

**MACMILLAN**  
CANCER SUPPORT

# UNDERSTANDING PRIMARY BRAIN TUMOURS





**I would encourage anybody going through something similar to seek out Macmillan. They can make the whole experience so much more manageable and bearable.**

**Claire, diagnosed with a brain tumour**

# About this booklet

**This booklet is about primary brain tumours in adults. Primary brain tumours are tumours that start in the brain. This booklet is for anyone who has been diagnosed with a primary brain tumour. There is also information for carers, family members and friends.**

The booklet explains the signs and symptoms of brain tumours, and how they are diagnosed and treated. It also has information about coping with a brain tumour.

This booklet does not have information about tumours that have started somewhere else in the body and spread to the brain. These are called secondary brain tumours or brain metastases. We have information on our website about secondary brain tumours.

Brain tumours can also affect children. If you need information about brain tumours in children, you can contact the Children's Cancer and Leukaemia Group. Turn to page 145 for their contact details.

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

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

## How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

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

On pages 144 to 151 there are details of other organisations that can help.

## Quotes

In this booklet, we have included quotes from people who have had a brain tumour, which you may find helpful. Some are from our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). The others are from people who have chosen to share their story with us. This includes Claire, who is on the cover of this booklet. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

## For more information

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

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

If you are deaf or hard of hearing, call us using 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**.



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# THE BRAIN AND BRAIN TUMOURS

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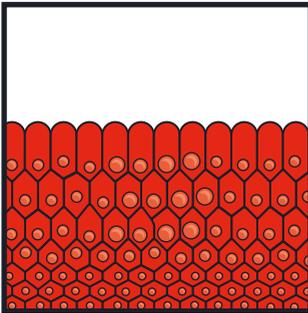
# What is a primary brain tumour?

A primary brain tumour is a tumour that starts in the brain.

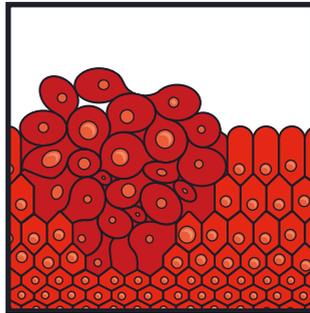
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets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

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

Normal cells



Cells forming a tumour



Primary brain tumours can be:

- low-grade – not cancer, sometimes called benign tumours
- high-grade – cancer, also called malignant tumours.

Low-grade brain tumours usually grow slowly and may not cause symptoms for a long time. They are very unlikely to spread outside of the brain. But they can cause problems as they grow and press on nearby areas of the brain. Some low-grade brain tumours do not come back after treatment but others do. These will need further treatment. Sometimes a low-grade brain tumour can change over time and become high-grade.

High-grade brain tumours grow faster than low-grade tumours. They cause problems by spreading into and damaging nearby areas of the brain. Some rare tumours may spread to other parts of the brain or the spinal cord. They very rarely spread to other parts of the body.

We have separate information about tumours that have started somewhere else in the body and spread to the brain. These are called secondary brain tumours or brain metastases. You can find more information on our website [macmillan.org.uk](https://www.macmillan.org.uk)

# The brain and spinal cord

Together, the brain and the spinal cord are called the central nervous system (CNS).

The brain manages how we think, feel, learn and move. It also controls other important things in the body, such as breathing and heart rate. The brain is protected by the skull.

The spinal cord is a long bundle of nerves down the middle of the spine (backbone). It starts at the base of the brain and goes down to the small of the back. Messages between the brain and other parts of the body travel through the spinal cord. The spine is made of bones called vertebrae. They protect the spinal cord.

The brain and spinal cord are also covered and protected by three layers of tissue (membranes) called the meninges. The area between two of these layers is called the subarachnoid space. This space contains a liquid called cerebrospinal fluid (CSF).

CSF also fills spaces inside the brain. These spaces are called ventricles. CSF makes a protective cushion for the brain. It also takes nutrients to the brain and removes waste products.

## Nerve cells (neurons)

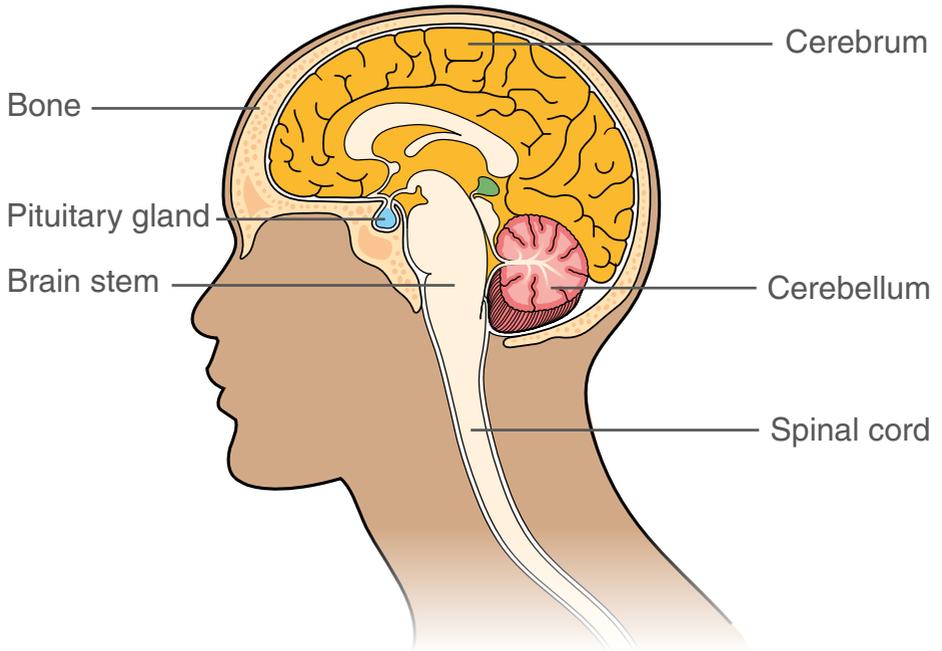
The brain and spinal cord are made up of billions of nerve cells called neurons. They form a network to communicate with each other. They use this to send chemical messages between the brain and other parts of the body.

Nerve cells are held in place and supported by glial cells. There are different types of glial cells including astrocytes, oligodendrocytes and ependymal cells.

## Parts of the brain

The main parts of the brain are the cerebrum, cerebellum, brain stem, cranial nerves and pituitary gland.

### Side view of the brain



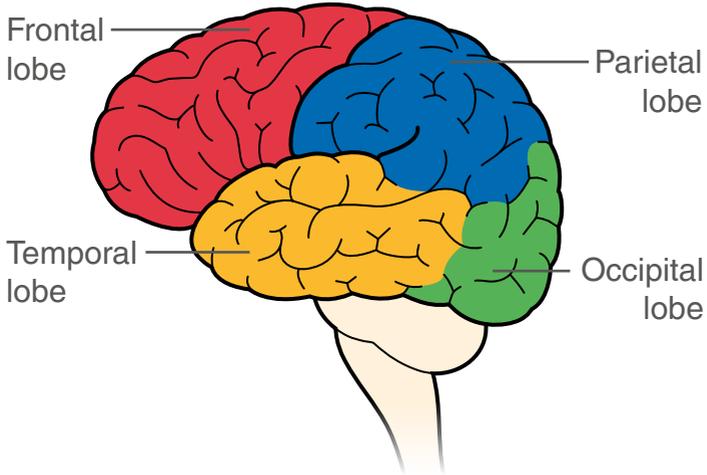
## Cerebrum

This is the largest part of the brain and is made up of two halves, called hemispheres. It controls thinking, memory, behaviour and personality. The right half of the cerebrum controls the left side of the body. The left half of the cerebrum controls the right side of the body.

Each half of the cerebrum is divided into four areas, called lobes:

- The frontal lobe is responsible for thinking, planning, problem solving and behaviour. Certain areas of the frontal lobe control movement in the arms and legs and how we produce speech.
- The parietal lobe helps us form words. It also helps us interpret touch and other sensations, and makes us aware of our body position.
- The temporal lobe manages memory, understanding and feelings. It processes what we hear and smell. It also helps us with organising information, learning and speech.
- The occipital lobe processes information about what we see, for example colour, shape and distance.

## Side view of the cerebrum lobes



## Cerebellum

This is the area below the cerebrum, at the back of the brain. It controls balance and co-ordination.

## Brain stem

The brain stem is at the bottom of the brain, connected to the spinal cord. It controls important body functions that keep us alive, such as:

- breathing
- heart rate
- blood pressure
- body temperature
- eye movements
- swallowing.

## Cranial nerves

These are nerves that go from the brain and brain stem to the eyes, nose, ears, tongue, face and shoulders. They carry messages from these areas about sensations such as taste, smell, sight and hearing. They also carry messages to muscles that control eye and face movements, speech and swallowing.

## Pituitary gland

The pituitary gland is behind the nose and just below the base of the brain. It makes hormones that control other hormone-producing glands in the body, such as the adrenal and thyroid glands. Hormones are chemical messengers that help control how organs and tissues in the body work.

## Pineal gland

The pineal gland is near the centre of the brain, between the two halves of the cerebrum. It makes a hormone called melatonin that helps control sleep patterns.

# Risk factors and causes

In most cases, experts do not know what causes a primary brain tumour. There are some things that may increase your risk of developing a brain tumour. These are called risk factors. It is important to remember that having a risk factor does not mean you will get a brain tumour. Only a small number of people develop a brain tumour because of one of these risk factors. Research is going on to find out more.

## Age

Brain tumours can develop at any age, but the risk is higher if you are older. A few types of brain tumour are more common in younger adults.

## Gender

Brain tumours are slightly more common in men than in women.

## Previous radiotherapy treatment

People who had radiotherapy to the head as children have a slightly higher risk of developing a brain tumour later in life.

## Genetic conditions

It is very rare for brain tumours to run in families. A small number of inherited genetic conditions are linked to a higher risk of certain types of brain tumour. These include:

- neurofibromatosis type 1 and type 2 (NF1 and NF2)
- tuberous sclerosis
- Li-Fraumeni syndrome
- von Hippel-Lindau syndrome
- Turcot's syndrome
- Gorlin syndrome
- Cowden's disease.

If your family is affected by one of these conditions, your GP can explain whether you have a risk of developing a brain tumour. They may refer you to a genetics clinic. Genetic Alliance UK also offers information and support about rare inherited conditions (see page 147).

## A weakened immune system

When a type of cancer called lymphoma starts in the brain or spinal cord, this is called primary central nervous system lymphoma (see page 37). This is more likely in people who have a weakened immune system, for example because of:

- HIV infection
- long-term treatment with drugs that lower the immune system (immunosuppressants).

## Other unproven causes

Hurting your head or brain in an accident has not been shown to cause brain tumours.

Mobile phones, power lines and viruses have all been suggested as possible causes of brain tumours. But research has not found any clear evidence to link any of these things to brain tumours.



**'The first symptoms I had were frequent headaches. I also started to have dizzy spells and slur. Eventually it got so bad I collapsed at home.'**

**Claire**

# Symptoms of a primary brain tumour

Symptoms depend on where the tumour is in the brain and how slowly or quickly it grows. They may develop suddenly, or slowly over months or even years.

The following symptoms can be caused by a brain tumour. But they can be caused by other conditions too.

As a tumour grows, it can press on or grow into nearby areas of the brain. This can cause symptoms because it stops that part of the brain from working normally. Symptoms can also happen because the tumour is increasing the pressure inside the skull.

These symptoms can be caused by conditions other than a brain tumour, but it is important to get them checked by your GP straight away.

## Headaches

A brain tumour can cause headaches, but it is unusual for this to be the only symptom. Headaches are usually dull and constant, and sometimes throbbing.

