several flights of stairs to climb. The nurse or social worker can arrange help before you leave hospital.

Some people take longer than others to recover from their operation. If you have any problems, tell your nurse, cancer doctor or GP. You can also talk to one of our cancer support specialists. They can help support you and help you contact a counsellor or local cancer support group. You can call them on **0808 808 00 00**.

Appointment

You will be given an appointment for a post-operative check-up. Most hospitals send the appointment letter to your home after you have left hospital. Some may give you the date of the appointment before you go home.

At your appointment, your doctor will talk with you about the results of your surgery and if you need any further treatment. It is also a good time to ask any questions and discuss any concerns you may have.

Driving

Your doctor will tell you when it is safe for you to start driving after your surgery. When you start driving, you should make sure that you do not have any side effects from the painkillers. You should also make sure you can turn your neck in all directions. You may need to tell your insurance company that you have had thyroid surgery. Some policies give time limits for not driving after surgery.

Getting back to work

Everyone recovers from surgery differently. Most people can return to work within a few weeks of having thyroid surgery. But you may need more time if your work involves:

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

If you are not sure, you may find it helpful to speak to an occupational health nurse or your GP. We have more information about returning to work in our booklet **Work and cancer** (see page 112).

Side effects of surgery

Thyroid hormones

If you have all of your thyroid gland removed, your body will no longer produce thyroid hormones. You will need to replace them by taking tablets for the rest of your life (see pages 55 to 57).

If you have had a lobectomy, you may also need to take thyroid hormones. Your doctor or specialist nurse can tell you if you will need to.

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.

Change in calcium levels

There is a risk that surgery to remove the thyroid gland will damage the parathyroid glands. These are 4 very small glands behind the thyroid gland. They make parathyroid hormone, which helps to control the level of calcium in your blood.

If your parathyroid glands are damaged, the level of calcium in your blood may become low (hypoparathyroidism). This 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 your calcium level is low, they will give you calcium either as a tablet or through a drip in your arm. They will check your calcium levels every day until they improve.

Your doctor will prescribe calcium, and sometimes vitamin D supplements, for you to take at home. They will arrange for you to have regular blood tests to check your calcium levels. You should take the calcium tablets at least 4 hours before or after taking thyroid hormone replacement tablets.

You often only need these supplements for a short time. Your doctor will tell you how long you need to take them for. If the calcium level in your blood continues to be low, your GP or a doctor specialising in hormones (endocrinologist) will check it regularly.

Scar

After your operation, you will have a small scar on the front of your neck. The scar is usually in one of your natural skin folds, and fades as it heals. If you have more extensive surgery to remove lymph nodes, you may have a bigger scar.

We have more information about covering scars in our booklet **Body image and cancer** (see page 112).

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 have had surgery to remove some of your lymph nodes. Your doctor will prescribe painkillers to help and may refer you to a physiotherapist.

Tiredness and mixed emotions

You usually feel tired for a few weeks after your thyroid gland has been removed. Many people also find they have a mixture of emotions after surgery. This is natural as your body adjusts to the effects of the surgery. You can contact your specialist nurse if you feel you need support. We have more information about tiredness in our booklet **Coping with fatigue (tiredness)** – see page 112.

Thyroid hormone drugs

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. You may have to take thyroid hormone replacement tablets even if you had just part of your thyroid gland removed. Thyroxine (T4) is the most common drug given.

Thyroid hormone tablets have 2 functions:

- keeping your body functioning at the correct speed
- reducing the risk of your cancer coming back.

Keeping your body functioning at the correct speed

Without hormone replacement tablets you would develop the signs and symptoms of hypothyroidism. These include:

- weight gain
- tiredness
- dry skin and hair
- hair thinning
- physical and mental slowness
- constipation
- feeling cold
- difficulty concentrating.

Reducing the risk of the cancer coming back

Thyroxine (T4) stops your body making thyroid-stimulating hormone (TSH). TSH helps the thyroid to produce thyroid hormones. But it can also encourage thyroid cancer cells to grow in people who have had papillary or follicular thyroid cancer.

If you have had your thyroid gland removed, you will be given thyroxine at a slightly higher dose. 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.

Taking your thyroid hormone tablets

Your doctor will tell you when to start taking hormone replacement tablets.

It is important to remember to take your thyroid hormone tablets every day. You should swallow your tablets with plenty of water. Take them 30 to 45 minutes before breakfast or your first meal of the day. You should take them without any other medications.

Calcium supplements may affect the way your body absorbs the thyroid hormone replacement tablets. If you take calcium supplements, you should take them at least 4 hours before or after taking your thyroid hormone tablets.

