MACMILLAN
CANCER SUPPORT

UNDERSTANDING THYROID CANCER (FOLLICULAR AND PAPILLARY)

> ‘Being diagnosed was just completely out of the blue. I was young and healthy. Then you get told the news and the shock is massive.’

Dave, diagnosed with papillary thyroid cancer

About this booklet

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

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

We hope it 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.

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

We have included quotes from people who have had thyroid cancer. Some are from Dave, who is on the cover of this booklet. The rest are from **healthtalk.org** and people who have shared their experiences with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

How to use this booklet

The booklet is split into sections to help you find what you need. You don’t have to read it from start to finish. You can use the contents list on the opposite page to help you.

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

At the end of this booklet there are details of other organisations that can help (see pages 109 to 115). There is also space to write down questions and notes for your doctor or nurse (see page 116).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

Contents

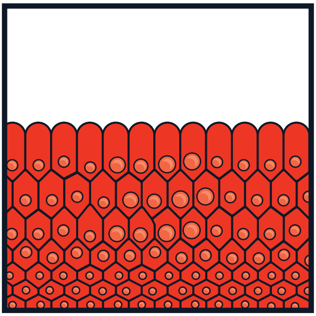
THE THYROID GLAND AND THYROID CANCER

What is cancer?

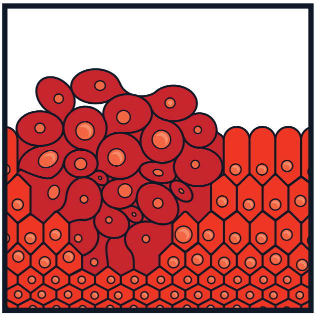
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



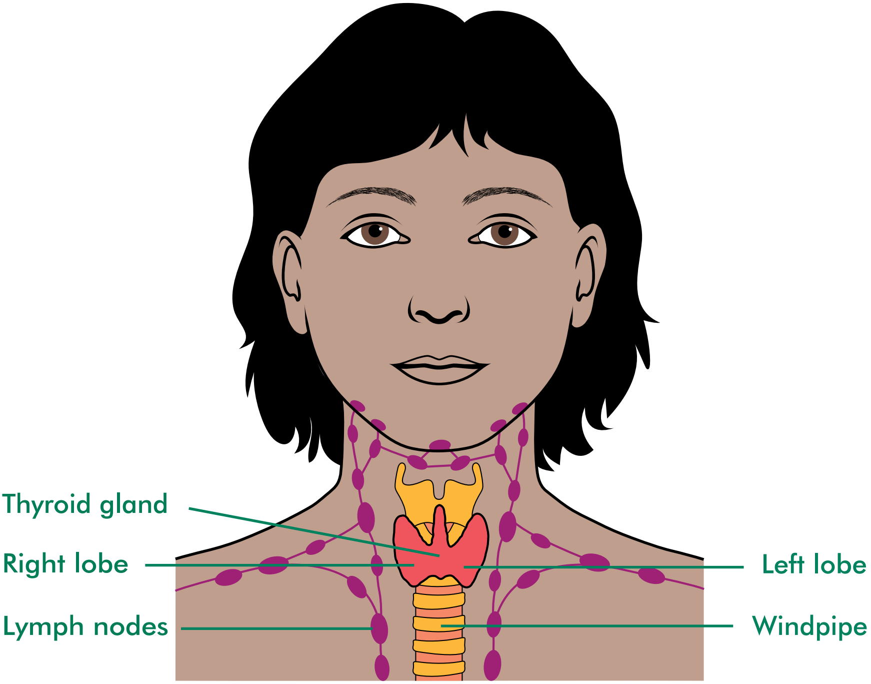
A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 12 to 13). When the cells reach another part of the body, they may begin to 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 two 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 to control and influence the way your body functions. Your thyroid gland makes the following hormones:

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

T3 and T4

These keep your body functioning at the right speed.

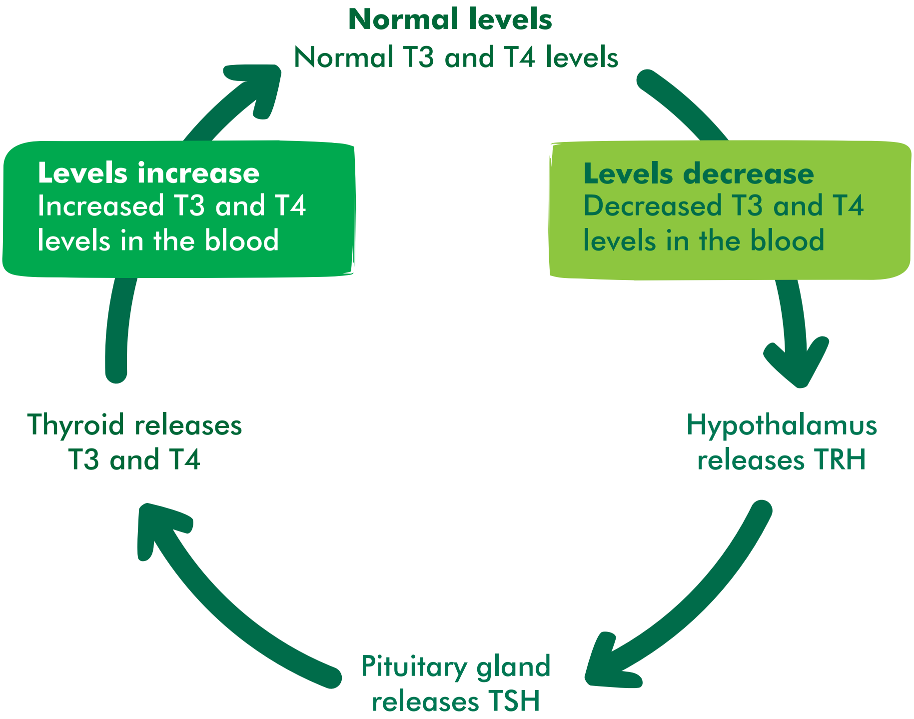
If your thyroid gland does not make enough hormones, your body's cells will work slower than normal. You will feel tired and may put on weight more easily. This is called **hypothyroidism**, **myxoedema** or an **underactive thyroid**.

