Understanding primary brain tumours

About this booklet

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

The booklet explains the signs and symptoms of primary brain tumours, and how they may be 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 about secondary brain tumours on our website. Visit macmillan.org.uk/secondary-brain-cancer

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 to help you.

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

At the end of the booklet, 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. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

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

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

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

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

Contents

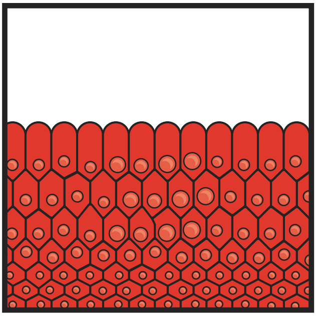
The brain and brain tumours

What is a primary brain tumour?

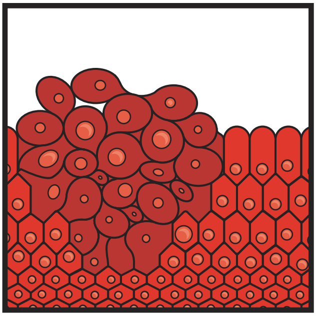
A primary brain tumour is a tumour that starts in the brain.

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

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.Visit macmillan.org.uk/secondary-brain-cancer

The brain and spinal cord

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

The brain controls 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. 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 3 layers of tissue (membranes) called the meninges. The area between 2 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.

The side view of the brain diagram shows a close-up of the meninges and subarachnoid space in the brain.

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.

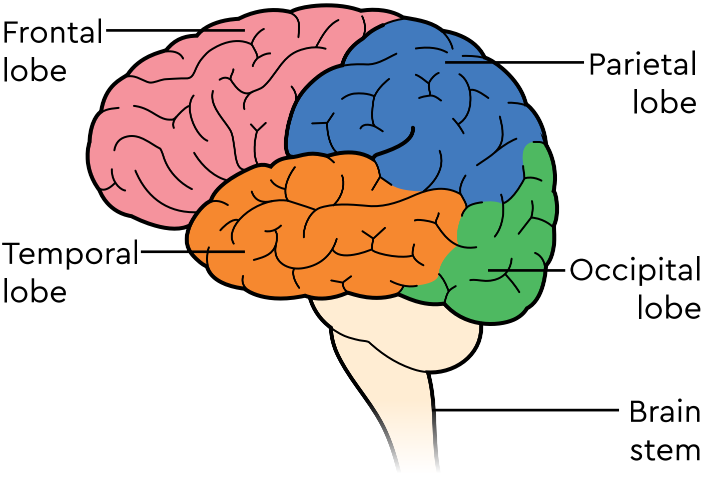
Cerebrum

This is the largest part of the brain and is made up of 2 halves, called hemispheres. The cerebrum controls thinking, memory, behaviour and personality. The right half of the cerebrum controls movement, feeling and vision on 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 4 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 understand words. It also helps us interpret touch and other sensations and makes us aware of our body position.
- The temporal lobe manages memory, feelings and understanding. It processes what we hear and smell. It also plays a part in helping us understand words, as well as helping 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. The cerebellum controls balance and co-ordination.

The cerebellum is separated from the cerebrum by a layer called the tentorium. Tumours in the cerebrum, above the tentorium, are called supra-tentorial. Tumours in the cerebellum, below the tentorium, are called infra-tentorial.

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 and face movements
- swallowing.

Cranial nerves

These are nerves that go from the brain and brain stem to the eyes, nose, ears, tongue, face and shoulders. Cranial nerves 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.

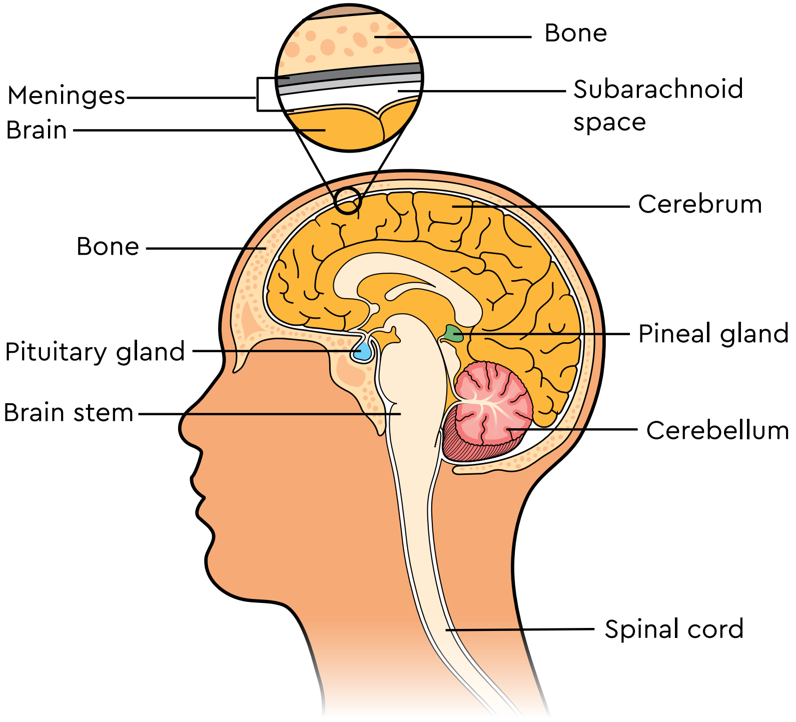
Pituitary gland

The pituitary gland is behind the bridge of the nose and just below the base of the brain. It makes hormones that control other hormone-producing glands in the body. These include 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 2 halves of the cerebrum. It makes a hormone called melatonin that helps control sleep patterns.

Side view of the brain



Symptoms of a primary brain tumour

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

As a tumour grows, it can press on or grow into nearby parts 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.

Symptoms of a brain tumour include:

- headaches – these may make you feel sick or affect your eyesight. They may wake you up at night or be worse in the morning.
- seizures
- changes in personality, behaviour, thinking, reasoning or memory.

Pressure inside the skull may also cause the following symptoms:

- headaches that are worse when coughing or sneezing
- feeling sick (nausea)
- eyesight changes
- problems with balance
- feeling confused.