Most people get headaches from time to time, often because of stress or tension. If your headaches are getting worse over time or are different from your usual headaches, see your GP.

It is very important you see a doctor if your headaches wake you up at night or are worse in the morning. And especially if you also feel sick or notice a change in your eyesight.

## Symptoms of increased pressure inside the skull

A tumour can increase the pressure inside the skull. This is called raised intracranial pressure. It can be caused by the size of the tumour, or because the tumour is blocking the flow of fluid in the brain.

The most common symptoms of this are headaches, feeling sick and vomiting. The headache may be worse in the morning or get worse when you cough, sneeze or bend down. Increased pressure can also cause symptoms, such as changes to your sight, feeling confused or problems with your balance.

## Seizures (fits)

This is another common symptom of brain tumours. There are different types of seizures. With some seizures, you may go blank and stop responding to people around you for seconds or minutes. Or you might notice odd smells and sensations.

Other seizures make your muscles relax and tighten so your body stiffens and jerks or twitches, or you may fall over. Sometimes people bite their tongue or cheek. You might lose consciousness or stop responding to people around you for a few minutes.

Having a seizure can be frightening for you and people close to you, especially the first time it happens. After a seizure, you may feel tired and sometimes confused for a short while. Try to rest and give yourself time to recover.

If you have a seizure, your specialist doctor or GP will usually prescribe drugs to help prevent them. These are called anti-convulsants or anti-epileptics.

## Changes in personality, behaviour or thinking

A tumour can cause changes in personality and behaviour. Some people have problems with their thinking, reasoning or memory. Sometimes family members or close friends are the first to notice if this happens.

These changes can be upsetting for you and your family or friends. We have more information about coping with changes on pages 103 to 106.

'I went to the opticians because I had a blind spot in my left eye. They sent me to hospital for a scan, which showed there was a brain tumour.'

**Vivek**

# Symptoms and tumour position

Different areas of the brain have different functions. A tumour may cause symptoms because its position stops a part of the brain from working normally.

Position of tumour	Possible problems
<b>Frontal lobe</b>	<ul style="list-style-type: none"><li>• Changes in personality or behaviour</li><li>• Difficulty planning or making decisions</li><li>• Unsteady or un-coordinated walking</li><li>• Weakness on one side of the body</li><li>• Memory problems</li></ul>
<b>Parietal lobe</b>	<ul style="list-style-type: none"><li>• Problems with speech and understanding</li><li>• Difficulty writing, reading and doing simple calculations</li><li>• Difficulty finding your way around</li><li>• Numbness or weakness on one side of the body</li></ul>

Position of tumour	Possible problems
<b>Temporal lobe</b>	<ul style="list-style-type: none"><li>• Muddled speech</li><li>• Memory problems</li></ul>
<b>Occipital lobe</b>	<ul style="list-style-type: none"><li>• Sight problems or losing part of your vision</li></ul>
<b>Cerebellum</b>	<ul style="list-style-type: none"><li>• Poor co-ordination</li><li>• Double vision or blurred vision</li><li>• Unsteadiness</li><li>• Slurred speech</li></ul>
<b>Brain stem</b>	<ul style="list-style-type: none"><li>• Double vision</li><li>• Dizziness</li><li>• Unsteady or un-coordinated walking</li><li>• Facial weakness</li><li>• Speech or swallowing problems</li></ul>

Position of tumour	Possible problems
<b>Pituitary gland</b>	<ul style="list-style-type: none"><li>• Symptoms of changing hormone levels, such as infertility, weight gain, high blood pressure, diabetes, mood swings, irregular periods, or enlarged hands and feet</li><li>• Tunnel vision</li></ul>
<b>Cranial nerves</b>	<ul style="list-style-type: none"><li>• Hearing or eyesight problems</li><li>• Feeling dizzy and having problems with balance</li><li>• Pain, numbness or weakness of the face</li><li>• Speech or swallowing problems</li></ul>





# DIAGNOSING BRAIN TUMOURS

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# How brain tumours are diagnosed

Many people are diagnosed with a brain tumour when they go to hospital after having a seizure (fit) or other sudden symptoms. Other people go to see their GP about symptoms.

If your GP thinks you may have a brain tumour, they may arrange for you to have a brain scan. Or they may refer you directly to a neurologist (a doctor who specialises in brain disorders). People with brain tumours are treated in specialist hospitals. You may have to travel a long way to your nearest one.

## At the hospital

A doctor will ask you about:

- your general health
- any previous medical problems
- your family history.

They may:

- do a physical examination to check your tummy (abdomen)
- listen to your chest.

The doctor will also do a check of your nervous system. This is called a neurological examination. As part of this examination, your doctor may:

- ask you simple questions to check your thinking and memory
- test your hearing and eyesight
- ask you to walk a few steps or do some simple actions to check your balance and movement
- check the strength of your arms and legs by asking you to push against something
- check your reflexes by tapping your arms and legs
- check if you can feel pinpricks on your skin, or feel the difference between hot and cold
- check the movement of your face and eyes
- shine a light at the back of your eye to check for swelling – this is a sign of increased pressure in the skull.

Your doctor will explain any other tests you need and when these will happen. You may find it helpful to bring a friend or family member with you to tests and appointments. If you have tests as an outpatient, you can usually go home soon after they are finished.

This can be a difficult time and you may feel very anxious. Your doctor can give you information and support. Tell them if there is anything you do not understand or if you have other questions.

## Brain CT scan

A CT scan makes three-dimensional (3D) picture of the brain. The 3D picture is built up using lots of detailed x-rays taken by the CT scanner. This test only takes a few minutes and is painless. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You may have an injection of a dye into a vein in your arm. This is called a contrast. It helps show certain areas of the brain more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction to the injection. The dye will safely leave your body in your pee (urine) over the next few days.

During the scan, you lie very still on a narrow bed. The bed moves slowly back and forward through a donut-shaped scanner.

## Brain MRI scan

This test uses magnetism to make a detailed picture of the brain. It can also be used to check your spine. It takes about 30 to 60 minutes and does not use any radiation.

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

If you cannot have an MRI scan, you can have another type of scan. Your doctor will give you more information.

You have the scan in the x-ray department at the hospital. The radiographer helps you prepare for the scan. They will ask you to remove any metal belongings, including jewellery and hair clips. You may be asked to put on a hospital gown.

During the scan, you need to lie very still on a bed inside a cylinder (tube). The bed moves slowly inside the scanner. It is painless, but lying still for that long can be slightly uncomfortable. The scan is also noisy, but you will be given either earplugs or headphones. It may be possible to listen to music during the scan.

Some people feel a bit claustrophobic in the scanner. If you are worried about this, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

You may have an injection of a dye into a vein in your arm during the scan. The dye is called a contrast. It helps show certain areas of the brain more clearly. It is only given when necessary. The dye rarely causes any serious side effects. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction to the injection. The dye will safely leave your body in your pee (urine) over the next few days.

Sometimes specialised types of MRI scan are used to look at blood vessels (MR angiography) or chemical activity (MR spectroscopy) in the brain.

## PET or PET-CT scan

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

PET scans are not available at all hospitals, so you may have to travel to a specialist centre to have one. The person who works the scanner is called a radiographer. They help you prepare for the scan. If you are pregnant or breastfeeding, you should phone the scanning department before the test for advice.

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

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

## SPECT scan

This test is similar to a PET scan. It looks at blood flow through the brain.

You are given an injection of a radioactive substance, usually in your arm. This substance travels in the blood to the brain. The PET scan then takes pictures (scans) of the brain.

## Biopsy

A biopsy is when a surgeon removes a small part of the tumour to find out what type of brain tumour it is. Brain tumour biopsies (see page 58) are usually done at the same time as surgery to remove the tumour.



## Lumbar puncture

A lumbar puncture is a test that checks for tumour cells in the cerebrospinal fluid (CSF). Not everyone needs to have this test. Your doctor will explain if it is likely to be useful.

A lumbar puncture is usually done using a local anaesthetic to numb the area. You may be asked to wear a hospital gown.

To take the sample of CSF, a doctor or specialist nurse puts a thin needle between the bones of the lower back. The needle goes into the fluid around the lower part of the spinal cord. They collect a few drops of the fluid into a pot. The sample will be looked at under a microscope. Having a lumbar puncture should not be painful, but you may feel some pressure as the needle is put in.

After removing the sample of CSF, the needle is then removed. A plaster or small dressing will be placed over the area. Most people do not have any problems with this test, although it may cause tingling down the back of your legs when the needle is put in. This is normal and does not cause any damage, but it can be worrying if you are not expecting it. Some people have a headache afterwards. It can help to drink plenty of water before and after the test. You can ask your nurse for some mild painkillers.

## Blood tests and chest x-rays

A blood test cannot diagnose a brain tumour. But some types of tumour release certain hormones or chemicals into the blood. If the tumour is affecting your pituitary gland or pineal gland, you may have blood tests to check for this.

Some people may have a chest x-ray to check their lungs and their general health.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation (see pages 144 to 151) can also provide support. You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** 7 days a week, 8am to 8pm.

'When I was first diagnosed it was a complete shock. It took me a few weeks to realise I had cancer. That sounds so silly, but I just didn't believe it could happen to me.'

**Rose**

# Types of brain tumour

There are many different types of brain tumour. These are some of the more common ones. We have more information about the following tumour types on our website [macmillan.org.uk](http://macmillan.org.uk).

Brain tumours are often named after the cell they develop from or the part of the brain they start in (see pages 11 to 14).

## Gliomas

More than half of all primary brain tumours are gliomas. These tumours develop from the supporting cells (glial cells) in the brain or spinal cord. Different types of glioma are named after the types of glial cell.

### Astrocytoma

Astrocytoma is the most common glioma. It develops from a type of star-shaped glial cell called an astrocyte. Astrocytomas can be grade 1 to 4. Different grades of astrocytoma have different names. For example, glioblastoma multiforme (GBM) is a type of grade 4 astrocytoma.

### Oligodendroglioma

Oligodendroglioma develops from a type of glial cell called an oligodendrocyte. These cells make up the fatty covering of nerve cells. There are two main grades of these tumours – grade 2 and grade 3.

### Ependymoma

Ependymoma develops from a type of glial cell called an ependymal cell. These cells line the fluid-filled spaces in the brain (ventricles) and the centre of the spinal cord. Ependymomas can be grade 1 to 3.

## Meningioma

Nearly a quarter (25%) of all primary brain tumours are meningiomas. These tumours start in the tissues that cover and protect the brain and spinal cord (the meninges). Meningiomas can be grade 1 to 3. They are usually low-grade, slow-growing tumours, but a small number are faster growing.

## Acoustic neuroma

Acoustic neuromas (also called vestibular schwannomas) are tumours that usually grow slowly. They develop from the cranial nerve that connects the inner ear to the brain, called the acoustic nerve. People with a genetic condition called Neurofibromatosis type 2 (NF2) have a higher risk of developing this type of tumour.

## Primary central nervous system lymphoma (PCNSL)

A lymphoma is a cancer of the lymphatic system, which is part of the body's immune system and helps fight infection. Lymphomas that start in the brain or spinal cord are called primary central nervous system lymphomas (PCNSL). They are rare and usually grow quickly. You may have slightly different tests and treatment for PCNSL.

## Haemangioblastoma

Haemangioblastoma is a rare, slow-growing tumour that usually affects the cerebellum and sometimes the brain stem or spinal cord. It develops from the cells lining the blood vessels in the brain.

## Medulloblastoma

Medulloblastoma is a high-grade tumour that develops in the cerebellum. This tumour is rare in adults but is one of the most common brain tumours in children.