If your thyroid gland makes too many hormones, your body's cells will work faster than normal. This is called **hyperthyroidism**, **thyrotoxicosis** or an **overactive thyroid**. You may 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, called the pituitary gland, release thyroid-stimulating hormone (TSH). TSH then stimulates the thyroid gland to produce more T3 and T4 (see diagram on the next page).

Most people who have a thyroid gland cancer have normal levels of T3 and T4.

Thyroid hormones



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.

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 four very small glands behind the thyroid gland. Calcium helps your muscles and nerves work, builds strong bones and helps your blood to clot.

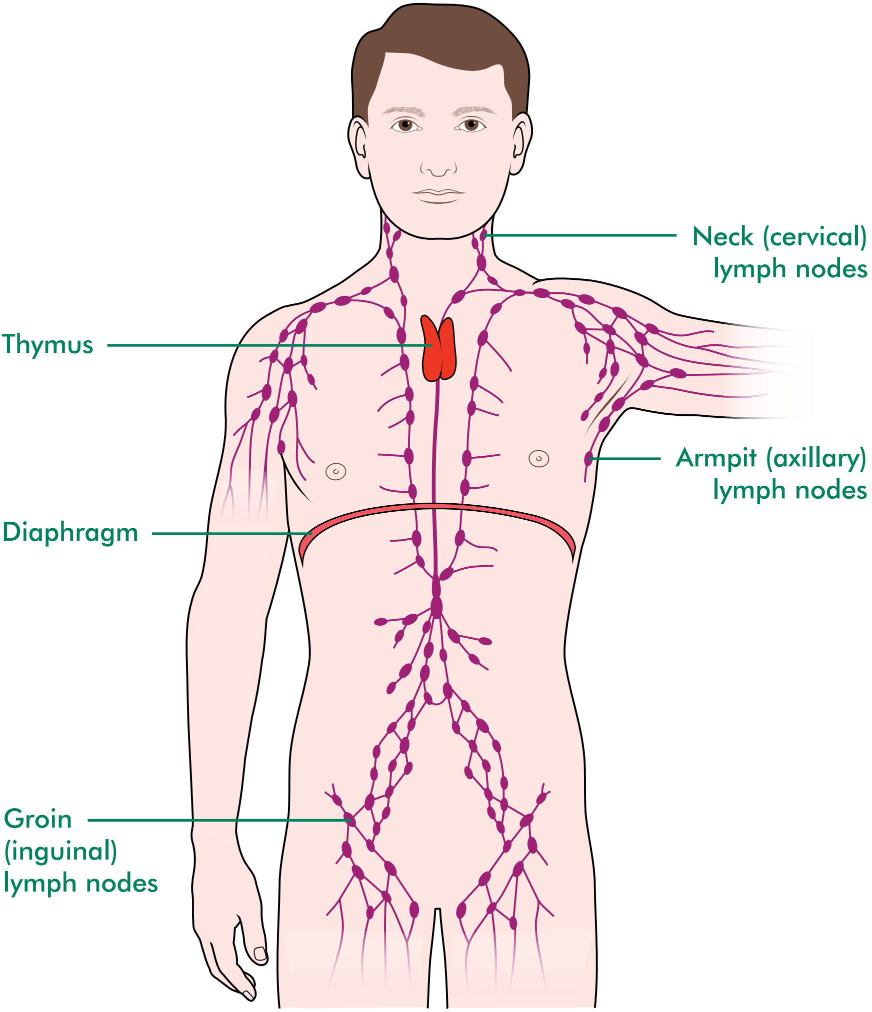
The lymphatic system

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

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight it.

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

The lymphatic system



Thyroid cancer

Thyroid cancer is not common. Each year, about 3,400 people in the UK are diagnosed with it. It is more common in women than men. Like most types of cancer, thyroid cancer is more common in people as they get older.

Types of thyroid cancer

There are different types of thyroid cancer.

Papillary

This is the most common type of thyroid cancer. It is usually slow-growing. Papillary thyroid cancer is more common in younger people and in women.

Follicular

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

This information is about papillary and follicular thyroid cancer. These two types of thyroid cancer together are sometimes 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 are cured.

Other types of thyroid cancer

Medullary

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

Anaplastic

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

Thyroid lymphoma

This type of thyroid cancer starts in the lymph tissue of the thyroid. The lymph tissue is part of the body's lymphatic system. Most thyroid lymphomas are a type of non-Hodgkin lymphoma (NHL).

If you would like information about other types of thyroid cancer, you can contact the Macmillan support line on **0808 808 00 00**.

Risk factors and causes

We don’t know yet what causes thyroid cancer in most people. But there are a number of things that may increase your risk of developing it. These are called risk factors. Having a particular risk factor doesn’t mean you will definitely get thyroid cancer. Sometimes people without any known risk factors will develop cancer.

Benign thyroid disease

Having an overactive or underactive thyroid (hyperthyroidism and 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 types of benign thyroid disease include:

- an enlarged thyroid (goitre)
- thyroid nodules (adenomas)
- inflammation of the thyroid (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 member of your family is affected.

Exposure to radiation

If you have had radiotherapy treatment to the neck area, particularly as a child or young adult, you have a higher risk of developing thyroid cancer many years later. Exposure to high levels of radiation in the environment can also increase your risk. For example, accidental exposure can happen after a nuclear accident like Chernobyl. But only a small number of thyroid cancers are caused by radiation exposure.

Family history

Your risk of developing thyroid cancer is higher if you have a close relative (parent, brother, sister or child) with thyroid cancer. Your risk is still quite small, because thyroid cancer is rare.

There is also a slightly increased risk of developing thyroid cancer if you have inherited an altered gene that causes a bowel condition called familial adenomatous polyposis (FAP). Family members of a person with FAP can have tests to see if they have the same altered gene. We can send you more information about FAP.

Being female

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

Weight

It is thought that people who are overweight may have a higher risk of getting thyroid cancer. A healthy diet and regular exercise may reduce the risk.

Symptoms

In most people, thyroid cancer develops very slowly. The most common symptom of thyroid cancer is a painless lump in the neck that gradually gets bigger. Most thyroid lumps are benign (non-cancerous).

Other symptoms include:

- a hoarse voice, for no obvious reason, that doesn't go away after a few weeks
- difficulty swallowing – a thyroid tumour pressing on the gullet (oesophagus) can cause this
- difficulty breathing – a thyroid tumour pressing on the windpipe (trachea) can cause this
- 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
- any of the other symptoms above.

These symptoms can be caused by conditions other than cancer.