All these symptoms can be caused by other conditions too. It is important to get them checked by your GP straight away. We have more information about brain tumour symptoms on our website. Visit macmillan.org.uk/signs-and-symptoms-of-a-brain-tumour

> "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, diagnosed with a brain tumour

Symptoms and tumour position

Different parts 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**
Frontal lobe	• Changes in personality or behaviour • Difficulty planning or making decisions • Unsteady or uncoordinated walking • Weakness on 1 side of the body • Memory problems
Parietal lobe	• Problems with speech and understanding • Difficulty writing, reading and doing simple calculations • Difficulty finding your way around • Numbness or weakness on 1 side of the body
Temporal lobe	• Difficulty speaking, such as mixing up your words • Difficulty finding the words you want to say • Memory problems

Occipital lobe	• Sight problems or losing part of your vision
Cerebellum	• Poor co-ordination • Double vision or blurred vision • Unsteadiness • Slurred speech
Brain stem	• Double vision • Dizziness • Unsteady or uncoordinated walking • Facial weakness • Speech or swallowing problems
Pituitary gland	• Symptoms of changing hormone levels, such as infertility, weight gain, high blood pressure, diabetes, mood swings, irregular periods, or enlarged hands and feet • Eyesight problems, such as tunnel vision
Cranial nerves	• Hearing or eyesight problems • Feeling dizzy and having problems with balance • Pain, numbness or weakness of the face • Speech or swallowing problems

Understanding your diagnosis

Finding out you have a brain tumour

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying for a while. Or your diagnosis might have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with a brain tumour. We have more information about possible causes, risk factors and symptoms of brain tumours on our website. We also have information about tests used to diagnose a brain tumour. Visit macmillan.org.uk/brain-tumour

You may be worried about telling people and about what treatment options you will have. You might choose to spend some time reading about the brain tumour, or you may prefer to wait until you see your specialist doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on **0808 808 00 00**. They will be able to talk to you about what has happened and any worries you have.

Types of brain tumour

There are different types of brain tumour. These are some of the more common types. We have more information on our website about the following brain tumours.

Gliomas

More than half of all primary brain tumours are gliomas. These tumours are made up of cells that look like glial cells. Glial cells are the supporting cells in the brain and spinal cord. Types of glioma include the following:

Astrocytoma

An astrocytoma is the most common type of glioma. It is made up of cells that look like a glial cell called an astrocyte. Astrocytomas can be grade 1 to 4. Different grades of astrocytoma have different names. For example, glioblastoma is a type of grade 4 astrocytoma.

Oligodendroglioma

An oligodendroglioma is made up of cells that look like a glial cell called an oligodendrocyte. These cells make up the fatty covering of nerve cells. There are 2 grades of these tumours – grade 2 and grade 3.

Ependymoma

An ependymoma is made up of cells that look like a 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

Meningiomas start in the tissues that cover and protect the brain and spinal cord (the meninges). Meningiomas can be grade 1 to 3. They are almost always benign, low-grade, slow-growing tumours. But a small number are faster-growing.

Vestibular schwannoma (acoustic neuroma)

A vestibular schwannoma (also called acoustic neuroma) is a tumour that usually grows slowly. It grows on the hearing and balance nerve (acoustic or vestibular) between the inner ear and the brain.

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. A lymphoma that starts in the brain or spinal cord is called a primary central nervous system lymphoma (PCNSL). It is rare and usually grows quickly.

You may have slightly different tests and treatment for PCNSL.

Haemangioblastoma

A 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

A medulloblastoma is a high-grade (malignant) tumour that most commonly 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 called 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 tumours can start in the spinal cord, but this is rare. Spinal cord tumours usually cause problems by invading, damaging or 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. Your doctor will use the information about the grade along with results of molecular markers (biomarkers). This can help them to understand how quickly a tumour may grow, and how best to treat it.

Low-grade 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 may cause problems as they grow and press on or invade nearby areas of the brain. This can cause symptoms such as seizures (fits). Other symptoms depend on which part of the brain is affected by the tumour. Sometimes a low-grade brain tumour can change over time and become high-grade.

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

Sometimes brain tumours behave differently to what is usually expected for the grade. This may happen if the tumour has certain genetic changes called molecular markers (biomarkers). For example, some brain tumours that look low-grade can have certain genetic changes that mean they behave more like high-grade tumours.

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 or malignant (cancerous).

Your doctor can explain more.

Grades 3 and 4

These tumours are high-grade (malignant) and grow more quickly.

Molecular markers (biomarkers) tests for brain tumours

Most types of brain tumours are tested for gene changes. These are called molecular marker tests or biomarker tests.

Molecular markers describe markers, proteins, or changes in the genetic structure of a tumour. The samples are tested for changes in the genes in the tumour cells.

Genes are the instructions cells need to work properly. Genes are inside every cell. Sometimes if the gene is permanently changed, it no longer gives the correct instructions. This gene change is called a gene mutation.

There are different types of genetic changes. These can include the loss of a gene, or part of the gene. These can affect how a cell behaves.

Molecular tests can give doctors more information to help:

- confirm a diagnosis
- find out the type of brain tumour
- know how the tumour may behave over time
- understand which treatment is likely to be most effective.

Different types of brain tumours have different types of gene changes (mutations). The most common types for gliomas include:

- IDH
- 1p/19q
- MGMT
- ATRX
- TP53
- TERT.

Having certain gene changes can mean that the brain tumour may behave differently to what is usually expected. For example, in some cases a low-grade tumour with certain genetic changes could behave more like a higher-grade tumour.

Your doctor may use information from both the grade and the molecular tests to:

- understand how quickly a tumour might grow
- help them decide on treatment.

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 biomarkers can be tested with a blood sample. The tests usually need to be sent to a specialist gene laboratory. This means it may take longer to get the results of your tests. The results will help doctors plan your treatment.

How a brain tumour may affect your right to drive

Following diagnosis and treatment for a brain tumour, most people will not be allowed to drive for a period of time. If you have a driving licence, you must tell the licencing agency (DVLA or DVA) that you have been diagnosed with a brain tumour. Advice on driving may vary even between people with the same tumour type. Your doctor or clinical nurse specialist can explain how this applies in your individual situation. You can find more information on the GOV.UK website. Visit gov.uk/guidance/neurological-disorders-assessing-fitness-to-drive

Whether you have to stop driving and for how long depends on:

- the type and grade of your tumour
- how the tumour was diagnosed
- what treatment you are having
- your symptoms and whether you have had any seizures
- the type of driving licence you have – for example Group 1 (cars and motorcycles) or Group 2 (lorries and buses).

You might have to surrender (give up) your licence for a period of time. If you send back your licence, it can be easier to reapply for a new licence. You can reapply for your licence if you meet the required criteria to drive again in the future.

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

You can be fined if you do not tell the DVLA or DVA about a medical condition that affects your driving. If you continue to drive when you have been advised not to, you:

- will not be covered by your insurance
- could be prosecuted if you have an accident.

Reapplying for your licence

If you have surrendered (given up) your licence, you may be able to apply to get it back after a period of time. This will depend on whether you meet the required criteria.

These include:

- how long it has been since any treatment
- your most recent brain scan results
- your current symptoms
- your eyesight.

You can contact the DVLA or DVA and submit forms to reapply. They may ask your doctor for medical information about you.

Your doctor or clinical nurse specialist can tell you more about this.