It is important to check with your pharmacist that the type of thyroid hormone tablets they have given 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, nurse specialist or pharmacist.

Your doctor or nurse will monitor your thyroid hormone levels at a specialist clinic. This helps make sure you are having the correct dose of thyroid hormone tablets. You will have regular blood tests to check the levels of thyroid hormones. It can sometimes take a few months to find the right dose of thyroid hormones for you. You may have some symptoms, such as tiredness, during this time. When the correct dose is found, you should not have any side effects from the tablets. This is because they are simply replacing the hormones that your thyroid gland would have produced naturally.

Radioactive iodine (RAI)

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

RAI may be given to:

- destroy any normal thyroid tissue still in the neck after surgery – this is called radioiodine remnant ablation (RRA)
- treat any thyroid cancer that could not be removed with surgery
- reduce the risk of thyroid cancer coming back (recurrence)
- treat thyroid cancer that has come back after treatment.

Usually, the thyroid gland takes iodine from our diet and uses it to make thyroid hormones. When you have RAI, the thyroid cells take in the iodine and get a very high dose of radiation. This destroys the thyroid cells and any cancer cells that may be left after surgery.

RAI does not affect other parts of the body in the same way. This is because other cells do not absorb iodine as much as thyroid cells.

You may be offered RAI treatment again if your tests show:

- there are still some thyroid cells after treatment
- the cancer has come back.

Preparing for radioactive iodine treatment

Before you have RAI treatment, you will usually be asked to start eating a low-iodine diet. You may be asked to stop taking your thyroid hormones.

Low-iodine diet

You will usually be asked to have a low-iodine diet for 1 to 2 weeks before your treatment starts. This is because having too much iodine in your body may make the treatment less effective. Your doctor or specialist nurse will give you more information and tell you when to start the low-iodine diet.

The following table shows which foods you can have on a low-iodine diet, and which ones you should limit or avoid.

Foods you can eat freely

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

Foods you should limit

- Milk – no more than 25ml (5 to 7 teaspoons) per day, which could be used in tea and coffee
- Butter – limit to a very thin layer (1 teaspoon or 5g) each day
- Cheese – no more than 25g (1oz) a week
- Other dairy products like dairy ice cream and yoghurt – limit to 1 portion per week
- Eggs – limit to 1 a week
- Products containing egg like mayonnaise, custard, pancakes, egg fried rice, Yorkshire puddings etc.

Foods you should avoid

- Fish, seafood, seaweed, kelp, laverbread
- Raw green vegetables like spinach or broccoli
- Cakes and biscuits containing butter and eggs
- Milk and white chocolate
- Take away-meals and fast foods or restaurant foods (as ingredients are unknown)
- Iodised salt and Pink Himalayan salt if imported or bought outside the UK
- Vitamins and mineral supplements, nutritional supplements and cough mixtures (unless prescribed by your medical team, for example vitamin D)

What if I eat something high in iodine by mistake?

Eating a high iodine food by mistake should not affect your treatment. You should keep following the low iodine dietary advice provided here.

Thyroid hormones

Radioactive iodine 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 be given a drug called Recombinant human thyroid-stimulating hormone.

Recombinant human thyroid-stimulating hormone (rhTSH, Thyrogen®)

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

The drug is 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 2 injections, 24 hours apart. You have them on the 2 days before your RAI treatment. The injections are given into the buttock (intramuscularly). You usually have the injections as an outpatient.

rhTSH is not suitable for everyone. Your doctor or specialist nurse can tell you if you can have this treatment.

rhTSH 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. Paracetamol may help with any aches or pains.

Less common way of increasing your TSH

If you are not able to have the rhTSH injection, your doctor may advise you to stop taking your thyroid hormones (T3 or T4) – see pages 9 to 10. This is because thyroid hormone replacement stops your body from making TSH. You usually stop taking them for 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 taking them. It is important to stop taking thyroid hormones when you are told to, or the RAI treatment 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 some time.

Pregnancy and breastfeeding

You cannot have RAI treatment if you are pregnant or breastfeeding. 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 usually have a pregnancy test before you have your treatment.

If you are breastfeeding, you must stop several 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. You usually have RAI 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.

Some people may have RAI treatment and go home on the same day. But most people need to stay in hospital, in a room on your own, for a few days after treatment. During this time, the level of radioactivity is checked regularly. You will have to follow certain safety measures and restrictions. These include:

- having no contact with people aged under 18 and pregnant women
- restrictions on the length of time visitors and staff can spend with you
- restrictions on what you can bring into hospital with you.

