



# Understanding Brain Tumours

A guide for people with brain or spinal  
cord tumours, their families and friends

Cancer  
information

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*Understanding Brain Tumours* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# Introduction

This booklet is designed to help you understand more about brain and spinal cord tumours.

Many people feel shocked and upset when told they have a brain or spinal cord tumour. We hope this booklet will help you, your family and friends understand how these tumours are diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about what to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet on to your family and friends for their information.

## How this booklet was developed

The information in this booklet was developed with help from a range of health professionals and people affected by cancer.

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer  
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13 11 20**

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# What is a tumour?

A tumour is an abnormal growth of cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as brain cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

## Benign and malignant tumours

Tumours are often classified as benign (not cancer, slow-growing and unlikely to spread) or malignant (cancer, faster-growing with the potential to spread). These terms are useful for tumours in other parts of the body. With brain tumours, however, the difference is not as clear.

A slow-growing brain tumour that is unlikely to spread could be called benign. Other slow-growing brain tumours are called low-grade. These grow slowly but can spread through the brain. Benign tumours in certain areas of the brain can still be life-threatening and may require urgent treatment.

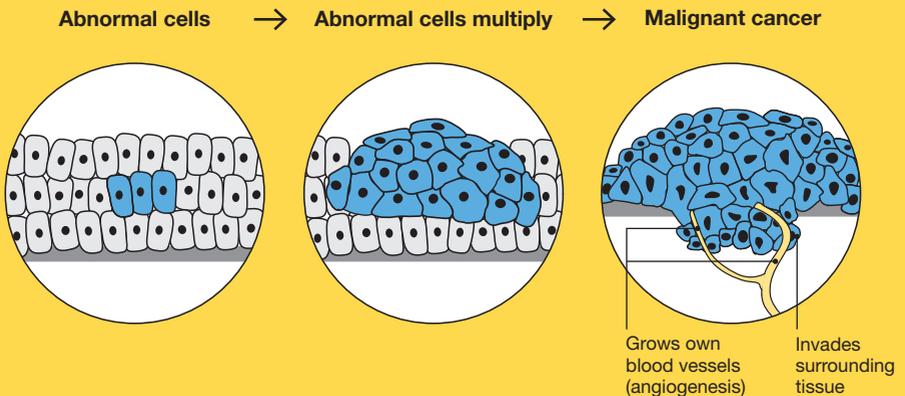
Malignant (cancerous) tumours are life-threatening and can grow rapidly. They may spread within the brain and spinal cord, or come back soon after treatment. However, some malignant tumours respond well to treatment.

## Primary and secondary cancer

A brain tumour may be a primary or secondary cancer. Cancer that first develops in the brain is called primary brain cancer. It rarely spreads to other parts of the body, but may spread to other parts of the brain.

Sometimes cancer starts in another part of the body and then travels through the bloodstream to the brain. This is known as a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, bowel cancer that has spread to the brain is still called metastatic bowel cancer, even though the person may be having symptoms caused by how the cancer is affecting the brain.

### How cancer starts





# The brain and spinal cord

The brain and spinal cord make up the central nervous system (CNS). Together, the different parts of the CNS control the activities of the mind and body.

**The brain** – The brain interprets information received via the nerves from the senses (taste, smell, touch, hearing and sight). It also sends messages via the nerves to the muscles and organs. The main parts of the brain are the cerebrum, the cerebellum and the brain stem.