## Pineal region tumours

These rare tumours affect the pineal gland in the centre of the brain. There are different types of pineal region tumours. The most common one is a germ cell tumour.

## Pituitary gland tumours

The most common tumours of the pituitary gland are adenomas. They are slow-growing tumours that can affect how the pituitary gland produces hormones.

## Craniopharyngioma

Craniopharyngioma tumours affect an area above the pituitary gland and near the cranial nerve from the eyes to the brain. They are rare and usually slow-growing. They can affect how the pituitary gland produces hormones and cause problems with eyesight.

## Spinal cord tumours

Several types of tumour can start in the spinal cord, but this is rare. These tumours usually cause problems by pressing on the nerves of the spinal cord. You may have slightly different tests and treatment for a tumour in the spinal cord.

# Grading brain tumours

The grade of a tumour describes how abnormal the cells look under a microscope. This can help your doctor understand how quickly a tumour might grow and whether it is likely to spread.

## Grade 1

These tumours are low-grade and grow slowly. They are sometimes called benign tumours because they are unlikely to come back after treatment.

## Grade 2

These tumours are also low-grade and usually grow slowly. Depending on the type of brain tumour, they may be more likely to:

- come back after treatment
- change over time and become high-grade.

Your doctor can explain more.

## Grades 3 and 4

These tumours are high-grade and grow more quickly. They are also called malignant tumours.

# Brain tumours and biomarkers

Some types of brain tumour are tested for gene changes. This is called testing for biomarkers or testing for molecular markers.

Genes are the instructions a cell needs to work properly. Every cell contains a set of genes. Sometimes the structure inside a gene is permanently changed, so the gene no longer gives the correct instructions.

It can be useful to know about gene changes in a brain tumour cell. If a tumour has certain genetic changes, this may give your doctor information about:

- which treatment is most likely to be effective for you
- how the tumour may develop.

Your doctor can tell you more about whether biomarker tests are helpful in your situation. This type of testing is done on a sample of tumour cells (biopsy). Some types of biomarker can be tested with a blood sample.

# How diagnosis affects your right to drive

Most people diagnosed with a brain tumour will not be allowed to drive for a time after their diagnosis. Your doctor, surgeon or specialist nurse will tell you if this applies to you. This change can be upsetting and frustrating. But you must follow the advice they give you.

If you have a driving licence, you must tell the licencing agency that you have been diagnosed with a brain tumour.

If you live in England, Scotland or Wales contact the Drivers and Vehicle Licensing Agency (DVLA). If you live in Northern Ireland, contact the Driver and Vehicle Agency (DVA).

You could be fined if you do not tell them. You could also be prosecuted if you have an accident.

The DVLA or DVA will tell you if and when you are allowed to start driving again. This depends on:

- the type and grade of your tumour
- whether you have had any seizures
- what treatment you are having
- the type of driving license you have.

They may ask you if they can get medical information about you from your doctor.

# Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. 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. 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](https://www.macmillan.org.uk/cancerregistry)





# TREATING BRAIN TUMOURS

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# Treatment overview

Treatments used for brain tumours include surgery (see pages 56 to 67), radiotherapy (see pages 69 to 81) and chemotherapy (see pages 82 to 92). You may have a combination of treatments. Your treatment depends on:

- the size and position of the tumour
- the type and grade of the tumour
- any biomarkers you have
- the symptoms you have.

For more information on types of tumours see pages 36 to 38.

## Treating low-grade (grade 1 and 2) tumours

If the tumour is not causing you problems, your doctor may suggest delaying treatment until it is needed. They will arrange for you to have regular scans to check the tumour and will monitor your symptoms carefully. This is called active monitoring (see pages 54 to 55).

If you need treatment, you may have surgery to remove the tumour. If surgery is not possible because of where the tumour is in the brain, or if it cannot be completely removed, you may have radiotherapy or chemotherapy, or both.

Some types of tumour have a higher risk of coming back after surgery, or of developing into a high-grade tumour. To reduce this risk, your doctor may advise you to have further treatment after surgery.

## Treating high-grade (grade 3 and 4) tumours

High-grade tumours grow more quickly and need to be treated straight away. If surgery is possible, the surgeon will remove as much of the tumour as they can. After surgery, you will usually have radiotherapy or chemotherapy, or both.

The main treatment is usually radiotherapy when surgery is not possible. This could be with or without chemotherapy. Some people may have chemotherapy alone as their main treatment.

## Treating rarer tumours

Some rare brain tumours are treated in other ways. For example, lymphomas and some types of pineal region tumours are usually treated with radiotherapy and chemotherapy. You may have a biopsy to diagnose these tumours, but you are not likely to need surgery to remove them. We have more information about rarer tumours on our website. To find out more visit [macmillan.org.uk](https://www.macmillan.org.uk)

## Treating symptoms

When you are diagnosed, you may need treatment for symptoms before you have any treatment for the tumour. You may also need help managing your symptoms during your main treatment, or for a while after it has finished.

You may need drugs called anti-convulsants to prevent seizures (see page 96). You may also need steroids to reduce swelling around the tumour (see page 94 to 95). Or you may have surgery to reduce pressure inside the skull (see page 62).

Sometimes a brain tumour cannot be removed or controlled anymore. If this happens you can still have treatment for any symptoms. You will have supportive care (sometimes called palliative care) from a specialist doctor or nurse who is an expert at managing symptoms.

We have more information in our booklet **Coping with advanced cancer** (see page 140).

# Before treatment

## How treatment is planned

In most hospitals, a team of specialists meet to plan your treatment. This multidisciplinary team (MDT) may include a:

- **neurosurgeon** – a doctor who operates on the brain or nervous system
- **neurologist** – a doctor who treats illnesses of the brain and nervous system
- **clinical oncologist** – a doctor who treats cancer with radiotherapy and chemotherapy
- **specialist nurse** – who gives information and support to people with brain tumours.

It may also include other healthcare professionals such as a physiotherapist, occupational therapist, neuropsychologist, speech and language therapist (SLT) or counsellor.

The MDT gives advice about your treatment based on results of your tests and your general health.

Your doctor and nurse will then talk to you about your treatment options. Together you make a decision about your treatment plan. Make sure you ask questions about anything you do not understand or feel worried about.

## 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. Before you are asked to sign the form you should be given full information about:

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

If you do not understand what you have been told, tell the staff straight away, so they can explain again. Some treatments are complex, so it is okay to ask someone to explain again. It is a good idea to have a family member or friend with you at the appointment, to help you remember what was said. You may also find it useful to write a list of questions before your appointment.

## Making your decision

Making decisions about treatment can be difficult. You may need to talk in detail to your doctor or nurse. If you are not ready to make a decision, you can always ask for more time.

You may choose not to have the treatment. Your doctor or nurse can explain what may happen in this situation and what your other options are. You do not have to give a reason for not wanting a treatment. But if you do, your doctor or nurse may be able to give you clearer information and support.

Whatever you decide, tell your doctor or nurse so they can record your decision in your medical notes.

We have more information in our booklet **Making treatment decisions** (see page 140).

'Some of the stuff that my Macmillan nurse Shez was talking about was quite frightening. But she said it in such a way that it was just another thing on the list. She made it easier for me.'

**Claire**



## The benefits and risks of treatment

Treatment can be given for different reasons. You may have treatment that aims to cure or to control a tumour for some time. Or you may have treatment to control the symptoms of a tumour. The possible benefits depend on your situation.

However, treatments can also have risks and side effects. These may be easy to manage or they may be more serious. Some risks are very common while others may only affect a few people.

You may have to weigh up any possible risks or side effects against the benefits of treatment. Your specialist doctor or nurse will talk to you about this. They will explain any risks or side effects and ways to reduce or manage them.

## 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.

# Active monitoring

This means regularly checking the tumour to find out if it is changing or growing. You see your specialist doctor regularly at a clinic and have scans to check the tumour. Your doctor will also ask you to contact them straight away if you have any new or changing symptoms. You can start treatment if your scan results or your symptoms show that the tumour is growing.

Active monitoring is not suitable for everyone. Your specialist doctor will explain the benefits and possible risks. Active monitoring might be helpful if:

- treating a tumour would be difficult because of its position
- treatment side effects are likely to be worse than the symptoms caused by the tumour
- you have a small, low-grade tumour with few or no symptoms.

Some people may have active monitoring before they have any treatment. But sometimes you are able to choose to have active monitoring after surgery. This may mean you can delay having further treatment, such as radiotherapy, until you need it.

You may find active monitoring difficult at first. But people usually find it gets easier with time. Your specialist nurse can give you support and advice on coping. You might find it helpful to talk about how you feel with family and friends. Or you may want to talk to people who are in a similar situation. You could try joining a support group or online forum.

'I had MRI scans every 6 weeks. After my last scan the tumour hadn't grown so my consultant was happy to continue monitoring it. My scans are now every 3 months and I'm so happy with this.'

**Laura**

# Surgery

Surgery is often the main treatment for brain tumours. The operation you have depends on the size of the tumour and its position. Only highly specialised surgeons do brain surgery. It is done in specialist centres or hospitals. They use technology that makes operations safer and easier to do.

You can have surgery to:

- take a sample of the tumour (a biopsy) for further tests or to diagnose the type of tumour (see page 58)
- remove all of the tumour (complete resection)
- remove as much of the tumour as is safe and possible (partial resection or debulking)
- reduce pressure in the skull.

Some people also have chemotherapy given directly into the brain during surgery (see page 87).

Some tumours cannot be removed with surgery. A tumour may be too difficult to reach, or the risk of damaging the brain could be too high. Your surgeon will talk to you about other treatment options.

## Your feelings

Any operation to the brain is major surgery. So it is natural to feel worried and frightened about it. You may have questions about:

- the risks of surgery
- whether the operation will change how your brain works in some way
- how you will feel after the operation
- how you will look and whether you will have scars.

Your surgeon and specialist nurse will talk to you about the operation and the possible risks and benefits. If there is a risk of damage to the brain during surgery, they will explain how this may affect you.

The surgeon may need to shave some of your hair during the operation. Some people find the thought of waking up with part of their head shaved very upsetting. If you are worried about this, your nurse or surgeon can explain what to expect before the operation.

Your specialist nurse can give you and your family support. Make sure you have as much information as you need. Talk about any concerns and ask any questions you have. Knowing what to expect can make it easier to cope and less frightening.