Your data and the cancer registry

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

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

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

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

Treating brain tumours

Treatment overview

Treatments used for brain tumours include surgery, radiotherapy and chemotherapy. 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
- the symptoms you have.

Treatment for brain tumours

If the tumour is slow-growing and not causing you problems, your doctor may suggest active monitoring or surveillance. This is sometimes called watch and wait. This is when you have regular scans to check for any growth or changes. Doctors will monitor your scans and symptoms carefully and start treatment if needed.

Some people may need to start treatment quickly, for example if the tumour is high-grade.

If you need treatment, you may be offered surgery to try to remove all or as much of the tumour as possible. This is called a gross total resection.

If it is not possible to remove all of the tumour, removing part of the tumour can still be helpful. This is called partial resection, sub-total resection or debulking. Sometimes radiotherapy or chemotherapy may be offered after surgery.

In some cases, where it is not safe to try and remove any of the tumour, or if the diagnosis is uncertain, you might be offered a biopsy.

You may be offered other treatments if:

- you are not able to have surgery
- you have a higher-grade tumour
- it was not possible to remove all the tumour.

Other treatments include radiotherapy and chemotherapy. They may also be offered if you have certain biomarkers. This may mean the tumour behaves differently or has a higher risk of coming back after surgery. Your doctor or specialist nurse will explain the treatment options to you. Some people may have chemotherapy on its own as their main treatment.

Treating rarer tumours

Some rare brain tumours are treated in other ways or in a different order. For example, lymphomas may need a biopsy, then treatment with chemotherapy or radiotherapy, or both. You may also have other types of treatment.

We have more information about rarer brain tumours on our website. Visit macmillan.org.uk/cancer-types

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 treatment and for a while afterwards.

You may need drugs called anti-convulsants to help reduce the risk of seizures. You may also need steroids to reduce swelling around the tumour. Or you may have surgery to reduce pressure inside the skull.

Sometimes a brain tumour cannot be removed or controlled any more. If this happens, you can still have treatment for any symptoms. You will have supportive care from a specialist team including doctors or nurses who are experts at managing symptoms. This is sometimes called palliative care.

We have more information about coping with advanced cancer in our booklet Coping with advanced cancer.

You can order our booklets and leaflets for free.
Visit be.macmillan.org.uk or call us on **0808 808 00 00**.

Before treatment

Before you have treatment, your treatment is carefully planned. Your doctor and nurse will explain your treatment options.

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 does operations (surgery) on the brain and nervous system
- clinical oncologist – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat tumours
- clinical nurse specialist (CNS) – a nurse who gives information and support to people with brain tumours. They are sometimes called a specialist nurse.
- neuroradiologist – a doctor who looks at scans and x-rays to diagnose problems
- neuropathologist – a doctor who looks at cells or body tissue under a microscope to diagnose the tumour type
- neurologist – a doctor who treats conditions of the brain and nervous system.

The MDT may also include:

- a physiotherapist
- an occupational therapist
- a neuropsychologist
- a 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 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 permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision.

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

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

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, they 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. We also have information on our website. Visit macmillan.org.uk/making-treatment-decisions

> **"Some of the stuff my Macmillan nurse talked about was frightening. But she said it in a way that made it easier for me."**
>
> Claire, diagnosed with a brain tumour

The benefits and risks of treatment

Different types of treatment may be used to treat brain tumours. The aim of the treatment will depend on your individual situation. It may be possible to remove the tumour. Or the aim may be to control the tumour and help manage symptoms.

Treatments can have risks and side effects. These may be easy to manage, or they may be more severe. Some side effects are more common while others 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. They can also tell you if your treatment is likely to cause any late effects, and how these can be managed.

Second opinion

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

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

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about. We have more information about getting a second opinion at macmillan.org.uk/second-opinion

Active monitoring

This means regularly checking the tumour to find out if it is changing or growing. It is sometimes called active surveillance or watch and wait. You have regular MRI scans to check the tumour. Then you usually have regular clinic appointments to discuss the results.

Active monitoring may be suggested if:

- you have a low-grade tumour with few or no symptoms
- the risks or side effects of having treatment at this time are likely to be greater than the benefits.

Active monitoring is not suitable for everyone. Some people have active monitoring before they have any treatment. This means you have active monitoring instead of having treatment straight away.

Sometimes you can choose to have active monitoring after surgery. This may mean you can delay having further treatment until it is needed. This might be beneficial in some situations, because treatment can cause side effects. Some of these side effects may be permanent.

Your specialist doctor will explain the benefits and possible risks. They will involve you in any decision-making. Deciding on what is right for you is a joint decision between you and your treatment team.

Your specialist doctor will discuss the results of your scans with you. They will ask how you are feeling and if you have any new symptoms. The scan results and any symptoms you might have help your doctor know if and when to recommend treatment. Your doctor will discuss the possibility of starting treatment if:

- your scan shows that your tumour is growing
- you develop new symptoms.

Some people may not need a clinic appointment after the scan. They may just be sent a letter with the results. If you have any new or changing symptoms between your scans, contact your doctor or specialist nurse straight away.

How often you have a scan and clinic appointment will depend on:

- the type of tumour you have
- how long you have had the tumour for.

You may find it difficult to cope with the uncertainty of active monitoring and not having treatment. You may worry the tumour might grow in between appointments. Make sure you understand why your treatment team are suggesting the option of delaying treatment.

Talk to your treatment team about any feelings of uncertainty. 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.

We have more information in our booklet Making treatment decisions and on our website. Visit macmillan.org.uk/making-treatment-decisions

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 called neurosurgeons 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 for further tests or to diagnose the type of tumour – this is called a biopsy
- remove all of the tumour – this is called a complete resection
- remove as much of the tumour as is safe and possible – this is called partial resection or debulking
- reduce pressure in the skull.

Occasionally, some people may also have chemotherapy given directly into the brain during surgery. If this would be helpful in your situation, your doctor will explain this to you.

Some tumours cannot be removed with surgery. A tumour may be too difficult to reach, or the risk of damaging some healthy parts of 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. 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, such as how you behave
- 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 benefits and risks. If there is a risk of damage to the brain during surgery, they will explain how this may affect you.

Your hair may sometimes be shaved 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 specialist nurse or surgeon can explain what to expect.

Your specialist nurse can give you and your family support. Make sure you have all the information 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 an operation where the surgeon removes a piece of the tumour and sends it to be tested at a laboratory. A biopsy can help give an accurate diagnosis of the tumour. It is done to find out the type and grade of the tumour. Some types of tumour are also tested for genetic changes in the tumour cells. These are called molecular marker (biomarker) tests.

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

The test results give your doctor information about:

- how the tumour may behave and grow
- how the tumour might respond to treatment.