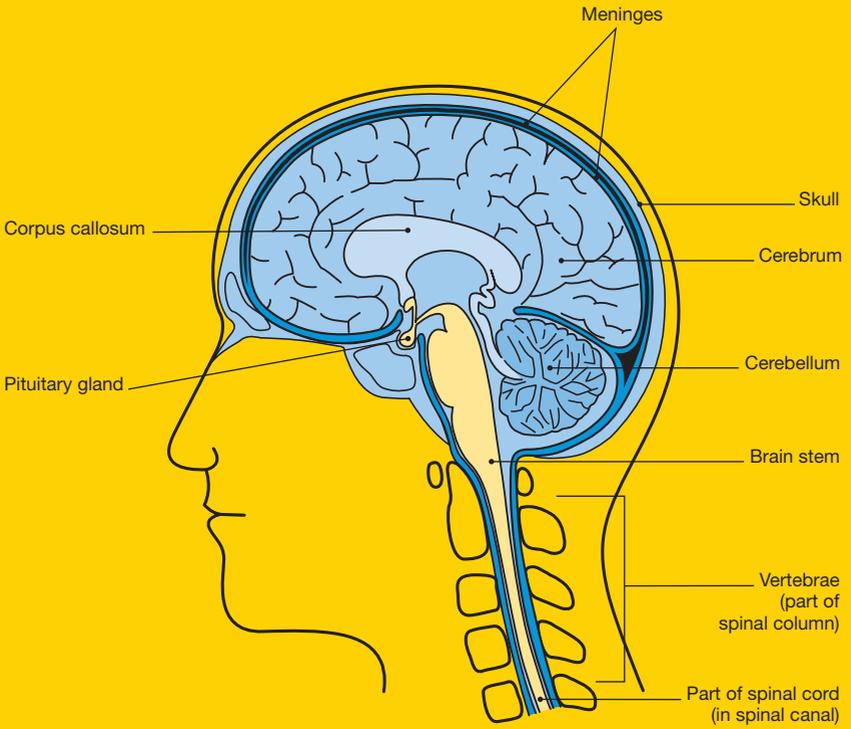
**Spinal cord** – The spinal cord extends from the brain stem to the lower back. It is made up of nerve cells and nerve bundles that connect the brain to all parts of the body through a network of nerves called the peripheral nervous system. The spinal cord lies in the spinal canal, protected by a series of bony vertebrae called the spinal column.

**Meninges** – Both the brain and spinal cord are surrounded by thin layers of protective tissue (membranes) called the meninges.

**Cerebrospinal fluid** – Inside the skull and vertebrae, the brain and spinal cord float in a liquid known as cerebrospinal fluid (CSF). The fluid-filled spaces inside the brain are called ventricles.

**Pituitary gland** – At the base of the brain is the pituitary gland, which is about the size of a pea. The pituitary gland releases chemical messengers (hormones) into the blood. These hormones control many body functions, including growth and development, and also tell other glands to start or stop releasing hormones.

# The central nervous system





The brain and spinal cord are made up of two main types of cells: neurons and glial cells. Neurons process and send information. Glial cells support the neurons by holding them in place, supplying nutrients and clearing away dead neurons, waste products and germs.

## The role of the brain

The brain is the most complex organ in the human body and is often called the body's command centre. It controls things you do voluntarily, such as speaking or making decisions, as well as those you do automatically, such as blood circulation and heart rate.

The largest part of the brain is the cerebrum, also known as the cerebral cortex. This is made up of different parts.

**The cerebral hemispheres** – The cerebrum is divided into two halves called hemispheres. The right hemisphere controls muscles on the left side of the body, and the left hemisphere controls muscles on the right side as well as speech.

**Corpus callosum** – The two hemispheres are connected by a band of nerve fibres called the corpus callosum (see diagram, previous page), which transfers information between them.

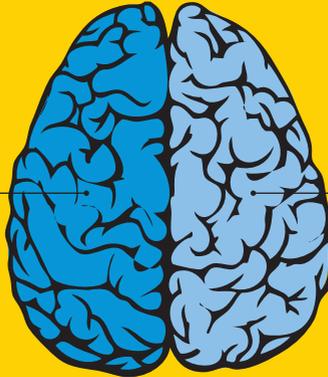
**Lobes of the brain** – Each hemisphere is divided into four main areas. These are called the frontal, parietal, occipital and temporal lobes. Each lobe controls different functions, as shown in the diagram opposite.