## Biopsy

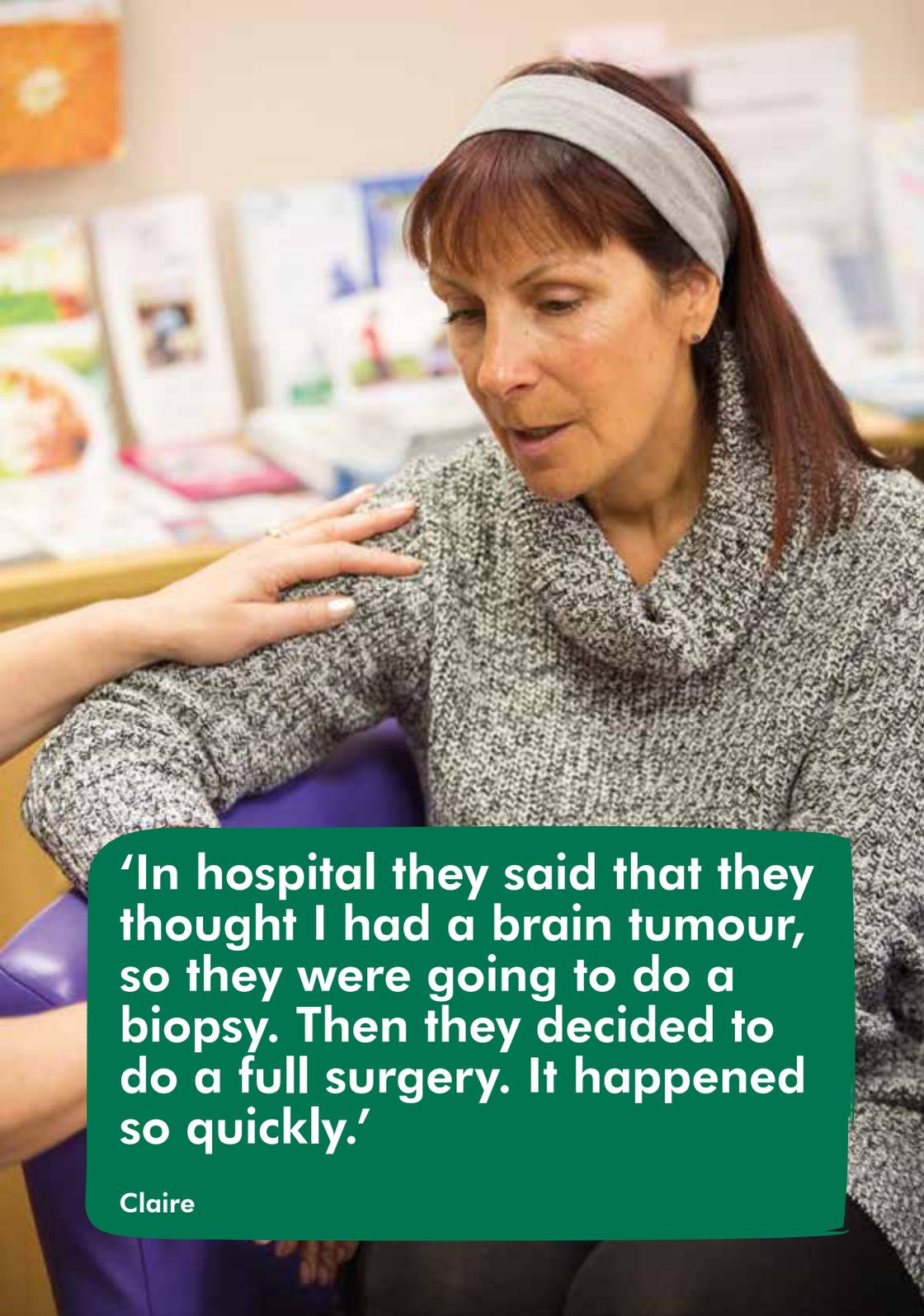
A biopsy is when the surgeon removes a piece of the tumour. Sometimes this is done before you have any other treatment. More often it is done as part of a larger operation to remove the tumour.

You usually have a biopsy taken under a general anaesthetic. Sometimes a local anaesthetic is used. The surgeon uses scans taken before and sometimes during the operation to guide them while taking the biopsy. They may take the biopsy:

- through a small hole they drill in the skull (burr hole)
- by removing a small piece of skull over the tumour (craniotomy). This is sometimes called an open biopsy.

The biopsy sample is sent to a laboratory for tests. These are done to find out the type and grade of the tumour (see pages 36 to 39). Some types of tumour are also tested for changes in the tumour cells called biomarkers (see page 40).

The tests give your doctor information about how the tumour may develop and grow. Knowing this helps them to plan the best treatment for you.



**‘In hospital they said that they thought I had a brain tumour, so they were going to do a biopsy. Then they decided to do a full surgery. It happened so quickly.’**

**Claire**

## Craniotomy

To remove part or all of the tumour, you have an operation called a craniotomy.

You usually have the surgery under a general anaesthetic. The surgeon removes a piece of skull over the tumour to make an opening. They use a powerful microscope and sometimes scans to look at the brain. This means they can carefully remove the tumour without taking away healthy areas of the brain. After they have removed part or all of the tumour, the surgeon replaces the piece of skull.

Sometimes the surgeon can remove the tumour through a very small opening in the skull using a neuroendoscope. This is a thin, flexible tube with a camera on one end and an eyepiece on the other. This type of surgery is sometimes called endoscopic or keyhole surgery. Your surgeon will explain whether this is possible for you.

If it is not possible to remove the whole tumour, the surgeon will remove as much of it as they can. This is sometimes called a partial resection or debulking.

After the operation, the tissue is sent to a laboratory for tests.

## 5-ALA (Gliolan)

Some people have a drug called 5-ALA (Gliolan) as a drink before the operation. It is also called 'the pink drink' or photodynamic diagnosis (PDD). During surgery, 5-ALA makes brain tumour cells glow pink or red under a blue light. This may help the surgeon decide which areas to remove. It is not used in all brain tumour operations. If your surgeon feels it would be helpful in your situation, they will discuss it with you.

5-ALA makes your eyes and skin sensitive to light for up to 24 hours after taking it. It is important to avoid direct sunlight and brightly focused indoor light during this time. While you are in hospital, the staff will make sure you are protected from bright, direct light.

## Craniotomy while you are awake

Sometimes the surgeon will suggest that you have a craniotomy while you are awake. This may sound frightening, but people usually cope with it well.

Because you are awake, the surgeon can ask you questions and check that your speech and movement are not being affected by the surgery. This reduces the risk of damage to your brain. It also means the surgeon may be able to remove more of the tumour. If there are changes to your speech or thinking, the surgeon stops operating and assesses the situation.

Usually you are given sedation or a general anaesthetic for the first part of the surgery. The surgeon uses local anaesthetic injections to numb the scalp. They gently wake you when they are ready to operate on the brain. You should not feel any pain during the operation. This is because the brain has no nerve endings.

You can see and talk to the doctors and nurses during the operation. You can tell them straight away if you are worried about anything that is happening.

## Shunts

If a brain tumour blocks the flow of fluid (CSF) around the brain, (see page 10) pressure can build up and cause symptoms (see page 20).

To reduce the pressure, some people have a small operation to place a long, thin tube called a shunt into the brain. The shunt lets some of the fluid drain from the brain to another area of the body. It may make you feel better by reducing some of your symptoms.

You cannot see the shunt from outside the body. But you may be able to feel it under the skin behind your ear. Your surgeon will explain what to expect.

### Other types of surgery

Sometimes the surgeon can do an operation called endoscopic third ventriculostomy (ETV) instead of placing a shunt. They use keyhole (endoscopic) surgery to make a small hole in the lining of the ventricles in the brain (see page 10). This lets fluid move past the blockage and reduces the pressure on the brain.

If a tumour has a fluid-filled part (called a cyst), you may have an ommaya reservoir placed into the brain instead of a shunt. This is a small tube and disc. The tube is placed in or near the tumour and the disc sits under the skin of the scalp. After the operation, if pressure builds up, your doctor can put a small needle through the skin into the disc and drain some fluid from the tumour.

## Before your operation

You will have tests before surgery to make sure you are well enough to cope with it. These are usually done a few days before your operation at a pre-assessment clinic. They may include heart and lung tests.

If you smoke, try to give up or cut down before your operation. This will help to reduce your risk of problems, such as a chest infection. It will also help your wound to heal after the operation. Your GP can give you advice and support to help you stop smoking.

If you are not already taking them, you may be given steroids. These drugs help to reduce swelling caused by the tumour. Always take steroids exactly as your doctor has prescribed. You usually take them for a while before and after surgery.

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

You will meet a doctor from the surgical team and a specialist nurse who will talk to you about the operation. You will also meet the anaesthetist. This is the doctor who gives you the anaesthetic.

## After your operation

When you wake up, you may be in the intensive care ward or high-dependency unit for about 24 hours. Or you may go straight back to a neurosurgical ward.

The doctors and nurses will monitor you carefully. They will do neurological checks, such as testing your reflexes and seeing how your eyes react to light. They will also take your temperature and blood pressure.

Your face and eyes may be swollen and bruised. This swelling should go down within 48 hours and the bruising should get better within a few days. Sometimes a swelling filled with fluid develops under the operation scar. This may take longer to go down, but will also get better over time.

## Drips and drains

You may have some tubes in place when you wake up. These are used to give you fluid and drugs, or to drain body fluids. They are not usually painful. Tell your nurse if something you are connected to is uncomfortable. Your nurse will remove each drip or drain when you no longer need it.

You may have some of the following:

- A drip going into a vein – this is used to give you fluids until you can eat and drink again.
- A drain from your wound – this is used to drain blood or fluid into a bottle. It is usually removed 1 to 2 days after the surgery.
- A fine tube that passes down the nose and into the stomach – this is called a nasogastric tube. It removes fluids from the stomach, to stop you being sick.
- A catheter – this is a tube that drains urine from your bladder. It is usually taken out when you are able to move around more.

## Pain

You may have a headache when you wake up after the operation. The nurses will give you regular painkillers until it gets better. Headaches usually get better after a few days. Always tell your nurse or doctor if you have pain, or if the pain starts to get worse.

## Moving around

You will be encouraged to get out of bed as soon as you feel able. This is important to help prevent chest infections and blood clots. It also helps with your recovery. Your nurse can check that you are ready to get up. A physiotherapist or nurse will help you to start moving around if needed.

## Your wound

The wound on your head may be covered with a dressing or bandage for the first few days. The nurses will check it regularly to make sure it is healing well. After about 7 to 10 days, they will remove your staples or stitches. This can be done at the hospital, at your GP practice or at home by a district nurse. If you have dissolving stitches, these will not need to be removed.

## Recovery and going home

When you go home and how quickly you recover will depend on the type of operation you have. Your healthcare team during recovery may include:

- a physiotherapist
- an occupational therapist
- a speech and language therapist (SLT), if needed.

They can help you plan to go home and arrange any further support you might need.