Knowing this helps your doctors plan the best treatment for you.

A biopsy is usually done under a general anaesthetic in hospital. It is a short operation. Sometimes these are done as a day case. Some biopsies are occasionally done under local anaesthetic.

The surgeon uses scans taken before and sometimes during the operation to guide them while taking the biopsy. They may take the biopsy in the following ways:

- Through a small hole they drill in the skull.
- By removing a small piece of skull over the tumour (craniotomy). This is sometimes called an open biopsy. The piece of skull is put back after the biopsy has been taken.

The doctors and nurses will monitor you closely after the operation. It can take 1 to 4 weeks to get results from the biopsy.

> **"In hospital, they said 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, diagnosed with a brain tumour

Craniotomy

To remove part or all of the tumour, you usually 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. They will usually fix it in place with small titanium plates.

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 1 end and an eyepiece on the other. This type of surgery is sometimes called endoscopic or keyhole surgery.

For some types of tumours affecting the pituitary gland or at the base of the skull, this surgery can also be done by passing the endoscope up the nose into the brain.

Your surgeon will explain which type of surgery is best for you.

If it is not possible to remove the whole tumour, the surgeon will remove as much as they can. This is called partial or sub-total 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 helps the surgeon decide which areas to remove. It is not used in all brain tumour operations. This is because some types of tumours will not glow with this drink. If your surgeon feels it would be helpful, they will discuss it with you.

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

Craniotomy while you are awake (awake craniotomy)

Sometimes the surgeon will suggest a craniotomy while you are awake. This may be offered if they think that keeping you awake during the operation may make it possible to:

- remove more of the tumour
- remove it more safely.

This is instead of general anaesthetic, when you are put to sleep for the whole operation.

This may sound frightening, but people usually cope with it well. You will have lots of chances to discuss the risks and benefits and any worries you may have with the neurosurgical team. This includes doctors, nurses and psychologists.

Because you are awake, the surgical team 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 remove more of the tumour. If there are changes to your speech or thinking, the surgeon stops operating and assesses the situation.

This surgery can be done with sedation or a general anaesthetic for the first part of the surgery. This is when the surgeon makes an opening through the skull. 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.

Some surgeons may suggest doing the operation with you awake throughout. They will numb the scalp and head with local anaesthetic injections.

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.

Surgery to reduce pressure in the skull

Surgery may be needed to drain a build-up of fluid within the brain. This may happen if there is a blockage stopping the fluid from draining to another area of the body. This is called hydrocephalus.

If a brain tumour blocks the flow of fluid (CSF) around the brain, pressure can build up and cause symptoms. Treatments can include placing a shunt, or an endoscopic third ventriculostomy (ETV), or removing the tumour to unblock the blockage.

Shunts

A shunt is an operation to place a long, thin plastic tube into the brain. The shunt lets some of the fluid drain from the brain to another area of the body. Usually this is into the tummy (abdomen). It may make you feel better by reducing your symptoms.

You cannot see the shunt from outside the body. But you may be able to feel it under the scalp or in your abdomen. Your surgeon will explain what to expect. Sometimes shunts will be removed, or they can be left in for many years.

Endoscopic third venticulostomy (ETV)

An endoscopic third ventriculostomy uses keyhole (endoscopic) surgery to make a small hole in the lining of the ventricles in the brain. It lets fluid move past the blockage and reduces the pressure on the brain.

Other types of surgery

Another type of surgery may be used to place an Ommaya reservoir in the brain instead of a shunt.

Ommaya reservoir

Sometimes a tumour has a fluid-filled part, called a cyst. If the tumour cannot be removed, you may have an Ommaya reservoir placed into the cyst.

An Ommaya reservoir is a small hollow disc that sits under the skin of the scalp. It is connected to a tube that goes into the fluid-filled part of the tumour. If pressure builds up after the operation, your doctor can put a small needle through the skin into the disc and drain some fluid from the tumour. After it is in place, it can be drained more than once if needed.

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 blood, heart and lung tests.

If you smoke, try to stop or cut down. This will help 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. We have more information about stopping smoking on our website. Visit macmillan.org.uk/stop-smoking

If you are not already taking them, you may be given steroids. They 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.

Talk to your doctor before your surgery if you take the following drugs:

- aspirin
- clopidogrel
- non-steroid anti-inflammatory drugs such as ibuprofen.

These drugs can thin the blood and increase the risk of bleeding after surgery. If you are on any blood-thinning medication, talk to your doctor before your surgery. They will give you advice about when you can take them.

You are usually admitted to hospital on the morning of your operation. Sometimes you will be admitted the day before.

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 doctor who gives you the anaesthetic (anaesthetist).

After your operation

When you wake up, you will be in the recovery unit. After this you usually go back to your ward. Sometimes you may go to the intensive care ward or high-dependency unit for about 24 hours.

The doctors and nurses will monitor you carefully. They will:

- do checks, such as testing your reflexes and seeing how your eyes react to light
- ask questions and ask you to do things, to check you understand what is happening and can follow instructions
- take your temperature and blood pressure.

Your face and eyes may be swollen and bruised. This swelling and bruising should improve within a few days. Sometimes a swelling filled with fluid develops under the operation scar. This is called a meningocele. This may take week or months to go down, but it will 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 you are 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 to give you fluids until you can eat and drink again.
- A drain from your wound 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 can move around more.

Pain

You may have a headache when you wake up after the operation. The nurses will give you regular painkillers. Headaches usually get better after a few days. Always tell your nurse or doctor if you have pain, or if the pain gets 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. You will usually be given special stockings to reduce the risk of developing a clot.

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.

You can usually wash your hair around 3 days after your surgery with the medicated shampoo the nurses give you. But try to keep your wound dry when you are washing your hair. If you do get water on the wound, gently pat it dry with a clean towel.

Once your stitches have been removed you can usually wash with your normal shampoo. Do not scrub the wound. Some people find their wound feels tight. This is a normal feeling. It is important not to pick or pull the scab off, even weeks after surgery.

Your doctor or nurse will explain how to look after the wound once you go home.

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 support you might need.

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

- a fever (high temperature)
- the wound swelling, feeling warm or leaking
- the wound looking red in people with white skin, or darker in people with black or brown skin
- 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 1 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 may also find our booklets Healthy eating and cancer and Physical activity and cancer helpful.

Your surgeon and healthcare team will tell you what to expect and how you can help your own recovery. You can contact your clinical nurse specialist if you are worried about anything.

You will usually go back to the hospital a few weeks after your operation for a check-up and to discuss your results.

You are not usually allowed to drive for a period of time after a brain biopsy or brain surgery. Contact the DVLA or DVA for more information about this. You can also talk to your surgeon or specialist nurse.