DIAGNOSING THYROID CANCER

How thyroid cancer is diagnosed

If you have symptoms, you will usually start by seeing your GP, who will examine you. If they are unsure what the problem is, or think your symptoms could be caused by cancer, they will refer you to a hospital for specialist advice and treatment. You should be seen at the hospital within two 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 examine you. You may have some of the following tests.

Blood tests

It is not possible to diagnose thyroid cancer through a blood test. But you may have blood tests to check your thyroid function and general health.

Ultrasound thyroid 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 sometimes thyroid cancer can spread to the lymph nodes.

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

Fine needle aspiration (FNA)

A doctor gently passes a small needle into the lump or swelling in your neck. You may have a local anaesthetic to numb the area. Sometimes the doctor uses an ultrasound scanner to help guide the needle to the right area. Then they take a small sample of cells and examine it under a microscope to check whether there are any abnormal cells.

If an FNA does not collect enough cells, sometimes it is done again.

Core biopsy

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

- the FNA doesn't collect enough cells
- the doctor who looks at the cells from the FNA under the microscope (pathologist) is not sure whether there are cancer cells present.

If you need to have surgery to remove all or part of your thyroid gland, your doctor may suggest you have the surgery straight away rather than having a core biopsy.

> '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**

Further tests

If the tests show that 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 whether it has spread to other parts of the body. This is called staging (see pages 28 to 32) and will help you and your doctor decide on the best treatment for you. You may have these tests after surgery.

Tests may include the following:

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you've ever worked with metal or in the metal industry, as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used.

Before the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

You may be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

If you are given a drink or injection, this may affect treatment with radioactive iodine (see pages 54 to 65). Your doctor or specialist nurse will be able to discuss this with you. You will probably be able to go home as soon as the scan is over.

Having a CT scan

PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You can't eat for six hours before the scan, although you may be able to drink. A radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

Vocal cord check

Your doctor will 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 and they can be damaged during surgery.

The doctor may use a local anaesthetic spray to numb your nose and throat. Then they pass a thin, flexible tube with a small camera at the end (nasendoscope) through your nose to look at how your vocal cords move. This can be a little uncomfortable, but it should not be painful.

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

Staging

The stage of a cancer describes its size and whether it has spread beyond the area of the body where it started. Staging systems are often updated to help doctors plan the best treatment and give an idea of what is likely to happen. This means they are becoming more detailed and complicated.

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

T N M 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 stands for Tumour

Doctors put a number next to the ‘T’ to describe the size and spread of the cancer:

T1 means the tumour 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 means the tumour is between 2cm and 4cm. It has not grown outside the thyroid gland.

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

T4 means the tumour has grown outside the thyroid gland and is attached to nearby structures.

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

N stands for Nodes

The N may have a number written next to it, which 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 the side of the neck or top of the chest.

M stands for Metastasis

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

M0 The cancer has not spread to other parts of the body.

M1 The cancer has spread to another part of the body.

Number stages

Doctors often combine the information from the TNM system into an overall number stage, from 1 to 4. Unlike most cancers, papillary and follicular thyroid cancer are also staged according to the age of the person.

Papillary or follicular thyroid cancer in people aged under 45

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 45 and over

Stage 1

The tumour is no bigger than 2cm 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 between 2cm and 4cm. It has not grown outside the thyroid gland. The cancer has not spread to the lymph nodes or other parts of the body.

Stage 3

The tumour is bigger than 4cm and has not grown outside the thyroid gland. The cancer has not spread to the lymph nodes or other parts of the body.

Or the tumour is any size or has spread just outside the thyroid gland. It is not affecting nearby structures. The cancer has spread to nearby lymph nodes in the middle of the neck, close to the thyroid gland. It has not spread to lymph nodes in the side of the neck or other parts of the body.

Stage 4A

The tumour is any size and the cancer has spread into surrounding structures in the neck, such as the muscles, nerves or blood vessels. It may or may not have spread to the lymph nodes, but it has not spread to other parts of the body.

Or the tumour is any size and the cancer may have spread just outside the thyroid gland. It has spread to lymph nodes in the side of the neck away from the thyroid gland, or in the top of the chest. It has not spread to other parts of the body.

Stage 4B

The tumour is any size and the cancer has spread to other parts of the neck. It may or may not have spread to the lymph nodes, but it has not spread to other parts of the body.

Stage 4C

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 or bones.

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

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**. To find details about the cancer registry in your area, see page 115.

TREATING THYROID CANCER

Treatment overview

The treatment you have will depend on the stage of your cancer and your general health. Follicular and papillary thyroid cancers can usually be treated successfully and most people are cured.

Surgery is usually the first treatment. You may also have treatment with radioactive iodine or thyroid replacement therapy. Occasionally, you may have external beam radiotherapy, targeted therapies or chemotherapy.

Surgery

Surgery is usually the main treatment for thyroid cancer.

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.

After thyroid surgery, you may need to take thyroid hormone therapy. This is to replace the hormones that the thyroid gland normally makes.

Thyroid replacement therapy

Your doctor may advise you to take thyroxine (levothyroxine) tablets. Thyroxine is a type of thyroid hormone (T4) (see pages 9 to 10). It is given to:

- replace the thyroid hormones that you will no longer be able to make if the thyroid gland has been removed
- reduce the risk of your cancer coming back after treatment.

After surgery, until you can have radioactive iodine treatment, you may be given the thyroid hormone liothyronine (T3).

Some people are given a combination of T3 and T4.

Radioactive iodine

Your doctor may suggest you have radioactive iodine after your surgery.

External beam radiotherapy

Occasionally, external beam radiotherapy is used to treat follicular and papillary thyroid cancer.

Targeted therapies

Targeted therapies are newer drugs that target the differences between cancer cells and normal cells. Your doctor may suggest them if your cancer comes back after other treatments.

Chemotherapy

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

How treatment is planned

In most hospitals, a team of specialists will meet to discuss and decide which treatment will be best for you.

This multidisciplinary team (MDT) will include:

- a surgeon who specialises in thyroid cancers
- an oncologist – a cancer doctor who specialises in radioactive iodine treatment, radiotherapy, chemotherapy and targeted therapy
- an endocrinologist – a doctor who specialises in glands and hormones
- a nurse specialist – sometimes referred to as your key worker
- a radiologist – a doctor who advises on x-rays and scans
- a nuclear medicine specialist – who analyses tests and scans that use radioactive substances, such as a thyroid scan
- a pathologist – who advises on the type and extent of the cancer.