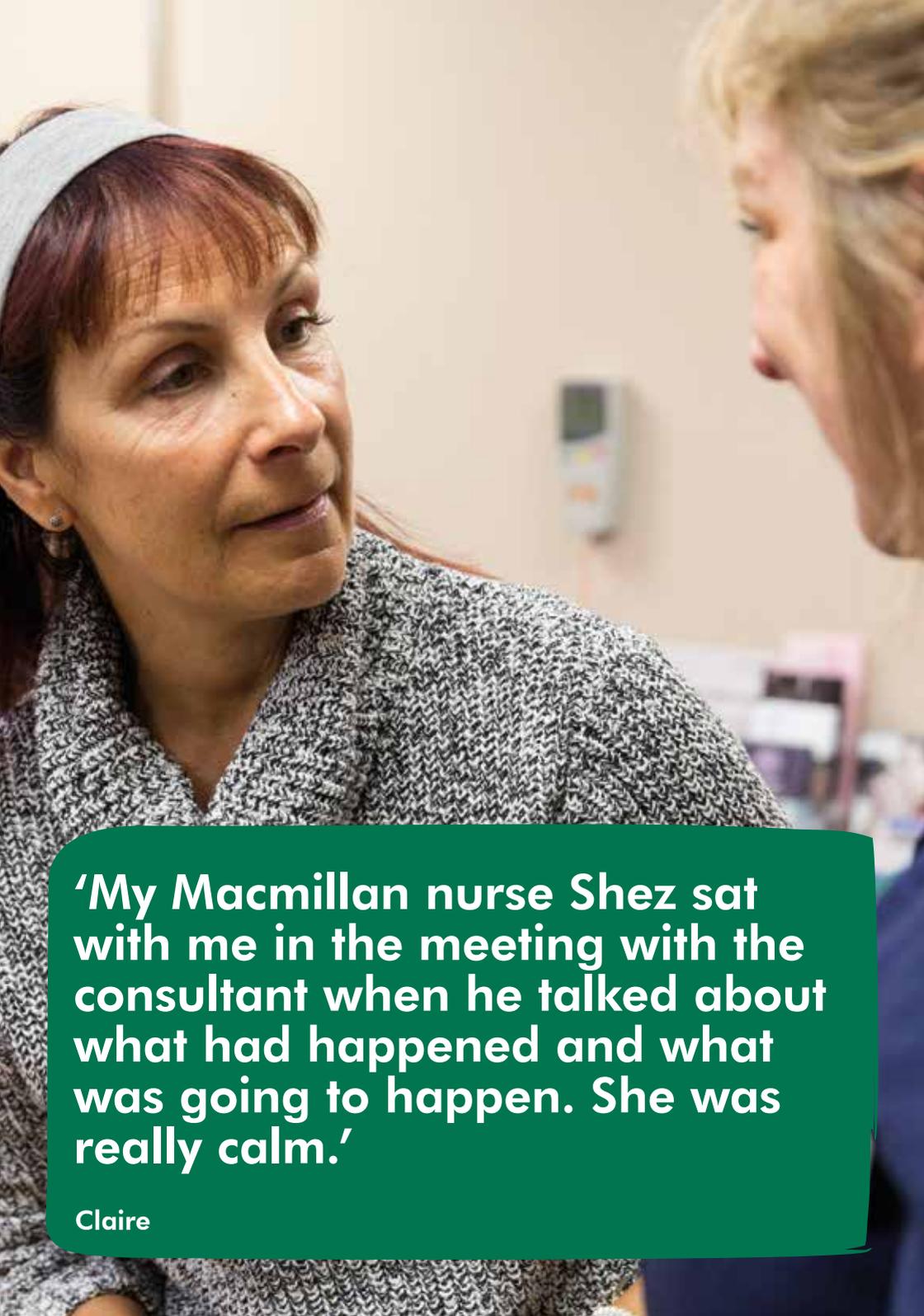
You will still be recovering when you leave hospital. You should take things slowly and follow the advice from your healthcare team. Contact the hospital straight away if you have any problems or new symptoms, including:

- a fever (high temperature)
- redness, swelling or leaking from your wound
- feeling or being sick
- feeling very drowsy
- weakness in your arms or legs
- problems with speech
- a seizure.

It is normal to feel very tired for several weeks or longer. For a few people, this may continue for a year or more. Getting enough rest and eating healthily will help you recover. Try to balance rest with some gentle exercise, such as regular short walks. This will help give you more energy. You can find out more information in our booklet **Coping with fatigue** (see page 140).

Your surgeon and healthcare team will tell you what to expect and how you can help with your own recovery. It is a good idea to make an appointment to see your GP when you go home. They can give you advice and support. You will usually go back to the hospital a few weeks after your operation for a check-up.

You are not usually allowed to drive after brain surgery for 6 months to 2 years, or longer. We have more information about this and about contacting the DVLA or DLA (see page 41).



**'My Macmillan nurse Shez sat with me in the meeting with the consultant when he talked about what had happened and what was going to happen. She was really calm.'**

**Claire**

# Radiotherapy

Radiotherapy uses high-energy rays to destroy tumour cells, while doing as little harm as possible to normal cells. Newer ways of giving radiotherapy to the brain are designed to limit the damage to healthy brain tissue.

You may have radiotherapy:

- as your main treatment
- after surgery, if a tumour cannot be completely removed
- after surgery, to reduce the risk of the tumour coming back
- with chemotherapy, if you have a high-grade glioma
- if a tumour comes back.

There are different types of radiotherapy. They can be used in different ways to treat a brain tumour. Your treatment is carefully planned by a radiotherapy team. This includes a clinical oncologist and radiographers, who are experts in giving radiotherapy treatment. Your team will explain your treatment plan, the dates and times of your appointments and what to expect.

## Standard external beam radiotherapy

Radiotherapy for a brain tumour is given from a radiotherapy machine outside the body. This is called external beam radiotherapy. It is normally given as a number of short, daily treatments in a radiotherapy department. Each daily treatment is called a treatment fraction. There are different types of radiotherapy machine. The most commonly used machine is called a linear accelerator (LINAC).

The treatments are usually given 5 days a week, from Monday to Friday, with a rest at the weekend. Some people only have treatment 3 days a week. Your treatment may last from 2 to 6 weeks, depending on the type of tumour and its size.

Usually, each appointment takes about 10 to 30 minutes. But the actual treatment only takes a few minutes.

## Stereotactic radiotherapy (SRT)

SRT is a way of accurately focusing external beam radiotherapy. This means the tumour gets the treatment but there is less risk of damage to nearby areas of the brain.

SRT can be given:

- in the same way as standard external beam radiotherapy, using short, daily treatments over several weeks
- as a few sessions of higher dose treatment
- as a single higher dose treatment – this is called stereotactic radiosurgery (SRS).

SRT is not suitable for everyone with a brain tumour. Your doctor can tell you if it is a suitable treatment for you and what to expect.

SRT can be given using a LINAC machine. It may also be given using a machine only used for SRT, such as Gamma Knife™ or CyberKnife™. A session of treatment can take from about 15 minutes up to 4 hours, depending on the type of machine used.

We have more information about having SRT for a brain tumour on our website. Visit [macmillan.org.uk](https://www.macmillan.org.uk)

## Proton beam therapy

Proton beam therapy is a type of external beam therapy that uses protons instead of high-dose x-rays. It is given using different equipment that is not available in all UK hospitals.

Proton beam therapy is recommended for some rare types of brain tumour. Your doctor will explain if you have one of these types of tumour and if this treatment might be suitable. If you need this treatment you will usually have to travel to a different hospital, or even abroad.

We have more information about having proton beam therapy on our website at [macmillan.org.uk](https://www.macmillan.org.uk)

## Masks and head frames

During radiotherapy you may need to wear a light-weight mask that covers your face and the front of your head.

When you have your treatment, you lie on a treatment couch. The radiographers gently place the mask over your head and fix it to the couch. This helps you stay still in the right position and makes the treatment as accurate as possible.

Masks are usually made from plastic mesh that is moulded to fit the shape of your face. The radiotherapy team make it for you before your treatment is planned. The mask fits tightly but should not be uncomfortable. You only wear it during your planning scans and each treatment session. You can breathe normally while you are wearing it.

For some types of SRT, you wear a light-weight metal head frame. Head frames are usually fitted on the same day that you have SRT. Some types can be fitted and are then taken off until your treatment session. Others are fixed. This means you wear the frame all day until your treatment session is over. Before your treatment, you can move around with it on and can eat and drink normally.

You may feel very nervous about wearing a mask or head frame. Most people cope well with the support of the radiotherapy team. If you are worried or uncomfortable tell them, so they can help you.

We have more information about having SRT with a head frame on our website at [macmillan.org.uk](https://www.macmillan.org.uk)

## Planning your treatment

Before you have radiotherapy, you have a brain CT or MRI scan (pages 30 to 31). Your radiotherapy team use information from the scan to plan how the machine will give your treatment. Usually you only need one visit but sometimes you may have a few visits to the radiotherapy department to plan your treatment.

The radiographers help you get into position for the scan. You may need to take off some clothes and wear a hospital gown. You lie on a treatment couch in the same position you will be in for treatment. If you need a mask or head frame, the radiographers gently fix this to the couch.

The radiographers may make a few ink marks on the mask or head frame. These marks will help them make sure you are in the correct position for each session of radiotherapy.

During the scan you will be alone in the room. The radiographers can see, hear and talk to you and are close by if you need them.

'I needed to have some appointments before the radiotherapy to get a mask made. It had to be very tightly fitted onto my face, which was a very unusual experience.'

**Claire**

## Having radiotherapy

When you have the treatment, you lie in the same position as you did for the planning scan. The radiographers will help you and make sure you are comfortable. They will tell you how long your treatment will take. When you are in the correct position, they leave the room and you are given your treatment.

The treatment itself is not painful. You may hear a slight buzzing noise from the radiotherapy machine. Depending on the type of radiotherapy machine, there may be equipment that moves around you during the treatment, or the couch you lie on may change position slightly.

In some treatment rooms you can listen to music to help you relax. If you would like to listen to your own music, ask your radiotherapy team if this is possible.

During the treatment the radiographers can see you at all times on a screen. They can also hear and talk to you through microphones and speakers in the treatment room.



## Side effects of radiotherapy

You may develop side effects during or after your treatment. These can depend on which area of the brain has been treated and the amount of radiotherapy given. Your radiotherapy team will explain what is likely with your treatment. Some side effects are mild and easy to cope with. Others may be managed with drugs or other treatments.

Side effects usually improve over a few weeks or months after your treatment. Sometimes side effects or symptoms of the brain tumour get worse for a while after treatment has finished. If this happens, you may worry that the treatment is not working. But it is usually a normal reaction to the radiotherapy. Side effects may also happen if your steroids have been reduced or stopped.

Tell your radiotherapy team straight away if your side effects get worse during or after treatment. They can give you advice on how to manage them.

'My Macmillan nurse warned me that for two weeks after the radiotherapy ended, I'd probably feel more and more tired. I found it useful to know what was in store.'

**Claire**

## Tiredness (fatigue)

Radiotherapy often makes people feel tired. Tiredness may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired. But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as short walks, for about 30 minutes a day
- eat a healthy diet and drink plenty of fluids
- ask others for help with everyday jobs.

After treatment finishes, you may continue to feel tired for weeks or months.

Radiotherapy to the brain can cause extreme tiredness 4 to 8 weeks after treatment. You may have very little energy, feel drowsy and spend a lot of time sleeping. It gradually gets better over a few weeks.

We have more information in our booklet and audiobook **Coping with tiredness (fatigue)** (see page 140).

## Headaches

Tell your radiotherapy team if you get headaches during your radiotherapy. They can give you painkillers or steroids (see pages 94 to 95) to help.

## Hair loss

Your radiotherapy team can explain how your treatment may affect your hair. You will lose some hair in the area being treated and sometimes on the opposite side of your head, where the radiation beams exit. Your hair will usually start to grow back within 2 to 3 months of finishing treatment. Sometimes it grows back a slightly different colour or thinner than before. We have more information in our booklet **Coping with hair loss** (see page 140).

'One of the darkest points was my hair falling out. I just looked different. It didn't look like me. But gradually it did because I got used to seeing what it looked like.'

Claire

## Skin irritation

Your skin in the area that is treated may:

- redden
- darken
- feel sore or itchy.

Your radiographer or specialist nurse will give you advice on taking care of your skin. If your skin becomes sore or itchy or changes colour, tell them straight away. They can give you advice and treatments if needed.

Skin reactions should get better within 4 weeks of the treatment coming to an end.

During your treatment, you are usually advised to do the following:

- Wash your hair or scalp gently with lukewarm or cool water. Use non-perfumed shampoo or soap.
- Pat your hair or scalp dry gently with a soft towel. Do not rub it and avoid using a hair dryer.
- Follow the advice given by you radiotherapy team's about using moisturisers.
- Wear a scarf or hat to protect your head from the sun or cold.
- If you shave your head, use an electric razor instead of wet shaving.

Your skin in the treated area may be more sensitive to the sun after treatment. You may find that this area burns more easily. Take extra care in the sun during treatment and for at least a year afterwards. Cover up or use suncream with a sun protection factor (SPF) of at least 30.

## Feeling sick

If you feel sick, your doctor can give you anti-sickness drugs (anti-emetics) to help. If you do not feel like eating, try replacing meals with nutritious, high-calorie drinks. Your doctor may be able to arrange these for you, or you can buy them from most chemists.

We have more information about coping with nausea and a loss of appetite in our booklet **Eating problems and cancer** (see page 140).