Radiotherapy to the brain

Radiotherapy uses high-energy rays to destroy the tumour cells and control the tumour, while doing as little harm as possible to normal cells. Radiotherapy machines 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 a tumour comes back.

Radiotherapy is always carefully planned by a team of experts. This includes a clinical oncologist and radiographers, who are experts in giving radiotherapy treatment. They will explain your treatment plan and what to expect.

Radiotherapy can be given in different ways.

External beam radiotherapy

Radiotherapy for a brain tumour uses a radiotherapy machine that aims high-energy rays at the brain. 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 fraction.

Your radiotherapy treatment is planned carefully to give the highest possible dose to the tumour, while limiting the dose to the surrounding healthy brain tissue.

There are different techniques used to shape and focus the radiotherapy beams to treat the tumour. These include intensity-modulated radiotherapy (IMRT) and volumetric-modulated arc radiotherapy (VMAT). Different hospitals may use different techniques, but they all work in similar ways and have the same benefits.

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 treatment itself only takes a few minutes. Your doctor, specialist nurse or radiographer will explain your treatment and how long it will take.

Other ways of having radiotherapy include:

- stereotactic radiosurgery (SRS)
- stereotactic radiotherapy (SRT)
- proton beam therapy.

The type of radiotherapy used will depend on the type and size of the brain tumour and your individual situation.

Stereotactic radiosurgery (SRS)

Stereotactic radiosurgery (SRS) gives radiotherapy as a single higher dose to a small area. SRS does not involve any surgery.

There are different types of radiotherapy machines that can deliver SRS. These include:

- Gamma Knife®
- CyberKnife®
- linear accelerator (LINAC).

The amount of time it takes to have the treatment depends on the type of machine that is used. A session of treatment can take from about 15 minutes up to 4 hours. Sometimes, it may take longer.

SRS is not suitable for everyone with a brain tumour. It is usually only used to treat small tumours. The most common type of tumours treated with SRS are brain metastases. These are tumours that have travelled to the brain from other parts of the body. SRS is also used for other types of tumours, including small benign (non-cancerous) tumours.

Your doctor can explain which treatment is best for you and how long the treatment may take.

Sometimes, you may have this type of radiotherapy in smaller doses over a number of days or weeks. This is called stereotactic radiotherapy (SRT). Each daily dose is called a fraction.

Stereotactic radiotherapy (SRT)

SRT is another way of accurately focusing external beam radiotherapy.

You may have SRT in the same way as standard external beam radiotherapy. This means using short, daily treatments usually over 6 weeks. This is called fractionated stereotactic radiotherapy (FSRT).

You may have SRT as a few sessions of higher-dose treatment. You usually have it for 3 or 5 sessions. This is called stereotactic radiotherapy or hypo-fractionated stereotactic radiotherapy.

A session of treatment usually takes about 15 to 30 minutes, depending on the type of machine used. SRT is not suitable for everyone with a brain tumour. It may depend on the type and size of the tumour.

Proton beam therapy

Proton beam therapy is a type of external beam therapy that uses protons instead of high-dose x-rays. Protons are parts of atoms. The protons are shaped into a beam that is targeted at the cancer.

Proton beam therapy is not used for all types of brain tumours. It is only used for a small number of people with certain types of brain tumour. For adults, these may include some tumours affecting the base of the skull and a rare type of tumour called medulloblastoma. Your doctor will explain if this treatment might benefit you.

You have proton beam therapy using specialised equipment that is not available in all UK hospitals. You may be referred to a specialist hospital if you are having this type of treatment. We have more information about having proton beam therapy at macmillan.org.uk/proton-beam-therapy

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.

For 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. This makes the treatment as accurate as possible.

The radiotherapy team makes the mask for you before your treatment. Masks are usually made from plastic mesh that is moulded to fit the shape of your face. This is a simple procedure where the plastic netting is warmed in a water bath. Once it is warm, it is gently stretched over your face.

The mask fits tightly but should not be uncomfortable. You only wear it during your planning scans and treatment sessions. You can breathe normally while you are wearing it.

If you are having SRS you may wear a light-weight metal head frame. Head frames are usually fitted on the same day as your treatment. Some frames can be fitted 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 nervous about wearing a mask or head frame. Most people cope well with the support of the radiotherapy team. Tell your team if you are worried or uncomfortable. They can help you.

We have more information about how a radiotherapy mask is made on our website. Visit macmillan.org.uk/radiotherapy-masks


SIEM
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Planning your treatment

During your planning appointment, you will have a scan of your brain. You wear the mask or frame while having a CT scan. Most people will also have an MRI scan.

Your radiotherapy team uses information from the scans to plan your treatment. They will explain your treatment plan and how many times you need to visit the radiotherapy department.

The radiographers help you get into position for the scan. 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 help 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 and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to.

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 may use foam supports to help.

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. They may take some x-rays during treatment to make sure you are in exactly the right position.

Having radiotherapy is not painful. You may hear a slight buzzing noise from the radiotherapy machine. The radiotherapy machine may move around you during the treatment, or the couch you lie on may change position.

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 and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to.

Side effects of radiotherapy

You may develop side effects during or after your treatment. These can depend on:

- the area of the brain that has been treated
- how much radiotherapy you have.

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 ends. 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 the amount of steroids you have been taking have been reduced or stopped.

If your side effects get worse during or after treatment, tell your radiotherapy team straight away. They can give you advice.

Tiredness (fatigue)

Radiotherapy often makes people feel tired. Tiredness (fatigue) 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:

- getting plenty of rest
- doing some gentle exercise, such as short walks, for about 30 minutes a day
- eating a healthy diet and drink plenty of fluids
- asking others for help with everyday jobs.

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 usually gradually gets better over a few weeks. But some people may continue to feel tired for weeks or months. Or sometimes longer.

We have more information about coping with fatigue on our website . Visit macmillan.org.uk/tired

Headaches

Tell your radiotherapy team if you get headaches during radiotherapy. They can give you painkillers or steroids to help.

> **"My Macmillan nurse warned me that for 2 weeks after radiotherapy ends, I'd probably feel more and more tired. I found it useful to know what was in store."**
>
> Claire, diagnosed with a brain tumour

Hair loss

Your radiotherapy team can explain how your treatment may affect your hair. You may lose some hair in the area being treated. You may also lose hair on the opposite side of your head. This is where the radiation beams exit. Your hair will usually start to grow back within 2 to 3 months after treatment ends. Sometimes it grows back a slightly different colour or thinner than before.

We have more information in our booklet Coping with hair loss and on our website at macmillan.org.uk/hair-loss

You can order our booklets and leaflets for free.
Visit be.macmillan.org.uk or call us on **0808 808 00 00**.