It may also include other healthcare professionals, such as a speech and language therapist, a dietitian, a physiotherapist, and a psychologist or counsellor.

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. They should also give you a telephone number for your 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**. Our service has a thyroid cancer information nurse who you can arrange to speak with.

The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly 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 will vary depending on your individual situation.

Most people with follicular or papillary thyroid cancer will be cured. But a cure is not always possible and treatment may be given to control the cancer for a period of time. 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 decide to accept treatment. But it may be more difficult to decide whether to have it if the treatment is aimed at controlling the cancer or reducing the risk of it coming back.

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

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Giving your consent

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

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion.

You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns 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 will depend on the size of the cancer and your general health.

Surgery to remove the thyroid gland

Total thyroidectomy

In this operation, 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

In this operation, the surgeon removes the lobe of the thyroid gland that contains the cancer. The isthmus may also be removed.

Sometimes, if the FNA result (see page 23) is not clear, a lobectomy is used to diagnose thyroid cancer. Your doctor or specialist nurse will discuss this with you. If a cancer is found, your doctor may then suggest you have another operation to remove the remaining lobe of the thyroid gland.

Surgery to the lymph nodes

Your surgeon may remove the lymph nodes in the front, or the front and side, of your neck. This is called a **neck dissection**. It is done to:

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

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

Before your operation

You are likely to visit a pre-assessment clinic before your operation. At the clinic, 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 and, in some hospitals, a specialist nurse. They will talk to you about your operation. This is a good chance 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.

Before and after surgery, a doctor will check your vocal cords. This is because the nerves that control your vocal cords are close to the thyroid gland. The doctor may use a local anaesthetic spray to numb your nose and throat. Then they will pass a thin, flexible tube with a small camera at the end (nasendoscope) through your nose to look at how your vocal cords move. This can be a little uncomfortable, but it should not be painful.

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

If you smoke, it is important to try to give up 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 can give you advice.

If you think you might need help when you go home after your operation, let the nurses know at the pre-assessment clinic. They can then help you make arrangements in plenty of time.

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

> ‘The surgical team all talked to me before my operation and I felt very reassured.’
>
> **Jo**

After your operation

After your operation, the nurses on the ward will help you to lie in a fairly upright position, supported by pillows. This helps to reduce swelling in your neck area. They will take your blood pressure and pulse, and check your oxygen levels at regular intervals.

Between 6 and 24 hours after your operation, they will take a sample of your blood to check the 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 have 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) going into your arm to give you fluids. This can be removed as soon as you are drinking enough.

You may have one or two tubes (drains) to drain fluid from your wound. These are usually removed within 24 to 48 hours.

Your surgeon may use stitches or clips to close your wound. Sometimes they use dissolvable stitches. If you have stitches or clips 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, and your doctor will prescribe painkillers for you. If you find they are not helping, let your nurse know as soon as possible so that they can change your painkillers.

The skin on your neck up to your jaw line 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.

> ‘Everyone takes different amounts of time to heal and recover. I didn’t have much pain at all, but if you do, just ask for painkillers.’
>
> **Heather**

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, and may need to start off 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 keep having 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 3 days after their operation. If you think you might have problems when you go home, let your nurse or the social worker know 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, you may find it helpful to talk to someone who is not directly involved with your illness. Our cancer support specialists can talk to you, and tell you how to contact a counsellor or local cancer support group. You can call them on **0808 808 00 00**.

Appointment

Before you leave hospital, you will be given an appointment for a post-operative check-up. Some hospitals will post this appointment to you after you have left hospital. At this appointment, your doctor will discuss with you the results of your surgery and whether 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 of painkillers. You should also make sure you can turn your neck in all directions. You may need to let your insurance company know you have had thyroid surgery, as some policies give time limits for not driving after surgery.

Getting back to work

Everyone recovers from surgery at their own pace. Most people can return to work within a few weeks of having thyroid surgery. But if your work involves heavy lifting, standing for long periods or walking around a lot, you may need more time before you can return to work. If you are not sure, you may find it helpful to speak to an occupational health nurse or your GP.

Our booklet **Work and cancer** has more information about getting back to work. You can order a free copy by calling **0808 808 00 00** or by visiting **macmillan.org.uk**

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 page 51).

If you have had a lobectomy, you may also need to take thyroid hormones, but this is unlikely. Your doctor or specialist nurse can tell you whether you will need to.

Hoarse voice

The thyroid gland is close to the nerves that control your vocal cords. Occasionally, 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 a temporary problem, 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 small risk that surgery to remove the thyroid gland will damage the parathyroid glands. These are four 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 possibly 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 four hours before or after taking thyroid hormone replacement tablets.

You will 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, one of your doctors will monitor it regularly. This will often be an endocrinologist or your GP.

Scar

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

Our booklet **Body image and cancer** has more information about covering scars. You can order a free copy by calling **0808 808 00 00** or by visiting **be.macmillan.org.uk**

> ‘The scar on my neck was pretty big and visible at first, but now it isn’t too bad.’
>
> **Dave**

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 more extensive 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

It is normal to feel tired for a few weeks after your thyroid gland has been removed. Many people also find that they experience a mixture of emotions after surgery. This is natural as your body adjusts to the effects of the surgery.

Thyroid replacement therapy

If you have had 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. The usual long-term thyroid hormone drug is thyroxine (T4).

If you are likely to need radioactive iodine treatment (see pages 54 to 65), you may be given the hormone tablet liothyronine sodium (T3, Triiodothyronine or Tertroxin®).

Thyroid hormone tablets have two functions:

Keeping your body functioning at the correct speed

Without hormone 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.

Reducing the risk of your cancer coming back

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

So, if you have had your thyroid gland removed, you will have thyroxine at a slightly higher dose than normal, to reduce the risk of the cancer coming back after surgery. This is called TSH suppression and will be part of your ongoing cancer care 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 four hours before or after taking your thyroid hormone tablets.

It's important to check with your pharmacist that the type of thyroid hormone tablets they have given you are exactly as prescribed. If you have any questions about your medication you should speak to your doctor, nurse specialist or pharmacist.

You will be carefully monitored in a specialist clinic to 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 in your blood. It can sometimes take many months to find the right dose of thyroid hormones for you. You may have a variety of symptoms, such as tiredness, during this time. Once the correct dose is found, you shouldn't have any side effects from the tablets as they are simply replacing the hormones that your thyroid gland would have produced naturally.