## Late effects

Radiotherapy may cause side effects that develop months or, more often, some years after treatment. These are called late effects. Newer ways of giving radiotherapy are better at protecting healthy brain tissue so late effects are becoming less common.

Your doctor will talk to you about the risk of late effects before your radiotherapy starts. Tell them if you are worried about any side effects. The benefits of having radiotherapy usually far outweigh the risk of late effects.

Possible late effects depend on the area of the brain being treated. They may include the following:

- Changes to your memory, thinking and reasoning. This is called cognitive impairment.
- A cataract, if you have radiotherapy close to your eye. The clear lens of the eye becomes cloudy and blurred and you cannot see as well. Cataracts can usually be easily treated with a small operation.
- Changes in hormone levels if your treatment involves the pituitary gland or part of the brain called the hypothalamus. This can cause different symptoms, including changes to your period, changes to your sex drive or severe tiredness.
- A second cancer in the treated area years later. This is rare.

After treatment, you will have regular check-ups with your doctor and nurse. Tell them about any side effects so they can help.

'The radiotherapy made me nauseous and fatigued. I had to sleep most of the day. My biggest symptom now 2½ years later is fatigue.'

**Rose**

# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs affect the way cancer cells grow and divide, but they also affect normal cells.

Chemotherapy may be given:

- at the same time as radiotherapy
- after radiotherapy to make treatment more effective
- as your main treatment
- if a brain tumour comes back after surgery and radiotherapy.

Chemotherapy is usually the main treatment for a lymphoma that starts in the brain (PCNSL).

## When is chemotherapy used?

Your doctor will tell you whether chemotherapy would be a useful treatment for you. The benefits of chemotherapy can depend on:

- the type, grade and biomarkers of a tumour
- your age and general health
- how effective other treatments have been.

Sometimes it is very clear that chemotherapy is likely to be effective in your situation. Or it may be clear that it is not likely to help.

Sometimes the benefit of chemotherapy is not certain. If this is the case, your specialist doctor and nurse will talk to you about the possible advantages and disadvantages of chemotherapy in your situation.

It can be difficult to decide about having chemotherapy. Make sure you ask your doctor and nurse for all the information you need and take your time making your decision. We have more information in our booklet **Making treatment decisions**.

During chemotherapy, your doctor and nurse will check how you are and how well treatment is working. This means you can stop treatment if the disadvantages start to outweigh the benefits.

## Chemotherapy drugs

There are many chemotherapy drugs, but not all of them can be used to treat brain tumours. Doctors use drugs that can pass through the brain's natural protection (called the blood-brain barrier) into the brain and spinal cord.

Different drugs are used in different situations. Your doctor will explain the drugs being used before you start treatment.

The main drugs used to treat primary brain tumours are:

- temozolomide (Temodal®)
- lomustine (CCNU), procarbazine and vincristine on their own or together (called PCV)
- carmustine (BCNU).

Other drugs may also be used – particularly for rarer types of brain tumours. We have more information about these and other chemotherapy drugs on our website. Visit **macmillan.org.uk**



## Chemotherapy on its own

There are different ways of giving chemotherapy for brain tumours. Temozolomide, lomustine or procarbazine are capsules that you swallow. Vincristine is a liquid that is given into a vein (intravenously). Carmustine is sometimes given as an implant called Gliadel wafers directly into the brain during surgery.

You usually take chemotherapy capsules yourself at home. Your doctor or nurse will tell you how and when to take them. You may be asked to take them for a certain number of days or weeks, with a rest period of a few weeks.

To have intravenous chemotherapy, you will need to go to a chemotherapy day unit. A chemotherapy nurse will give it to you as one or more sessions of treatment. You usually have a rest period of a few weeks between each session.

The chemotherapy and the rest period is called a cycle of treatment. The length of a cycle depends on the chemotherapy drugs you are taking. Most cycles are 4 to 6 weeks long. Your doctor or nurse will explain what to expect.

## Chemotherapy given with radiotherapy

If you have a high-grade glioma, you may be treated with temozolomide and radiotherapy together. This means you take temozolomide capsules every day during your course of radiotherapy. The radiotherapy usually lasts 3 to 6 weeks.

Having both treatments causes more side effects, so you need to be physically well enough to cope. You also have more risk of getting a chest infection. To make this less likely, your doctor will prescribe antibiotics.

When you finish radiotherapy, you will also stop taking temozolomide for a time. You then start taking temozolomide again for up to 6 cycles. Your doctor or nurse will explain how often you need to take it.

## Chemotherapy given during surgery

Chemotherapy can also be given as a single treatment directly into the brain. This is sometimes used for people having surgery to remove a high-grade glioma.

During surgery, the surgeon puts small discs called Gliadel<sup>®</sup> implants or wafers into the area of the brain affected by the tumour. The discs contain the chemotherapy drug carmustine. They dissolve over 2 to 3 weeks and the drug is slowly released into the brain. You may have a course of radiotherapy treatment as well.

This type of chemotherapy causes slightly different side effects to capsules or intravenous chemotherapy. Some side effects are caused by the surgery itself. But a very small amount of carmustine will get into your blood. This can reduce the number of white blood cells in your blood and make you more likely to get an infection.

## Sex and contraception

You should use contraception to protect your partner. Small amounts of chemotherapy or other drugs can get into your body fluids. This includes fluid made in the vagina and the fluid that contains sperm. Your doctor may advise that for a few days after treatment you:

- use a condom (or a latex barrier such as a dental dam) for oral sex
- use a condom for vaginal or anal sex.

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. This means it is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell you more about this.

Ask your doctor or nurse for more information about your treatment and contraception.

## Fertility

Unfortunately, some chemotherapy drugs can affect whether you can get pregnant or make someone pregnant (your fertility). But you should still use contraception to prevent pregnancy during your treatment. If you are worried about your fertility, it is important to talk with your doctor before you start treatment. We have more information about fertility that you may find helpful in our booklets:

- **Cancer treatment and fertility – information for women**
- **Cancer treatment and fertility – information for men.**

## Side effects of chemotherapy

Chemotherapy can cause side effects. These can often be managed or controlled with drugs and usually gradually improve after treatment has finished. Different drugs cause different side effects. Your doctor or nurse will explain what to expect.

The main side effects are described here, as well as some ways to reduce or control them. You may get some of these side effects but you are unlikely to get them all. Always tell your doctor or nurse about any side effects so they can help.

## Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

**It is important to follow any specific advice your cancer treatment team gives you.**

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time.

## **Anaemia (low number of red blood cells)**

This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

## **Bruising and bleeding**

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

## Feeling sick

You may feel sick in the first few days after treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

## Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery. You can find our more information in our booklet and audiobook

### **Coping with fatigue.**

## Hair loss

The chemotherapy drugs used to treat brain tumours may cause hair thinning. Complete hair loss is uncommon. Hair starts to grow back about 3 to 6 months after treatment ends. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

We have more information in our booklet **Coping with hair loss** (see page 140).



# Treating symptoms

Before, during or after treatment for a brain tumour, you may also need medicines to help manage symptoms. Symptoms can be caused by the tumour (see pages 19 to 24). Or they may be from treatment.

Symptoms can be difficult to cope with, but they can usually be controlled. Sometimes this is called supportive treatment. It may include taking anti-sickness drugs and painkillers. You may also need steroids to reduce swelling around the tumour or anti-convulsants to help prevent seizures.

## Steroids

Doctors often prescribe drugs called steroids to reduce the swelling around brain tumours. They can make you feel better by improving the symptoms caused by increased pressure inside the skull (for example, headaches). The most commonly used steroid is called dexamethasone.

You may have steroids before, during and also after your main treatment. It is important to take them exactly as your doctor has explained. Your pharmacist or nurse will give you a steroid card. Always carry this card with you. It is so that in an emergency a doctor will know you are taking steroids.

Never stop taking your steroids suddenly as this can make you very ill. Your doctor will give you advice about slowly reducing the dose when it is time to stop taking them.

## Side effects

Steroids can cause the following side effects:

- Indigestion – taking your tablets with food will help with this. Tell your doctor if you have tummy pain. They may prescribe drugs to help or prevent this
- Increased appetite and weight gain – if you are worried about gaining weight, talk to your doctor or nurse.
- Difficulty sleeping – taking your tablets in the morning may help you sleep better.
- Feeling restless or agitated – tell your doctor if this is a problem.
- Raised blood sugar levels – tell your doctor if you are always thirsty or peeing more often than usual. You may need a simple blood or urine test to check your blood sugar levels.

Taking high doses of steroids for a long time may cause more side effects. These can include:

- mood changes, such as feeling sad
- swollen feet and legs
- raised blood pressure.

You may also be more likely to get an infection. Your muscles may get weaker, especially at the tops of your legs. So it is important to do some regular, gentle exercise.

Talk to your doctor or specialist nurse if you are worried about any side effects. These will go away over time as your doctor reduces your steroid dose.

## Anti-convulsants

If you have had seizures, your specialist doctor will usually prescribe drugs called anti-convulsants. These are also called anti-epileptics. There are different types and some people may need more than one. Sometimes it can take a while to get the right drugs or dose to control the seizures.

Frequently used anti-convulsants include:

- levetiracetam (Keppra®)
- sodium valproate (Epilim®)
- lamotrigine (Lamictal®)
- clobazam
- carbamazepine (Tegretol®)
- topiramate
- phenytoin (Epanutin®).

It is important to take your anti-convulsants exactly as your doctor has prescribed. Some anti-convulsants make the contraceptive pill less effective so you may need to use a different contraceptive. Ask your doctor or nurse for more information.

### Side effects

These will depend on which drug or drugs you take. Your doctor or nurse will explain the likely side effects to you.

If you get a skin rash when you start taking anti-convulsants, contact the hospital straight away. This can be a sign of an allergic reaction.

Side effects usually get better after the first few weeks. If they continue, tell your doctor. They may be able to give you a different drug.

# Clinical trials

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

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

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

## Taking part in a trial

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

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

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

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

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

We have more information about cancer clinical trials in our booklet **Understanding cancer research trials (clinical trials)** (see page 140).

## Giving blood and tissue samples

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

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

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

The samples may be used to:

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

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



# AFTER YOUR TREATMENT

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## After treatment

After your treatment has finished, you usually have regular check-ups and scans. This will vary depending on your situation and the type of tumour. Your doctor or nurse can tell you more about this and how often you need to go to the clinic.

These appointments are a good time to talk to your doctor about any worries or problems you have. If you notice any new symptoms between check-ups, do not wait for your next appointment. Contact your doctor or nurse for advice.

Many people find they get anxious before check-ups and scans. This is natural. You may find it helps to talk to someone you trust about how you are feeling.

Or you can call the Macmillan support line on **0808 808 00 00**. Find out more ways to get support on pages 140 to 143.

'Obviously there are some wobbles along the way. Around the time of the MRI scans I tend to overthink and stress myself out. I guess that's natural though.'

**Adam**

# Coping with changes

As you recover from treatment, you may have to adjust to some changes. These may be caused by the treatment you have had or the tumour.

## Tiredness (fatigue)

You are likely to feel tired for some time after treatment. This usually slowly gets better.

Sometimes people have ongoing problems with tiredness. This can make it difficult to do even simple everyday tasks. It may also affect how you feel physically and emotionally.

Always tell your healthcare team if tiredness is making things difficult. There are ways you can manage it. We have more in our information about coping with tiredness in our booklet and audiobook **Coping with fatigue** (see page 140).

## Changes to thinking, mood, motivation or personality

Changes to thinking or behaviour do not affect everyone. If you do have this type of change, it may get better over time.

Sometimes changes are permanent. Your doctor will explain more about your situation.