Each hospital has different routines for giving RAI treatment. The staff looking after you will explain these before your treatment. You may find these 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 treatment unit to talk through the treatment.

You will need to flush the toilet twice each time you use it. The nurses will also encourage you to shower once or twice each day. This helps to wash any radioactivity from your skin.

Side effects of radioactive iodine treatment

Many people do not have any side effects after RAI treatment. Side effects may include some of the following:

- Soreness or tightness around your neck or in the surgical scar.
- Feeling a bit sick (mild nausea). This 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 4 to 8 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 manage it.

Pregnancy and fertility

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

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

RAI treatment does not normally affect fertility. But there is a very small risk for men who need more than one treatment. In this case, you may be offered the option of storing sperm so it can be used to make someone pregnant in the future (sperm banking). Women have a slightly higher risk of a miscarriage in the first year after RAI treatment. Your doctor or nurse can give you more information and support about this.

Going home

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

- avoiding close contact with children, babies, pregnant women and pets
- 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 going to the cinema, the pub, 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 team looking after you will give you more detailed information. They will also give you some written information about the treatment and safety measures you can take. You should carry this document with you for 7 days after treatment.

Travelling after radioactive iodine treatment

For up to 3 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.

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
- if the cancer has spread to other parts of your body, for example the bones.

External beam radiotherapy 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. 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 (see page 25) to help with planning.

Having external beam radiotherapy

You normally have external radiotherapy as a series of short, daily outpatient treatments. You then have a rest with no treatment at the weekend. It is given in the radiotherapy department, using equipment like a large x-ray machine. How many treatments you have depends on the aim of your treatment. The treatment is not painful.

Before each treatment session, the radiographers explain to you what you will see and hear. They position you on the treatment couch and carefully fit your mask if you have one.

When you are in the correct position, the radiographers leave the room. They 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 can cause general side effects such as tiredness (fatigue). We have more information about this in our booklet **Coping with fatigue (tiredness)** – see page 112. If you find reading tiring, you can also listen to the booklet at **macmillan.org.uk/fatigueaudio**

Side effects of radiotherapy to the neck can include:

- discomfort or pain when swallowing
- a dry throat, and sometimes mouth
- thick, sticky saliva
- taste changes
- skin changes in the area being treated – the skin may become sore, red or darker than normal.

Your doctor, specialist nurse or radiotherapist will discuss any possible side effects with you before you start your treatment. They can also give you information to help you cope with any side effects.

Targeted therapy

Targeted therapies target something in or around the cancer cell that is helping it grow and survive. The 2 main targeted therapy drugs used to treat follicular or papillary thyroid cancer are:

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

They may be used if the cancer has come back, or has spread and is no longer responding to radioactive iodine treatment.

Sorafenib and lenvatinib are types of drugs called tyrosine kinase inhibitors (TKIs), or multi-kinase inhibitors. They work by blocking (inhibiting) signals in the cancer cells that make them grow and divide. They can help to shrink the cancer and control the growth, sometimes for a long time.

You take sorafenib as tablets you swallow twice a day. You take lenvatinib as capsules you swallow once 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.

Your doctor or specialist nurse will give you more information about the drugs and the possible side effects. 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.

Other targeted therapies

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 you had the NTRK, RET or the BRAF gene. Your cancer doctor may send some thyroid tissue from your biopsy or surgery to be checked for these changes.

Your cancer doctor will discuss with you if any of these drugs are suitable and available for you.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is rarely used to treat thyroid cancer. It is sometimes used if the cancer comes back or has spread to other parts of the body.

We have more information in our booklet **Understanding chemotherapy** (see page 112).

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

Giving blood and tumour samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

AFTER YOUR TREATMENT

Your follow-up

Your follow-up depends on the type of thyroid cancer you have, and your situation. 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 are with a nurse or by phone.

At your appointments, your doctor examines you and you 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 look out for 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 test

Thyroglobulin is a protein normally made by thyroid cells. Papillary or follicular thyroid cancer cells can also produce it. Levels of thyroglobulin can be detected in the blood.

When your thyroid gland has been removed and you have had radioactive iodine (see pages 58 to 69), 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 having radioactive iodine treatment. It is used to see if you need more radioactive iodine.

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 (see pages 65 to 66).

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

Ultrasound scan of the neck

You may have regular ultrasound scans of your neck.

Radioactive iodine scan

Some people may have a radioactive iodine scan a few months after treatment to check for any thyroid cancer cells in their body. Your doctors can tell you if you need this 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 are asked to 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 (see pages 60 to 61) 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 (computerised tomography) – see page 25
- an MRI scan (magnetic resonance imaging) – see page 26
- a PET-CT scan (positron emission tomography) – see page 27.