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells while doing as little harm as possible to normal cells. It works by destroying cancer cells in the area that is being treated.

There are two ways of giving radiotherapy to treat thyroid cancer:

- radioactive iodine
- external beam radiotherapy.

Radioactive iodine

Radioactive iodine is a type of radioisotope treatment that targets thyroid cells. Radioisotopes are radioactive substances given by mouth as a drink or capsules, or injected into a vein.

Radioactive iodine is usually given:

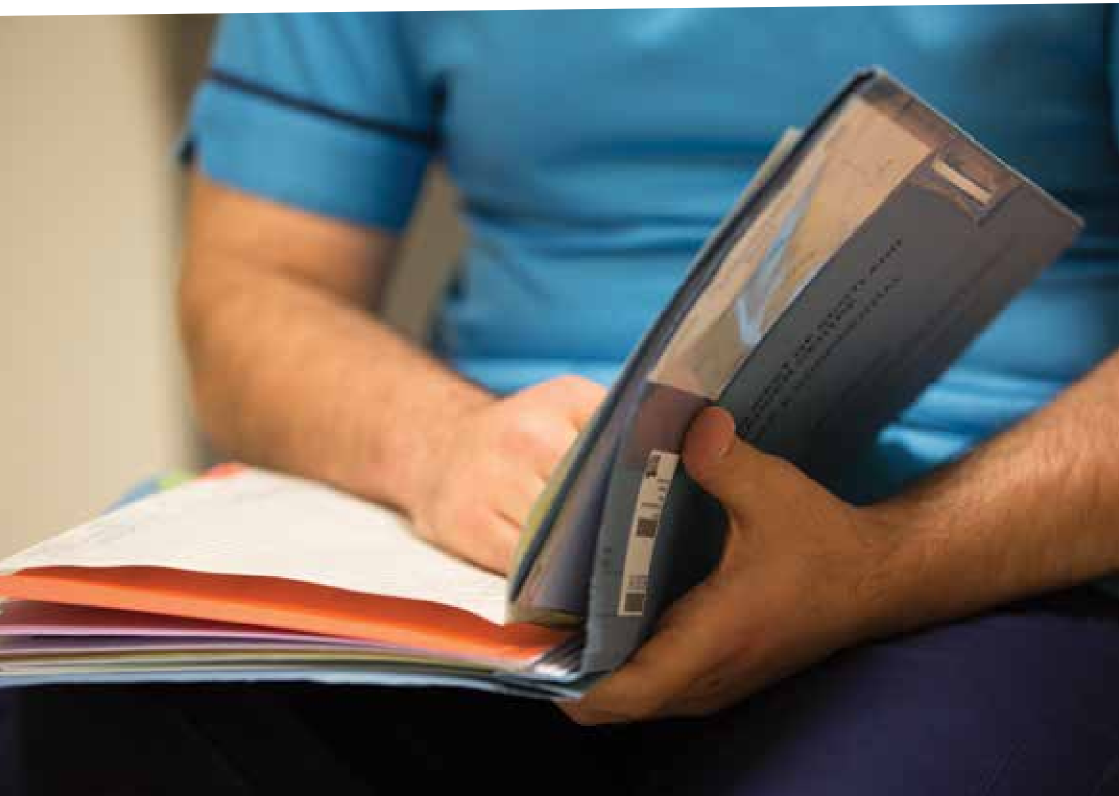
- to destroy any thyroid tissue that is still in the neck after surgery – this is called radioiodine remnant ablation (RRA)
- to treat any thyroid cancer that could not be removed with surgery
- to treat thyroid cancer that has come back after initial treatment.

The radioactive substance used for treatment is called iodine-131. You usually have it as a capsule, or occasionally as a drink.

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

Radioactive iodine has very little effect on other parts of the body. This is because other cells do not absorb iodine as much as thyroid cells.

If your tests show there are still some thyroid cells after treatment, or if the cancer comes back, you can have radioactive iodine treatment again.



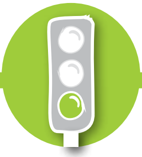
Preparing for radioactive iodine treatment

Before you have radioactive iodine 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 tables show you 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.
- Cooked green vegetables.
- Fresh or frozen meat.
- Normal table salt and sea salt.
- Tea and coffee without milk.
- Rice, dried pasta and potatoes.
- Fresh bread.
- Non-dairy spreads.
- Olive oil, vegetable oils and nut oils.
- Water, soft drinks, fruit juices and alcoholic drinks.
- Milk substitutes, such as rice, coconut, almond or soya milk (avoid brands that contain carrageenan).
- Dark chocolate (min. 70% cocoa).

Foods you should limit

- Milk – no more than 25ml (5 to 7 teaspoons) each day, which could be used in tea and coffee.
- Cheese – no more than 25g (1oz) a week.
- Eggs – no more than one a week.
- Butter – no more than a very thin scraping each day.

Foods you should avoid

- Fish, seafood, seaweed, kelp, laverbread.
- Dairy products such as milk, butter, margarine, cheese, yoghurt and ice-cream.
- Eggs and foods that contain egg yolk – for example custard, mayonnaise, fresh egg pasta, egg fried rice.
- Milky coffee and tea, hot chocolate and malted milk drinks.
- Cakes and biscuits made with butter and eggs.
- Milk chocolate and white chocolate.
- Any foods where you’re not sure of all the ingredients, such as takeaways or meals in restaurants.
- Iodised salt and Pink Himalayan salt if bought outside the UK.
- Vitamin and mineral supplements, nutritional supplements and cough mixtures (unless prescribed by your doctor).

Thyroid hormones

Radioactive iodine needs a high level of thyroid-stimulating hormone (TSH) to be effective.

Thyroid hormone replacement stops you making TSH. So you may need to stop taking your thyroid hormones (T3 or T4) for a few weeks before and during your treatment. Your doctor or nurse will tell you when to stop taking them.

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

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

These symptoms should go away once you start taking the thyroid hormone tablets again, but it can take some time.

It is important to stop taking thyroid hormones when you are told to, or the radioactive iodine treatment may not be as effective.