Some people find it hard to think clearly, concentrate or remember things. Others may react or behave in a way that can seem out of character.

Some people find they have difficulty getting started on any activity (feeling motivated). Although this type of change is not always so obvious, it can have a big effect. You may find it hard to organise your day, get things done or arrange activities like meeting friends or exercising.

With any of these changes it can help to follow a daily routine and try to get enough sleep.

If you have memory problems, you could try to:

- use a diary, mobile phone or tablet calendar to record and easily check your plans
- use pill boxes to organise your medication
- use checklists and alarms to organise your tasks.

If you have difficulty thinking clearly or making decisions, you may be able to have therapy to help with this. This is called cognitive re-training.

Always tell your healthcare team if you notice changes to your thinking, mood or personality. They can talk to you about things that may help. They may arrange for you to see an occupational therapist, neuropsychologist or psychiatrist. They can help you find ways of improving or coping with changes.

Sometimes changes are caused or made worse by the drugs you are taking. For example, steroids can affect your mood. If you think a drug is making things worse, talk to your doctor.

Depression or anxiety can also make it harder to cope. We have more information about coping with difficult emotions in our **How are you feeling? The emotional effects of cancer** booklet.

## Body image

Sometimes treatment or the brain tumour can affect your appearance. Some changes are temporary and some are permanent. Changes may include:

- scars from surgery
- hair loss
- weight gain
- loss of fitness
- changes in movement, balance or co-ordination
- changes in speech.

Your doctor or nurse will talk to you about possible changes before treatment starts.

There is no right or wrong way to feel about a change to your body. You may find a physical change does not upset you. Some people see a body change as a sign of survivorship.

For some people, even a small change in appearance can make them feel less confident. If you are worried about a body change, talk to your doctor or nurse. They can give you advice and support. They may suggest ways to adjust to a change. We have more information about coping with body changes in our **Body image and cancer** booklet (see page 140).



# Help with your recovery

Your healthcare team includes professionals who can help you during and after your treatment. They may be involved in the early stages of your recovery or for a while after your treatment has finished. You may see them when you are in hospital, as an outpatient in a clinic, or in your own home.

## Physiotherapists

A physiotherapist can help you maintain or improve your strength, balance and co-ordination. They can also help you adjust to living with any permanent changes and show you how to use the abilities you have as well as possible. They can show you exercises to do and give you advice and equipment to help you with this.

## Speech and language therapists

A speech and language therapist (SLT) can help if you have problems speaking or communicating clearly. They can also help if you have difficulty eating, drinking, or swallowing. They will give you advice and show you exercises to do.

## Occupational therapists

An occupational therapist will help you get back to doing everyday tasks. This could include washing, dressing, eating, shopping or managing your money. They can also provide equipment to help to make things easier.

## Specialist nurses

A specialist nurse is often involved during and after your treatment in hospital. They are usually the main person you contact if you have problems after treatment.

If needed, a district or community nurse may visit you at home. Your GP or someone at the hospital can arrange this before you go home. The nurse can help you with things like looking after your wound or managing your medicines.

Some people have support from a specialist nurse to manage any symptoms caused by the tumour. This nurse may be called a palliative care nurse or Macmillan nurse. They support people who are living with a brain tumour and are experts in symptom control. They can give you and your family emotional support and information about other services that may help you. They can also support people who are nearing the end of life.

## Emotional help

People often have to cope with some difficult feelings after having treatment. Talking to family and friends can help. Sometimes people need more support to cope with how they are feeling. If needed, your doctor, nurse or GP may be able to arrange expert help from a counsellor or psychologist.

We have more information about coping with difficult emotions in our booklet **How are you feeling? The emotional effects of cancer** (see page 140).

# Taking care of yourself

After treatment, you are likely to feel tired and you may still have some side effects or symptoms. You may be adjusting to changes and learning new ways of coping.

It is important to take care of yourself. Give yourself time and things will gradually improve. Try to follow advice from your healthcare team.

## Rest

Your body needs time to recover and you may need to take time to rest. If you can, ask family and friends to help out so you can save energy for the things you want to do. Do not be afraid to ask if you need things done. Your healthcare team may be able to give you information about organisations that give practical support in your area.

## Eat well

Try to eat healthily, as this can help you recover. Eat plenty of fruit and vegetables. Try to eat less salt, red or processed meat, and foods that are high in saturated fats. We have more information about healthy eating in our booklet **Healthy eating and cancer**.

There has been a lot of publicity about alternative diets for treating cancer over the past few years. If you are thinking about trying one of these, talk to your doctor or nurse. It can be helpful to take control of what you eat but some diets can be unbalanced or harmful. It is also important to know that there is no evidence that these diets can shrink a cancer, increase a person's chance of survival, or cure the cancer.

## Be active

Even regular short walks can help you feel less tired and reduce stress. You can slowly build up what and how much you do, as you recover. We have more information in our booklets **Physical activity after treatment**, and **Move more: Your guide to becoming more active** (see page 140).

## Stop smoking

If you smoke, speak to your GP for advice. Trying to quit smoking may be stressful and difficult to do, but in the long term it will help you feel better and be healthier.

'I started off walking about 50 metres. I gradually felt myself getting stronger. I didn't need quite so much assistance with everything.'

Claire

## Drink sensibly

If you drink alcohol, stick to sensible drinking guidelines:

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

There is more information about alcohol and drinking guidelines at **[drinkaware.co.uk](http://drinkaware.co.uk)**

If you are taking anti-convulsants for seizures, you may need to drink less or not drink any alcohol. Drinking can change how these drugs work and may affect control of your seizures.

## Relax

Learning how to relax may help you cope. You could try:

- deep breathing
- muscle relaxation exercises
- listening to relaxing music
- imagining yourself somewhere safe and calm
- physical activity, such as walking, swimming or yoga
- complementary therapies, such as massage.

You may find guided relaxation exercises online or be able to borrow relaxation CDs or DVDS from your local library. Hospitals or support groups sometimes offer these too. They may also have courses or complementary therapies to help you relax. We have more information in our booklet **Cancer and complementary therapies**.



**'Having to put that mask on and going through the radiotherapy, I learned a lot about myself. I learned about meditation.'**

**Claire**

# Moving forward

You may find it helps to keep life as normal as possible, by staying in contact with friends and keeping up your usual activities. Or you may decide things have changed and you want to set new goals or focus on different priorities. Perhaps you want to spend more time with family, go on holiday or start a new hobby. Sometimes making plans can help you realise that you still have choices.

## Talking to others

When treatment finishes, you might find it helpful to talk about your experience and share your thoughts and feelings with other people. You may find it helpful to join a self-help or support group (see pages 140 to 143). They give you a chance to talk to other people who had similar experiences to you and learn how they coped.

The following organisations can also provide information about local support for people affected by brain tumours:

- **Brain Tumour Charity – [thebraintumourcharity.org](http://thebraintumourcharity.org)**
- **Brain Tumour Support – [braintumoursupport.co.uk](http://braintumoursupport.co.uk)**
- **Brainstrust – [brainstrust.org.uk](http://brainstrust.org.uk)**
- **Headway – [headway.org.uk](http://headway.org.uk)**
- **Meningioma UK – [meningioma.uk](http://meningioma.uk)**

More information about these organisations can be found on pages 144 to 151.

You can also find support online using:

- support groups
- social networking sites
- forums
- blogs
- our online community at **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

You can use these to share experiences, ask questions and get advice.

'It can help to join an online group for people with your condition. You'll find people to relate to. You can talk to them if you'd prefer to protect your family from how you feel.'

**Jordan**



# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

It is common to have many different emotions when you are told you have a brain tumour.

We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

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

Talking to family, friends or other people in a similar situation, may help. Or you may get support from your healthcare team.

**'If you aren't a person who's comfortable bringing up how you're feeling, a good way to get started is to talk about your treatment. Or start a journal. That way you can acknowledge your emotions.'**

**Jordan**

## Shock and denial

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

## Fear and anxiety

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

## Sadness and depression

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

## Avoidance

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

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

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

## Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions and more likely when you feel frightened, stressed, out of control or unwell. You may get angry with your family, friends, or your partner. Tell them you are angry at your illness and not at them. Finding ways to help reduce feelings of stress and anger and help you relax. This can include:

- talking about or writing down how you feel
- doing gentle exercise
- doing deep breathing exercises
- having relaxation therapy
- doing yoga or meditating.

## Guilt and blame

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

## Feeling alone

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

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

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to someone. Our website can help you find out about local support groups. Visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people going through the same thing on our Online Community. Visit **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

## If you need more help

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

Talk to your doctor or nurse if:

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

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

We have more information about coping with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (see page 140).



# Relationships

Your experience of having a brain tumour may have improved and strengthened your relationships with people close to you.

However, having a brain tumour is stressful and this sometimes affects relationships. Any problems usually improve over time, especially if you can talk openly with each other.

## If you have a partner

Coping with a brain tumour can put a lot of strain on a relationship. Some couples become closer but problems sometimes develop, even between close and loving couples. If a relationship was already difficult, the stress of a major illness may make problems worse.

Partners may assume that they know what each other is thinking, but they may not always be right. Talking openly about your feelings and listening to each other can help you understand each other's point of view. We have more information in our booklets **Cancer and your sex life** and **Cancer and relationships**.

## Family and friends

Your family and friends may not always understand if you are not feeling positive. They may not know how much your treatment is affecting your life. Talking about how you feel will help them give you the support you need. We have more information in our booklet **Talking about cancer** (see page 140).

## Talking to children

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

Talking to children about the brain tumour can:

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

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

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

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

## Teenagers

Some teenagers may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence. It's important that they can go on with their normal lives as much as possible and still get the support they need.

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. If they find it hard to talk to you, you can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer, which might be helpful.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer**. We also have a video on our website about talking to children. You can find more information on our website at **macmillan.org.uk**

# Supporting someone with a brain tumour

This can be stressful for everyone involved. It can be especially difficult if you are a main carer. Ask for support from people close to you who are willing to help. Remember to take time off regularly to look after your own physical and emotional health.

If you know someone with a brain tumour, you might find it hard to talk to them about the tumour or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking about how you feel may make them feel alone.

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

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Supporting someone with a brain tumour can be challenging. You may find it difficult to know how to help them manage symptoms or cope after treatment. Some people have permanent physical changes or changes to how they think or behave. Many people have ongoing worries about the risk a tumour will come back.

One of the hardest things to cope with is personality changes in someone you love. Sometimes it can help to remember that these changes are caused by the tumour or treatments. Always tell the specialist doctor or nurse about any changes and especially ones that are difficult. They can give both of you advice and support. They may arrange extra support from other specialists such as a neuropsychologist or occupational therapist.

You might find it helpful to focus on coping with the behaviour, rather than trying to change it:

- Keep to a simple routine and do things the same way and at the same time each day.
- Tell the doctor or nurse if anything makes the behaviour worse, for example tiredness or taking certain drugs.
- Contact the hospital straight away if there are sudden or dramatic changes in behaviour.

## More information and support

You may think it is the person with the brain tumour who needs help. But if you are close to someone affected by a brain tumour, you may need information and support too. You may want to order our free booklets and leaflets:

- **Talking with someone who has cancer**
- **Be there for someone facing cancer**
- **Looking after someone with cancer.**

We also have more information for carers on our website [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers) Our Online Community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community) has groups run by and for carers. If you need to talk, call the Macmillan Support Line free on **0808 808 00 00** (see page 140).





# WORK AND FINANCIAL SUPPORT

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# Work

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

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the brain tumour or treatment may affect your ability to work, they can support you better.

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

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

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

## Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

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

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 140).

'I actually enjoyed going back to work. After a long time on the sofa watching TV, I was glad to be able to do it.'