> **"One of the darkest points was my hair falling out. I just looked different. It didn't look like me. But gradually I got used to seeing what I looked like."**
>
> Claire, diagnosed with a brain tumour

Skin irritation

Your skin in the treated area may become sore or itchy.

If you have white skin the treated area may become red. If you have black or brown skin, the area might get darker.

Your radiographer or specialist nurse will give you advice on taking care of your skin. Tell your radiotherapy team straight away if you have these symptoms. They can give you advice and treatments if needed.

Skin reactions should get better within 4 weeks of treatment finishing.

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. Avoid rubbing it or using a hair dryer.
- Follow the advice your radiotherapy team gives you 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 1 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 to help. If you do not feel like eating, try having nutritious, high-calorie drinks. You 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 on our website. Visit macmillan.org.uk/eating-problems

Fits (seizures)

Radiotherapy can cause some swelling in the brain. This can make it more likely to have a seizure. This may depend on the area you are having treatment, or if you were already having seizures before treatment. Medication to control seizures can help reduce the risk of seizures. These are called anticonvulsants. It is important to talk to your doctor, nurse or radiographer about any symptoms you have.

Late effects of radiotherapy to the brain

Radiotherapy can cause side effects that develop months or years after treatment. These are called late effects. Current ways of giving radiotherapy are better at protecting healthy brain tissue, so late effects are becoming less common and less severe.

Possible late effects depend on the amount and area of the brain being treated.

Your doctor will talk to you about the risk of late effects before your radiotherapy starts. This is called consent for treatment. You can weigh up the benefits and risks of having radiotherapy. The benefits of having radiotherapy usually outweigh the risk of late effects.

After treatment, you will have regular follow-up appointments with your doctor, nurse or radiographer. Tell your treatment team if you are worried about any side effects. They can help you manage them.

We talk about the late effects of radiotherapy to the brain over the next 3 pages.

Changes to your memory, thinking or reasoning

This is called cognitive impairment. Some short-term memory loss, or being forgetful, is common after radiotherapy. This can sometimes get worse in the years after treatment. Your doctor, specialist nurse or radiographer can talk to you about ways to help you cope with this. We also have more information on how to manage cognitive changes.

Changes in hormone levels

If your treatment involves the pituitary gland or part of the brain called the hypothalamus your hormone level may change. This can cause different symptoms, including:

- severe tiredness
- changes to your period
- changes to your sex drive.

You may have hormone treatments. You may also be referred to a doctor specialising in hormone problems, called an endocrinologist.

Hearing problems

You may notice a ringing sound in your ear (tinnitus), muffled hearing or a feeling of having blocked ears. You may be referred to a specialist team called the ear, nose and throat (ENT) team.

Eye problems

If you have radiotherapy close to your eye, your eye might feel dry. This can be treated with eye drops. The clear lens of the eye might become cloudy or blurred which means you cannot see as well. This is called a cataract. If a cataract develops, it is usually some years after radiotherapy. Cataracts can usually be easily treated with a small operation. Eye problems are less common with modern radiotherapy techniques.

Radiation necrosis

Radiation necrosis is when a small area of brain tissue is damaged by radiotherapy. Many people do not have any symptoms, but a small number of people may. Symptoms are different for different people but can include nausea, headaches and risk of seizures. Your doctor, specialist nurse or radiographer can explain more about this. They can give you advice. They may also give you medicine to help.

A higher risk of having a stroke

This is due to changes in the small blood vessels in the brain in the years after treatment. Having a healthy diet, exercising regularly and not smoking can reduce the risk of a stroke. If you have high blood pressure or diabetes, it is important they are controlled and treated. Make sure that any doctors treating you know that you have had radiotherapy treatment to the brain.

Second cancer

Some people may develop a second cancer in the treated area years later. This is less common with modern radiotherapy techniques. Your doctor will explain more about this when you sign your consent form for treatment.

Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. These drugs affect the way cancer cells grow and divide, but they also affect normal cells.

You may have radiotherapy:

- at the same time as radiotherapy – this is called concurrent treatment
- after radiotherapy – this is called adjuvant treatment
- as your main treatment
- if a brain tumour comes back.

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

When is chemotherapy used?

Your doctor will tell you if chemotherapy might be helpful for you. Side effects of drugs may vary. Your doctor will talk to you about the risks, benefits and side effects of having chemotherapy. If you decide to have chemotherapy, your treatment team will explain the side effects and give you a chance to ask questions.

Having chemotherapy may depend on:

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

During chemotherapy, your doctor and nurse will check how you are. You will have follow-up brain scans to check how well treatment is working.

Chemotherapy drugs

The main drugs used to treat primary brain tumours are:

- temozolomide
- CCNU, also called lomustine
- procarbazine
- vincristine.

We have more information about these drugs at macmillan.org.uk/treatments-and-drugs

You may have 1 drug, or you may have a combination of drugs.

When CCNU, procarbazine and vincristine are given together, the combination is called PCV. Or you may only have 1 or 2 of those drugs. Your doctor will explain which chemotherapy drugs you may have.

Other drugs may also be used if you have a rarer type of brain tumour.

Chemotherapy given with radiotherapy

If you have a high-grade glioma (glioblastoma), you may have 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 may cause more side effects, so you need to be physically well enough to cope. You also have more risk of getting a chest infection. To help with this, 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. You usually take it for 5 days every 4 weeks. Your doctor or nurse will explain how often you need to take it.

Chemotherapy on its own

There are different ways of giving chemotherapy for brain tumours. Temozolomide, lomustine and procarbazine are capsules you swallow. Vincristine is a liquid that is given into a vein (intravenously).

You usually take chemotherapy capsules 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.

Intravenous chemotherapy is given in a chemotherapy day unit. A chemotherapy nurse will give it to you as 1 or more sessions of treatment. You usually have a rest period of a few weeks between each session.

Each session of chemotherapy is called a cycle. The length of the cycle depends on the chemotherapy drug. The number of cycles you have will depend on your tumour type and your individual situation.

For example, PCV is given for 10 days every 6 weeks. Temozolomide capsules are usually taken for 5 days every 4 weeks.

Rarely, a chemotherapy drug called carmustine is given as an implant of small discs called Gliadel wafers. These are put directly into the brain during surgery. We have more information about Gliadel wafers on our website at macmillan.org.uk/gliadel-wafers

Your doctor, nurse or pharmacist will explain what chemotherapy you might have and what to expect.

Sex and contraception

If you have sex in the first few days after chemotherapy, you should use barrier protection such as a condom or dental dam. This will protect your partner if any of the drug is in your semen or vaginal fluid.

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. 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, nurse or pharmacist for more information about your treatment and contraception. We have more information in our booklet Cancer and your sex life.

Fertility

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 in our booklet Cancer and fertility.

You can order our booklets and leaflets for free.
Visit be.macmillan.org.uk or call us on **0808 808 00 00**.