Recombinant human thyroid-stimulating hormone (rhTSH)

Instead of having to stop your thyroid hormones, you may be given recombinant human thyroid-stimulating hormone (rhTSH). This is also known as thyrotropin alfa (Thyrogen®).

rhTSH is a drug that is similar to the TSH produced in your body. It allows you to carry on taking your hormone-replacement tablets, so you avoid the symptoms of thyroid hormone withdrawal. You have two injections 24 hours apart, on the two days before your radioactive iodine treatment. You have the injections 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 and tummy pain
- fatigue.

These side effects are usually mild and only last for 24 to 48 hours.

Pregnancy and breastfeeding

You cannot have radioactive iodine 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 breastfeeding, you must stop several weeks before you have your radioactive iodine treatment. This helps to reduce 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 your radioactive iodine treatment

You will usually be admitted to the ward on the day of your radioactive iodine treatment. You will usually have the radioactive iodine as a capsule. After this, your doctor or nurse will ask you to have a hot drink, so the iodine can be absorbed. Before and after the treatment, you can eat normally and you will be encouraged to drink plenty of fluids.

Because the iodine is radioactive, you will become radioactive for a while after the treatment. The radioactivity gradually leaves your body in your:

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

This means you will need to stay in hospital in a single room for a few days after your treatment. During this time, the level of radioactivity will be measured regularly with a monitor (Geiger counter). You will have to follow certain safety measures and restrictions. These include:

- 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 radioactive iodine treatment. The staff looking after you will explain the restrictions in detail before you have 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 let them know if you have any 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. You will also be encouraged to have 1 or 2 showers each day to wash any radioactivity from your skin.

> ‘In the end I watched a lot of box sets and did a lot of crochet, and the time goes by quicker than you’d think.’
>
> **Laura**

Side effects of radioactive iodine treatment

Many people do not have any side effects after radioactive iodine treatment. You may have the following side effects:

- 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 once 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 let your doctor or nurse know if you have any of these symptoms, as they can prescribe medicines to help.

Rarely, a dry mouth can become a long-term side effect of radioactive iodine treatment. This usually only happens if you have had more than one treatment. It happens if the salivary glands absorb the radioactive iodine. Let your doctor or specialist nurse know if you get a dry mouth or if it does not improve. They will be able to help you manage it.

> ‘My employers were great and let me phase myself back into work after my surgery. Then I needed to have the radioactive iodine treatment, which wasn’t too bad at all.’
>
> **Dave**

Pregnancy and fertility

After radioactive iodine treatment, you should not:

- become pregnant for at least six months
- father a child for at least four months.

It is important to use contraception during this time.

Radioactive iodine treatment does not normally affect fertility. But there is a very small risk for men who need to have more than one treatment. In this case, you may be offered sperm banking. Women have a slightly higher risk of a miscarriage in the first year after radioactive iodine 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.

The length of time you need to take these precautions for will depend on how quickly your body clears the radioactivity. Before you go home, the doctor who worked out how much radioactive iodine you needed (medical physicist) will give you more detailed information. They will also give you some written information about the treatment and precautions to take. You should carry this document with you for seven days after treatment.

Travelling after radioactive iodine treatment

For up to six months after radioactive iodine 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 your tumour
- if your cancer has spread to other parts of your body, for example the bones.

External radiotherapy does not make you radioactive. It is perfectly 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 your cancer so that 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 your treatment. You will also have a CT scan to help with planning.

Having external beam radiotherapy

Having external beam radiotherapy

You will normally have external radiotherapy as a series of short, daily outpatient treatments with a rest at the weekend. It is given in the radiotherapy department using equipment similar to a large x-ray machine. How many treatments you have will depend on the aim of your treatment.

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

Once you are in the correct position, the radiographers will leave the room. There will be a camera or window so they can see you. Many treatment rooms have an intercom, so the radiographers can talk to you while you are having treatment. You will also be able to speak to them if you need to.

Side effects of external beam radiotherapy

Radiotherapy can cause general side effects such as tiredness (fatigue).

Specific 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 interfere with the way that cancer cells grow. They are sometimes called biological therapies.

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

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

They can both be used if the cancer has come back or spread (advanced or metastatic cancer) 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. Kinases are proteins that regulate the way cells grow and divide. The drugs work by blocking (inhibiting) signals in the cancer cells that make them grow and divide. Blocking the signals makes the cells die. The drugs can also stop the cancer cells developing new blood vessels. This reduces their supply of oxygen and nutrients, so the tumour shrinks or stops growing.

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

The side effects are generally mild and include:

- a skin rash
- tiredness
- sore hands and feet
- feeling sick and being sick
- loss of appetite
- a sore mouth
- joint and muscle pain
- hair thinning.

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

Sorafenib and lenvatinib may not be widely available on the NHS. If a drug is not available on the NHS, there may be different ways you are still able to have it. Your doctor can give you advice. They may be able to apply for funding to get it. Call us on **0808 808 00 00** for more information on what you can do if a treatment is not available.

Other targeted therapies

Clinical trials are being carried out to see if other targeted therapies may be useful for treating follicular or papillary thyroid cancer. This includes the drugs:

- axitinib (Inlyta®)
- cabozantinib (Cometriq®, Cabometyx®)
- nintedanib (Vargatef®)
- pazopanib (Votrient®)
- sunitinib (Sutent®)
- vandetinib (Caprelsa®).

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It is rarely used to treat cancer of the thyroid. But you may have chemotherapy if the cancer comes back or, in some cases, if it has spread to other parts of the body.

Our booklet **Understanding chemotherapy** discusses this treatment and its side effects in more detail. You can order a copy by calling **0808 808 00 00** or by visiting **be.macmillan.org.uk**