**Vivek**

# Financial help and benefits

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

## Statutory Sick Pay

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

## Benefits

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

Here are some benefits that you might be able to get.

## Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

## Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and

## Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean you have difficulty getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

## Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

## 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 do not qualify for it, you can apply for Carer's Credit.

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

## Macmillan Grants

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

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

## Insurance

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

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 140). Our Online Community forum Travel insurance may also be helpful. Visit [macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)

## More information

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

You can also get information about benefits and other types of financial help from Citizens Advice (see page 149).

Our booklet **Help with the cost of cancer** has lots more information (see page 140).



# FURTHER INFORMATION

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# About our information

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

## Order what you need

You may want to order more booklets or leaflets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

## Online information

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

## Other formats

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

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

Find out more at [macmillan.org.uk/otherformats](https://www.be.macmillan.org.uk/otherformats)

If you would like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we'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](https://www.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](https://www.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.

## Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit [publications.macmillan.org.uk](https://www.macmillan.org.uk/publications) and search 'book reviews'.

'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**

### Work support

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

## Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

## Other useful organisations

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

### Brain tumour support organisations

#### **Brain and Spine Foundation**

**Helpline** 0808 808 1000

#### **Email**

[helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk)

**[www.brainandspine.org.uk](http://www.brainandspine.org.uk)**

Provides support and information, including an online community, to people affected by brain and spine conditions.

#### **Brain Tumour Action**

**Tel** 0131 466 3116

**[www.braintumouraction.org.uk](http://www.braintumouraction.org.uk)**

Provides information, support and counselling to brain tumour patients, their relatives and friends.

#### **Brain Tumour Research**

**Tel** 0190 886 7200

#### **Email**

[info@braintumourresearch.org](mailto:info@braintumourresearch.org)

**[www.braintumourresearch.org](http://www.braintumourresearch.org)**

Funds research and campaigns to increase investment into brain tumour treatments.

#### **Brain Tumour Support**

**Support line** 0145 442 2701

#### **Email**

[info@braintumoursupport.co.uk](mailto:info@braintumoursupport.co.uk)

**[www.braintumoursupport.co.uk](http://www.braintumoursupport.co.uk)**

Provides support for anyone affected by any type of brain tumour. Support is given from diagnosis and for as long as support is needed.

**Brainstrust****Tel** 0198 329 2405**Email** [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk)**www.brainstrust.org.uk**

Provides information and support, including an online community, to anyone affected by a brain tumour.

**British Acoustic Neuroma Association****Tel** 0124 655 0011**Email** [admin@bana-uk.com](mailto:admin@bana-uk.com)**www.bana-uk.com**

Provides information and support to people affected by acoustic neuroma. Offers online information and forums, support groups, peer-to-peer advice and support.

**Changing Faces****Tel** 0300 012 0275

(Mon to Fri, 10am to 4pm)

**Email**[support@changingfaces.org.uk](mailto:support@changingfaces.org.uk)**www.changingfaces.org.uk**

Supports people who have any condition or injury that affects their appearance. Has a helpline, email, Skype, online information, workshops and skin camouflage clinics.

**Children's Cancer and Leukaemia Group (CCLG)****Tel** 0333 050 7654**www.cclg.org.uk**

Provides information for children and young people with cancer and their families. Also supports health professionals, develops standards of care and promotes research and development.

**Epilepsy Action****Helpline** 0808 800 5050

(Mon to Thu, 8.30am to 8.00pm, Fri, 8.30am to 4.30pm, and Sat, 10.00am to 4.00pm)

**Email** [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)**www.epilepsy.org.uk**

Supports people affected by epilepsy. Provides a freephone helpline, email support, online information and booklets, local branches throughout the UK and an online community.

### **Headway – the brain injury association**

**Helpline** 0808 800 2244

(Mon to Fri, 9am to 5pm)

**Email**

helpline@headway.org.uk

**www.headway.org.uk**

Works to improve life after brain injury, including brain tumours. Provides support, services and information to brain injury survivors, their families and carers. Includes an online community.

### **Meningioma UK**

**Helpline** 0178 737 4084

**Email**

enquiries@meningioma.uk.org

**www.meningioma.uk.org**

Offers support and information to people affected by a meningeal tumour of the brain or spinal cord. Includes an online community and support groups.

### **The Brain Tumour Charity Information and support line**

0808 800 0004

(Mon to Fri, 9am to 5pm)

**Email** support@

thebraintumourcharity.org

**www.thebraintumourcharity.org**

Provides support and information to people affected by a brain tumour, including family and friends. Offers online and phone support and support groups.

### **The Pituitary Foundation**

**Helpline** 0117 370 1320

(Mon to Fri, 10am to 4pm)

**Email** helpline@pituitary.org.uk

**www.pituitary.org.uk**

Provides help to people who suffer from disorders of the pituitary gland, including tumours. Has an online forum and a list of local support groups in the UK.

## General cancer support organisations

### Cancer Black Care

**Tel** 0208 961 4151

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

### Cancer Focus Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

#### **Email**

[nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer in Northern Ireland.

### Cancer Research UK

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**[www.cancerresearchuk.org](http://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](mailto:info@cancersupportscotland.org)

[cancersupportscotland.org](http://cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

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

### Genetic Alliance UK

**[www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)**

An alliance of over 200 patient organisations working to improve the lives of patients and families affected by genetic, rare and undiagnosed conditions.

### Maggie's Centres

**Tel** 0300 123 1801

#### **Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

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

### **Penny Brohn UK**

Helpline 0303 300 0118

(Mon to Fri, 9.30am to 5pm)

#### **Email**

helpline@pennybrohn.org.uk

**www.pennybrohn.org.uk**

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

### **Tenovus**

**Helpline** 0808 808 1010

(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.

### **General health information**

#### **Health and Social Care in Northern Ireland**

**www.hscni.net**

Provides information about health and social care services in Northern Ireland.

#### **NHS.UK**

**www.nhs.uk**

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

#### **NHS Direct Wales**

**www.nhsdirect.wales.nhs.uk**

NHS health information site for Wales.

#### **NHS Inform**

**Helpline** 0800 22 44 88

(Mon to Fri, 8am to 10pm,  
Sat and Sun, 9am to 5pm)

**www.nhsinform.scot**

NHS health information site for Scotland.

**Patient UK****[www.patient.info](http://www.patient.info)**

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

**Financial support or legal advice and information****Benefit Enquiry Line****Northern Ireland**

**Helpline** 0800 220 674

(Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)

**Textphone** 0289 031 1092

**[www.nidirect.gov.uk/money-tax-and-benefits](http://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](http://www.citizensadvice.org.uk)**

**Wales**

**Helpline** 03444 77 2020

**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

**Scotland**

**Helpline** 0808 800 9060

**[www.cas.org.uk](http://www.cas.org.uk)**

**Northern Ireland**

**Helpline** 0800 028 1881

**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

**GOV.UK**

**[www.gov.uk](http://www.gov.uk)**

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

**NIDirect**

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

Has information about benefits and public services in Northern Ireland.

## Equipment and advice on living with a disability

### British Red Cross

**Tel** 0344 871 1111

**Textphone** 0207 562 2050

### Email

[contactus@redcross.org.uk](mailto:contactus@redcross.org.uk)

**[www.redcross.org.uk](http://www.redcross.org.uk)**

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### Disabled Living Foundation (DLF)

**Helpline** 0300 999 0004

(Mon to Fri, 10am to 4pm)

**[www.dlf.org.uk](http://www.dlf.org.uk)**

Provides free, impartial advice about all types of disability equipment and mobility products.

### Scope

**Helpline** 0808 800 3333

(Mon to Sat, 8am to 8pm, and Sun 10am to 6pm)

**Textphone** Use Type Talk by dialling **18001** from a textphone followed by 0808 800 3333.

**Email** [helpline@scope.org.uk](mailto:helpline@scope.org.uk)

**[www.scope.org.uk](http://www.scope.org.uk)**

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

## LGBT-specific support

### LGBT Foundation

**Tel** 0345 330 3030

(Mon to Fri, 10am to 6pm)

**Email** [helpline@lgbt.foundation](mailto:helpline@lgbt.foundation)

**[www.lgbt.foundation](http://www.lgbt.foundation)**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

## Support for carers

### Carers UK

#### Helpline

(England, Scotland, Wales)

**0808 808 7777**

(Mon and Tues, 10am to 4pm)

**Helpline** (Northern Ireland)

0289 043 9843

**www.carersuk.org**

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

## 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** 0207 654 8000

**Email** enquiries@phe.gov.uk

**www.ncras.nhs.uk**

**Tel** (Ireland) 0214 318 014

**www.ncri.ie**

### Scottish Cancer Registry

**Tel** 0131 275 7050

**Email** nss.csd@nhs.net

**www.isdscotland.org/health-topics/cancer/scottish-cancer-registry**

### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

**Tel** 0292 037 3500

**Email** general.enquiries@wales.nhs.uk

**www.wcisuwales.nhs.uk**

### Northern Ireland Cancer Registry

**Tel** 0289 097 6028

**Email** nicr@qub.ac.uk

**www.qub.ac.uk/nicr**



## Disclaimer

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

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Catherine McBain, Consultant Clinical Oncologist. With thanks to: Professor Michael Brada, Consultant Clinical Oncologist; Mr Andrew Brodbelt, Consultant Neuro-oncology Surgeon; Julie Emerson, Specialist Allied Health Professional in Brain and CNS Rehabilitation; Dr Fiona Harris, Consultant Clinical Oncologist; Mr Venkat Iyer, Consultant Neurosurgeon; and Mr Babar Vaqas, Consultant Neurosurgeon.

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

We welcome feedback on our information. If you have any, please contact [\*\*cancerinformationteam@macmillan.org.uk\*\*](mailto:cancerinformationteam@macmillan.org.uk)

## Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at [\*\*cancerinformationteam@macmillan.org.uk\*\*](mailto:cancerinformationteam@macmillan.org.uk)

National Institute for Health and Care Excellence. Brain tumours (primary) and brain metastases in adults. NICE guideline [NG99]. 2018. Available from [www.nice.org.uk/guidance/ng99](http://www.nice.org.uk/guidance/ng99) (accessed October 2019).

Lonjaret, Guyonnet, Berard et al. Postoperative complications after craniotomy for brain tumor surgery. *Anaesth Crit Care Pain Med* 36. 2017.

National Institute for Health and Care Excellence. Improving outcomes for people with brain and other central nervous system tumours. Cancer service guideline [CSG10]. 2006. Available from [www.nice.org.uk/guidance/csg10](http://www.nice.org.uk/guidance/csg10) (accessed October 2019).

Stupp, Brada, van den Bent, Tonn and Pentheroudakis. High-grade malignant glioma: ESMO clinical practice guidelines. *Ann Oncol* 25 (suppl 3). European Society for Medical Oncology. 2014. Available from [www.esmo.org/guidelines/neuro-oncology/high-grade-malignant-glioma](http://www.esmo.org/guidelines/neuro-oncology/high-grade-malignant-glioma) (accessed October 2019).

# 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.



## **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](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

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Valid from

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Expiry date

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Issue no

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Security number

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Signature

Date

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## Don't let the taxman keep your money

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

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

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

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

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



If you'd rather donate online go to [macmillan.org.uk/donate](https://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

**This booklet is about primary brain tumours. It is for anyone who has been diagnosed with a primary brain tumour. There is also information for carers, family members and friends.**

**The booklet explains the signs and symptoms of a primary brain tumour, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.**

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** (7 days a week, 8am to 8pm) or visit [macmillan.org.uk](https://www.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](https://www.macmillan.org.uk/otherformats) or call our support line.

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CANCER SUPPORT**