Side effects of chemotherapy

Chemotherapy can cause side effects. These can often be managed or controlled with drugs. Side effects 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. You may get some side effects we have not mentioned here. 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 your white blood cell count is low, you may be more likely to get an infection. A low white blood cell count is called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. If you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

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

Your white blood cell count 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, until your cell count increases.

Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may feel:

- very low in energy
- breathless
- dizzy and light-headed.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia. 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.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red, brown or purple spots that may look like a rash – these spots can be harder to see if you have black or brown skin.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Feeling sick

Your doctor, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or if you are sick (vomit) 1 to 2 times in 24 hours, contact the hospital on the 24-hour number as soon as possible. They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

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.

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.

You can order our booklets and leaflets for free.
Visit be.macmillan.org.uk or call us on **0808 808 00 00**.

Immunotherapy and targeted therapy for brain tumours

Immunotherapies are treatments that use the immune system to find and attack cancer cells. Targeted therapies target something in or around the cancer cell that is helping it grow and survive.

These types of treatment are not currently routinely used to treat brain tumours in the UK. This is because so far clinical trials have not shown these treatments to be more effective than other treatments for brain tumours.

But these types of treatments are being researched further in clinical trials. Depending on your situation, you may be able to take part in a clinical trial. If you have questions about this, talk to your doctor.

We have more information on immunotherapy and targeted therapy on our website. Visit macmillan.org.uk/immunotherapy and macmillan.org.uk/targeted-therapy

Treating symptoms

You may need medicines to help manage symptoms. This may be before, during or after treatment for a brain tumour. Symptoms can be caused by the tumour. 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 drugs to help reduce the risk of seizures. These are called anti-convulsants.

Steroids

Drugs called steroids are given to help reduce the swelling around brain tumours. They can make you feel better by improving the symptoms caused by increased pressure inside the skull, such as headaches. The most commonly used steroid is called dexamethasone.

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

Never stop taking your steroids suddenly, as this can make you 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. 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 your sleep.
- Feeling restless or agitated – tell your doctor if this is a problem.
- Raised blood sugar levels – tell your clinical nurse specialist or 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. 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 steroids are reduced.

Managing seizures with anti-convulsants

If you have had seizures, your specialist doctor will usually prescribe drugs called anti-convulsants. These are also called anti-epileptic drugs (AEDs). There are different types, and some people may need more than 1 type. Sometimes it can take a while to get the right drugs or dose to control the seizures.

These treatments are usually only started if you have had seizures. But occasionally they may be suggested to help prevent seizures. For example, they may be given around the time of your surgery.

Commonly used anti-convulsants include:

- levetiracetam (Keppra®)
- sodium valproate (Epilim®)
- lamotrigine (Lamictal®)
- clobazam
- topiramate (Topamax)
- carbamazepine (Tegretol®)
- brivaracetam (Briviact)
- lacosamide (Vimpat).

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 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 which can improve side effects.

Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website. Visit macmillan.org.uk/clinical-trials

Taking part in a clinical trial

Your 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.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of tumour you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

After your treatment

After treatment

After your treatment has finished, you usually have regular check-ups and scans. How often you have these depends on such things as:

- the type of tumour
- the grade,
- if there were any gene changes
- the treatments you had.

Your doctor or nurse can tell you more about this.

These appointments are a good time to talk to your doctor or specialist nurse 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 specialist 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**.

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. These changes will depend on:

- the type of tumour
- where the tumour is in the brain
- the treatments you had.

Most side effects are short-term and will improve gradually when the treatment is over. Some treatments can cause side effects that do not get better. These are called long-term effects. You may also get side effects that start months or years later. These are called late effects. Your doctor or specialist nurse can tell you what you could expect.

We talk about some possible side effects over the next few pages.

> **"After my surgery I've had to learn everything again – walking, running, cycling. My balance has been especially affected."**
>
> Mason, diagnosed with high-grade anaplastic astrocytoma

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. They may also do some tests to check if there are any other causes of your tiredness that can be managed.

Try to pace yourself and plan your days so you have time for regular rests. Having a healthy diet and doing some gentle exercise, like short walks, can give you more energy. We have more information in our booklets:

- Coping with fatigue (tiredness)
- Physical activity and cancer
- Healthy eating and cancer.

Our information on taking care of yourself may also help.

You can order our booklets and leaflets for free.
Visit be.macmillan.org.uk or call us on **0808 808 00 00**.

> "The fatigue can be really bad. Some days I feel fine. Other days I'm being sick. Even a 45-minute trip to do some groceries leaves me completely shattered. „

Mason, diagnosed with high-grade anaplastic astrocytoma

Changes to thinking, mood, motivation or personality

Changes to thinking or behaviour do not affect everyone. If you 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. 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 calendar to record and check your plans
- pill boxes to organise your medication
- 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. 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, tell your doctor or specialist nurse.

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

Body image

Sometimes treatment or the brain tumour can affect your appearance or how you feel about yourself. 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 specialist 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. Some people find that physical changes do not upset them. For others, 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 help you adjust. We have more information about coping with body changes in our booklet Body image and cancer.

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 meet them when you are in hospital, in a clinic, or in your own home.

Your doctor or nurse may refer you to a neurological rehabilitation (neuro-rehab) service. This service may be able to refer you to a physiotherapist, speech and language therapist, or occupational therapist, and offer emotional support.

Who you may meet will depend on the help that you need. You may have help from 1 of the following healthcare professionals.

Physiotherapist

A physiotherapist can help you maintain or improve your strength, balance and co-ordination. They can 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 give you exercises, advice and equipment to help.

Speech and language therapist

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 therapist

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 nurse

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 are experts in symptom control and support people who are living with a brain tumour. They can give you and your family emotional support and information about other services that may help. They can also support people who are nearing the end of life.

Counsellor or psychologist

People often have to cope with some difficult feelings after treatment. Talking to family or 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..

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 or friends to help with things you need done. This way you can save energy for the things you want to do. Your healthcare team can give you information about any organisations that give practical support in your area.

Be active

Going for regular short walks can help you feel less tired and reduce stress. You can slowly build up what and how much you do. We have more information in our booklet Physical activity and cancer.

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.

There have been a lot of claims made over the past few years about alternative diets for treating tumours. If you are thinking about trying one of these, talk to your doctor or nurse.

There is currently no evidence that these diets can shrink or cure a tumour, or increase someone's chance of survival. Some diets may lack important nutrients or be unbalanced in other ways. They may even be harmful. This may lead to unplanned weight loss during treatment and may make side effects worse.

It can be confusing to have different advice about what to eat. Dietitians, doctors and specialist nurses recommend a well-balanced and enjoyable diet as the best way to keep healthy.