Having chemotherapy

Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

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

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

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

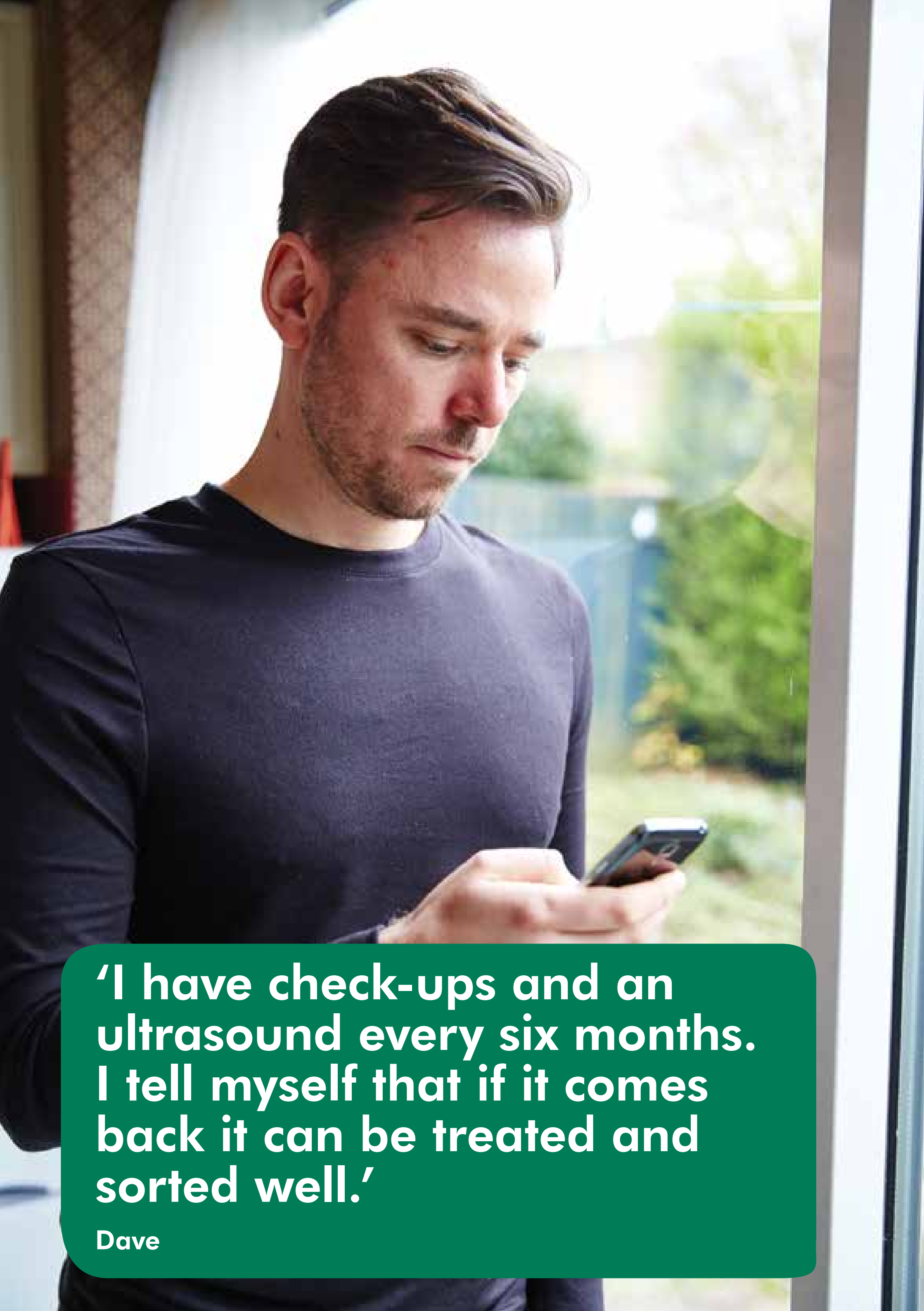
If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. We can send you a free copy.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.



> ‘I have check-ups and an ultrasound every six months. I tell myself that if it comes back it can be treated and sorted well.’
>
> **Dave**

AFTER YOUR TREATMENT

Your follow-up

Your follow-up will depend on the type of cancer you have and your situation. You usually have regular check-ups every few months in the first year. Eventually they will be reduced to every six months or yearly. Some follow-up appointments are with a nurse or by telephone.

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

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

You can ask if there are specific symptoms you should look out for and what you can do to help with your recovery. If you notice any new symptoms between appointments, you can contact your doctor or specialist nurse for advice.

Follow-up tests

Thyroglobulin test

Thyroglobulin is a protein that is normally made by the 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 to destroy any remaining thyroid cells and thyroid cancer cells, your body should no longer make thyroglobulin. If a small amount of thyroid tissue is left, or there are still some thyroid cancer cells in your body, there will be thyroglobulin in your blood. 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

This test is done 9 to 12 months after having radioactive iodine treatment. It is used to see if you need any more radioactive iodine.

You may need to stop taking your thyroid hormone replacement some weeks before the blood test. Or you may be given recombinant human thyroid-stimulating hormone (rhTSH) before your blood test. If you have rhTSH, you will not need to stop taking your thyroid hormone replacement tablets.

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

Ultrasound scan of the neck

You may have a regular ultrasound scan of your neck.

Radioactive iodine scan

Some people may have a radioactive iodine scan a few months after treatment to check whether there are any thyroid cancer cells in their body. Your doctors will tell you if you need to have a 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 will be asked to lie on a couch and a machine called a gamma camera will be positioned over your neck. The scan itself is painless.

To make the scan more sensitive, you may be asked to stop taking your thyroid replacement tablets and have a low-iodine diet for a few weeks before your scan. Or you may be given recombinant human thyroid-stimulating hormone (rhTSH).

Your doctor or nurse will give you more detailed information about this test if you need to have 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:

- an MRI scan (magnetic resonance imaging)
- a CT scan (computerised tomography)
- a PET-CT scan (positron emission tomography).

Well-being and recovery

Many people survive follicular and papillary thyroid cancer. But it may be 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.

Taking good care of yourself may help you recover more quickly.

Positive lifestyle choices

To help you stay as well as possible, you may want to make changes to your lifestyle. Even if you had a healthy lifestyle before your diagnosis, you may want to focus more on making the most of your health.

A healthy lifestyle doesn’t have to be difficult or expensive. It is about making small changes to the way you live. This will improve your health and sense of well-being. It will also lower your risk of getting other illnesses and some other cancers.

A healthy lifestyle includes:

- having a well-balanced diet
- being physically active
- reducing stress
- being involved in your healthcare.

When planning changes, you will need to think about any side effects of treatment. Don’t try to do too much, too soon.

If you are thinking about making any major changes to your lifestyle, it is a good idea to talk to your doctor or specialist nurse first.

Eat well and keep to a healthy weight

A well-balanced diet should include:

- plenty of fresh fruit and vegetables (at least five portions a day)
- foods 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.

Our booklet **Healthy eating and cancer** has more information to help you make changes to your diet.

Don’t drink too much alcohol

NHS guidelines suggest that both men and women should:

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

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.