Having a CT scan

Well-being 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 some small changes to your lifestyle choices can help.

Eat well and keep to a healthy weight

A well-balanced diet should include:

- plenty of fresh fruit and vegetables (at least 5 portions a day)
- foods that are high in fibre, such as beans and cereals
- 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 or a dietitian at the hospital.

We have more information in our booklet **Healthy eating and cancer** (see page 112).

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.

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits. There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

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. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

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** (see page 112).

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.

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, and looking out for them
- 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.

Practical help

You may need help at home during or after treatment. A nurse or hospital social worker may be able to arrange this. If you have children, the social worker may arrange help with childcare. We have information about organising childcare at **macmillan.org.uk** that you may find helpful.

A social worker or benefits adviser can tell you about benefits you may be able to claim and possible help with other costs. Call us on **0808 808 00 00** to speak to a Macmillan welfare rights adviser. We also have more information in our booklet **Help with the cost of cancer** (see page 112).

If you need help with a wound, district nurses can visit you at home to help with this.

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**.

Complementary therapies

Some people find that complementary therapies help them relax or cope with treatment or side effects. Some hospitals or support groups offer therapies such as relaxation or aromatherapy.

We have more information in our booklet **Cancer and complementary therapies** (see page 112).

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 in the UK.

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**

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 112).

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

You may find it helps to try to keep doing your usual activities.

- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

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 might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

Our booklet **Talking with someone who has cancer** has lots more information (see page 112)**.**

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 in our booklet **Looking after someone with cancer** (see page 112).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (see page 112).

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 12 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 12 months.

Help for carers

Carer's Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit **macmillan.org.uk/grants**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00** (Monday to Friday, 8am to 6pm).

We have more information in our booklet **Travel and cancer** (see page 112). Our Online Community forum on Travel insurance may also be helpful.

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice.

Our booklet **Help with the cost of cancer** has lots more information (see page 112).


Online community
Travel insurance?

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 soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

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

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 112). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 112).

FURTHER INFORMATION

About our information

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

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
- eBooks
- 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**.

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 free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Macmillan Information and Support Centres

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

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

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 to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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**

The Macmillan healthcare team

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.

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.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to changes to your home.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants (Monday to Friday, 8am to 6pm).

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

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 **01423 810093**
Email **info@btf-thyroid.org**
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 **01207 545 469** (Mon to Fri, 10am to 4pm)
Email **enquiries@butterfly.org.uk**
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 **01342 316315**
www.parathyroiduk.org
An information website and self-help group for people with hypoparathyroidism – a condition that may develop as a result of thyroid surgery.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Maggie's

Tel **0300 123 1801**
Email **enquiries@maggies.org**
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.

Equipment and advice on living with a disability

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
Email **enquiries@disabilityrightsuk.org**
www.disabilityrightsuk.org
Provide information and support for disabled people. Sells Radar keys that allow disabled people to access the National Key Scheme's locked public toilets.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
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 their 'How to find a therapist' page.

British Infertility Counselling Association

www.bica.net
Professional infertility counselling association. Provides information and contact details for counsellors listed on their website.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 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** (Mon to Fri, 9am to 6pm)
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 10am to 6pm)
Email **info@lgbt.foundation**
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)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

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

Northern Ireland – Northern Ireland Cancer Registry (NICR)

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

Your notes and questions

Disclaimer

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.

With thanks to: Sonja Hoy, Clinical Nurse Specialist; Mr Radu Mihai, Consultant in Endocrine Surgery; Dr Laura Moss, Consultant Clinical Oncologist; and Prof Jonathan Wadsley, 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**

British Medical Journal. Best practice guidelines, thyroid cancer. 2020.
European Society Medical Oncology (ESMO): Thyroid cancer, clinical practice guidelines for diagnosis, treatment and follow-up. 2019.
National Institute for Health and Care Excellence (NICE). TA535: Lenvatinib and Sorafenib for treating differentiated thyroid cancer after radioactive iodine. 2018. www.nice.org.uk/guidance/ta535 [accessed May 2021].

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, benefits 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

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

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.

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?

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

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

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

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

MACMILLAN
CANCER SUPPORT

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

The booklet talks about the signs and symptoms of thyroid cancer. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

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**

Trusted
Information
Creator

Patient Information Forum

11th edition. **MAC11655_E11_R**. Next planned review July 2024 (content currently being reviewed). Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.