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

Stop smoking

If you smoke, speak to your GP for advice. Stopping smoking may be stressful and can be difficult. But in the long-term it will help you feel better and be healthier. There is lots of support to help you stop.

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

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 from your local library. Hospitals or support groups sometimes offer these too. They may also have courses or complementary therapies to help you relax. Before you use a complementary therapy, talk to your doctor or specialist nurse. Some therapies may affect your treatment.

We have more information in our booklet Cancer and complementary therapies.

> **“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

Planning ahead

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 you want to set new goals or focus on different priorities. 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 support group. They give you a chance to talk to other people who had similar experiences and learn how they coped.

Organisations such as the Brain Tumour Charity, Brain Tumour Support, Brainstrust, and Headway can also provide information about local support for people affected by brain tumours.

You can also find support online using:

- support groups
- social networking sites
- forums
- blogs
- our online community at macmillan.org.uk/community

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

Your feelings and relationships

Your feelings

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

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

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

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

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

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

Relationships

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

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

If you are a family member or friend

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

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

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

Talking to children and teenagers

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

The website riprap.org.uk offers information and support for teenagers who have a parent with cancer.

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

Supporting someone with a brain tumour

Supporting someone with a brain tumour can be difficult, especially if you are a main carer. Ask for support from people close to you who want to help. Remember to take time off regularly to look after your own physical and emotional health.

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. It may help to remember that these changes are caused by the tumour or treatments. They are not intentional. Always tell the doctor or specialist 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. The following tips might help:

- 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.

We have more information that you many find helpful in our booklet Looking after someone with cancer.

Work and financial support

Work

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

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

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

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

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

Help with money and benefits

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

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

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

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them 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 if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

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

Macmillan Grants

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

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

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

Insurance

If you have, or have had, a brain tumour, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful.

> "Michael had lost a lot of weight while in hospital for surgery. When he returned home, we found all his clothes were too big for him. The Macmillan Grant allowed us to buy him new clothes which helped him feel better in himself. „

Sarah, whose husband Michael was diagnosed with a brain tumour

Further information

About our information

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

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

Order what you need

You may want to order more booklets or leaflets like this one. Visit 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 You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

The language we use

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

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

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We 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.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. 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 accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. 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 energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

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

Call us on **0808 808 00 00** to find out more about Macmillan Grants.

Help with work and cancer

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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser.

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Brain tumour support organisations

Brain and Spine Foundation

Helpline **0808 808 1000**
www.brainandspine.org.uk
Provides support and information including an online community for people affected by brain and spine conditions.

Brain Tumour Charity

Information and Support Line **0808 800 0004**
www.thebraintumourcharity.org
Provides support and information to people affected by a brain tumour. Includes online and phone support and support groups.

Brain Tumour Research

Tel **0190 886 7200**
www.braintumourresearch.org
Funds research and campaigns to increase investment into brain tumour treatments.

Brain Tumour Support

Support line **0145 442 2701**
www.braintumoursupport.co.uk
Provides support for anyone affected by any type of brain tumour, at any point from diagnosis and for as long as support is needed.

Brainstrust

Tel **0198 329 2405**
www.brainstrust.org.uk
Provides information and support including an online community for anyone affected by a brain tumour.

British Acoustic Neuroma Association

Tel **0124 655 0011**
www.bana-uk.com
Provides information and support to people affected by acoustic neuroma. Includes online information and forums, support groups, peer-to-peer advice and support.

Changing Faces

Tel **0300 012 0275**
www.changingfaces.org.uk
Supports people who have any condition or injury that affects their appearance. Has a helpline and online information, and runs workshops and skin camouflage clinics.

Epilepsy Action

Helpline **0808 800 5050**
www.epilepsy.org.uk
Supports people affected by epilepsy. Provides freephone helpline, email, online information and booklets, local branches throughout the UK and anonline community.

Genetic Alliance UK

www.geneticalliance.org.uk
0300 124 0441
An alliance of over 200 charities and support groups working together to improve the lives of people in the UK with genetic, rare and undiagnosed conditions.

Headway – the brain injury association

Helpline **0808 800 2244**
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.

Pituitary Foundation

Helpline **0117 370 1371**
www.pituitary.org.uk
Provides help to people who suffer from disorders of the pituitary gland, including tumours. Has an online forum and list of local support groups in the UK.

General cancer support organisations

Cancer Black Care

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

Cancer Focus Northern Ireland

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

Cancer Research UK

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

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

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

Maggie's

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

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

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

UK Council for Psychotherapy (UKCP)

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

Emotional and mental health support

Mind

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

Samaritans

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

Financial support or legal advice and information

Advice NI

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

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

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

England

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

Scotland

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

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Civil Legal Advice

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

Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

DVA

Helpline **0300 200 7861**
www.nidirect.gov.uk/contacts/driver-vehicle-agency-dva-northern-ireland
The official agency for licensing and testing vehicles and drivers in Northern Ireland.

DVLA

Helpline **0300 790 6809**
www.gov.uk/government/organisations/driver-and-vehicle-licensing-agency
The government agency that deals with vehicle tax, registration, driving licences and medical conditions.

GOV.UK

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

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
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.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Living Made Easy

Helpline **0300 123 3084**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Motability Scheme

Tel **0300 456 4566**
www.motability.co.uk
The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

Scope

Helpline **0808 800 3333**
Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**
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**
lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

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

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**
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 is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

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

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

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

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

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

Northern Ireland – Northern Ireland Cancer Registry (NICR)

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

Your notes and questions

Your notes and questions

Your notes and questions

Disclaimer

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

Thanks

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

With thanks to: Professor Michael Brada, Consultant Clinical Oncologist; Professor Andrew Brodbelt, Consultant Neuro-oncology Surgeon; Dr Fiona Harris, Consultant Clinical Oncologist; Sheila Hassan, Radiographer; Mr Ciaran Hill, Consultant Neuro-oncology Surgeon; Dr Jeremy Rees, Consultant Neurologist.

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

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

Sources

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

EANO-ESMO Clinical Practice Guidelines for prophylaxis, diagnosis, treatment and follow-up: Neurological and vascular complications of primary and secondary brain tumours. 2021. Available from www.eano.eu/publications/eano-guidelines/eano-esmo-clinical-practice-guidelines-for-prophylaxis-diagnosis-treatment-and-follow-up-neurological-and-vascular-complications-of-primary-and-secondary-brain-tumours [accessed March 2023].

NICE Guideline NG99. Brain tumours (primary) and brain metastases in over 16s. 2018 (updated 2021). Available from: www.nice.org.uk/guidance/ng99 [accessed March 2023].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

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

MACMILLAN
CANCER SUPPORT

This booklet is about 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 talks about the signs and symptoms of primary brain tumours and how they may be treated. It also has information about feelings, practical issues and money.

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

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

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

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

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