Our booklet **Giving up smoking** has practical advice about how to stop smoking.

Get physically active

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

Our **Move more** guide to becoming more active may help you get started. Call us on **0808 808 00 00** and we will send you a copy.

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 or things that make you laugh.
- Try complementary therapies, such as meditation or yoga.
- Talk to someone about your feelings or have counselling.
- Try painting or drawing.
- Write a journal or online blog.

Get involved in your healthcare

Being involved in your healthcare means:

- taking any medicines as directed
- going to your follow-up appointments
- being aware of the symptoms of the cancer coming back, and looking out for them
- letting your doctor or specialist nurse know what is important to you.

Getting help and support

Different people can help you during and after treatment.

Practical help

If you 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.

A social worker or benefits adviser can tell you about benefits you may be able to claim and possible help with other costs.

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 (see pages 88 to 91). But as you recover and get back to your everyday life, these usually get easier to deal with. Talking to family and friends often helps.

If you think you may be depressed or feel helpless or anxious a lot of the time, talk to your cancer specialist or nurse. 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.

Our booklet **Cancer and complementary therapies** has more information on this.

Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through.

Online support

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experience and ask questions, get advice or just 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.

> 'On the Online Community I could really open up to people who'd been through it.'
>
> **Jena**

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

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

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

> 'I realised that talking about your feelings is not a bad thing at all and doesn't show weakness.'
>
> **Craig**

If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it’s best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you’re letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it’s 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, to help friends and family support their loved ones affected by cancer. Visit **macmillan.org.uk/learnzone** to find out more.

Our booklet **Talking to someone who has cancer** has more suggestions if you have a friend or relative with cancer.

If you’re looking after a family member or friend with cancer, you may find our booklet Looking after someone with cancer helpful. It’s based on carers’ experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

We have more information about this in our booklet **Talking to children and teenagers when an adult has cancer**. For a free copy, call **0808 808 00 00** or visit **be.macmillan.org.uk**

What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses.
However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.


senator

WORK AND FINANCIAL SUPPORT

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

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

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- contribution-based (contributory) – you can get this if you have paid enough national insurance
- income-related (means tested) – you can get this if you don’t qualify for contribution based ESA or if your income is low.

ESA is gradually being replaced by a new benefit called Universal Credit. This benefit is for people below retirement age who are out of work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people aged between 16 and 64. It is for people who have problems moving around and looking after themselves. You must have had these difficulties for at least three months and expect them to last for at least nine months. PIP replaces an older benefit called Disability Living Allowance (DLA) for adults.

Attendance Allowance (AA) is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have had these problems for at least six months. If you are terminally ill, and may be expected to live for less than six months, you can apply for PIP, DLA or AA under the special rules. It does not have to be certain and it does not matter if you live longer than six months. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

We've just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (for England, Wales and Scotland) and **nidirect.gov.uk** (for Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 112).

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 111 to 113.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful.

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life 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'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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**

Information 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'd 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's 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.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've 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 a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. 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're 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**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

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
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.

Hypopara UK

Tel 01342 316315
Helplines 01342 316315
(England and Wales)
01475 522 576 (Scotland)
Email
lizglenister@hypopara.org.uk
www.hypopara.org.uk
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
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org

Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn Cancer Care

Helpline 0303 3000 118
(Mon to Fri, 9.30am to 5pm)
Email
helpline@pennybrohn.org.uk
www.pennybrohn.org.uk

Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline 0808 808 1010 (Daily, 8am to 8pm)
Email info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 022 4250 (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

Civil Legal Advice

Helpline 0345 345 4345 (Mon to Fri, 9am to 8pm, Sat, 9am to 12.30pm)
Minicom 0345 609 6677
www.gov.uk/civil-legal-advice

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

Department for Work and Pensions (DWP)

Disability Living Allowance
Helpline 0345 712 3456
Textphone 0345 722 4433
Personal Independence Payment
Helpline 0345 850 3322
Textphone 0345 601 6677
Carer's Allowance Unit
Tel 0800 731 0297
Textphone 0800 731 0317
www.gov.uk/carers-allowance

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

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

The Money Advice Service

Helpline
0800 138 7777 (English)
0800 138 0555 (Welsh)
(Mon to Fri, 8am to 8pm,
Sat, 9am to 1pm)
Typetalk
18001 0300 500 5000
Email enquiries@moneyadviceservice.org.uk
www.moneyadviceservice.org.uk
Runs a free financial health check service and gives advice about all types of financial matters across the UK. Has an online chat service for instant money advice.

Money Advice Scotland

Tel 0141 572 0237
Email info@moneyadvicescotland.org.uk
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

National Debtline (England, Wales and Scotland)

Tel 0808 808 4000
(Mon to Fri, 9am to 8pm,
Sat, 9.30am to 1pm)
www.nationaldebtline.org
A national helpline for people with debt problems. The service is free, confidential and independent. Has an online chat service with an expert debt advisor.

Personal Finance Society – 'Find an Adviser' service

www.thepfs.org/yourmoney/find-an-adviser
Use the website to find qualified financial advisers in your area of the UK.

Unbiased.co.uk

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

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline
(England, Scotland, Wales)
0808 808 7777
(Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK.
Has an online forum and can put people in contact with support groups for carers in their area.

Cancer registries

The cancer registry

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 one in each country in the UK:

National Cancer Registration and Analysis Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel 013 1275 7777
Email nss.csd@nhs.net
www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

You can search for more organisations on our website at **macmillan.org.uk/organisations** or call us on **0808 808 00 00**.

YOUR NOTES AND QUESTIONS

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Nicholas Reed, Consultant Clinical Oncologist.

With thanks to: Dr Claire Arthur, Consultant Clinical Oncologist; Geraldine Hamilton, Cancer Information Nurse Specialist; Ingrid Haupt-Schott, Clinical Nurse Specialist; Sonja Hoy, Clinical Nurse Specialist; Mr Radu Mihai, Consultant in Endocrine Surgery; Dr Laura Moss, Consultant Clinical Oncologist; and Dr Jonathan Wadsley, Consultant Clinical Oncologist.

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

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

Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

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Can you do something to help?

We hope this booklet has been useful to you. It’s just one of our many publications that are available free to anyone affected by cancer. They’re 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’re there 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

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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

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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.

Registered with FUNDRAISING REGULATOR

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

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about the most common types of thyroid cancer, which are called follicular and papillary thyroid cancer.

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

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

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