# The parts of the brain

Top view

**Left cerebral hemisphere**

controls right side of the body and speech



**Right cerebral hemisphere**

controls left side of the body

Side view

**Frontal lobe**

controls thinking, planning and problem-solving (executive function), emotions and personality, and body movement (motor function)

**Parietal lobe**

processes information from the senses

**Occipital lobe**

processes visual information

**Cerebellum**

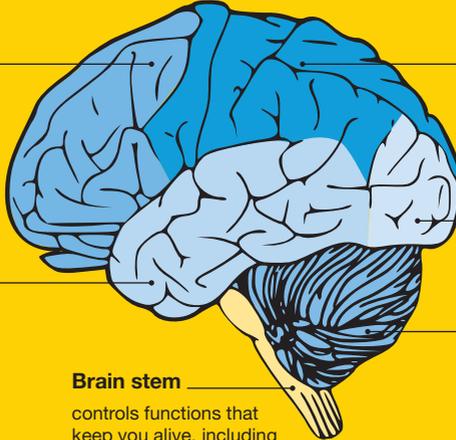
coordinates movement and balance

**Temporal lobe**

controls memory, understanding and language

**Brain stem**

controls functions that keep you alive, including breathing, temperature, blood pressure and sleep





## Key questions

### **Q: What is a brain or spinal cord tumour?**

**A:** A brain or spinal cord tumour occurs when abnormal cells grow and form a mass or a lump. The tumour may be called benign (not cancerous) or malignant (cancerous), but both types can be serious and may need urgent treatment (see pages 28–44).

### **Q: How common are they?**

**A:** Every year an estimated 2000 malignant brain tumours are diagnosed in Australia. Malignant spinal cord tumours are rare. About 55 people are diagnosed with malignant spinal cord or other central nervous system tumours each year.<sup>1</sup>

Benign brain and spinal cord tumours are more common than malignant tumours. Data is not collected Australia-wide, but in 2013, there were more than 1000 benign brain and spinal cord tumours in Victoria, Queensland and Western Australia combined.<sup>1</sup>

### **Q: What types are there?**

**A:** There are more than 40 types of primary brain and spinal cord tumours (also called central nervous system or CNS tumours). They are classified based on the type of cell (as seen under a microscope) and how the cells are likely to behave (based on their genetic make-up). Doctors use this classification to work out the best treatment.

## Most common types of primary brain tumours

<b>glioma</b>	<ul style="list-style-type: none"><li>• starts in glial cells</li><li>• common category of brain cancer</li><li>• different types of glioma grow from different types of glial cells (see next four rows)</li></ul>
<b>astrocytoma</b>	<ul style="list-style-type: none"><li>• a type of glioma</li><li>• starts in glial cells called astrocytes</li></ul>
<b>glioblastoma (GBM)</b>	<ul style="list-style-type: none"><li>• a type of fast-growing (high-grade) astrocytoma</li><li>• makes up more than half of all gliomas</li></ul>
<b>oligodendroglioma</b>	<ul style="list-style-type: none"><li>• a type of glioma</li><li>• starts in glial cells called oligodendroglia</li></ul>
<b>ependymoma</b>	<ul style="list-style-type: none"><li>• a type of glioma</li><li>• starts in glial cells called ependymas</li><li>• more common in children than adults</li></ul>
<b>medulloblastoma</b>	<ul style="list-style-type: none"><li>• a high-grade tumour that starts in the cerebellum</li><li>• rare in adults but more common in children</li></ul>
<b>meningioma</b>	<ul style="list-style-type: none"><li>• starts in the membranes (meninges) covering the brain and spinal cord</li><li>• common primary brain tumour, often low-grade</li></ul>
<b>pituitary tumour</b>	<ul style="list-style-type: none"><li>• starts in the pituitary gland</li><li>• almost always low-grade</li></ul>
<b>schwannoma</b>	<ul style="list-style-type: none"><li>• starts in Schwann cells, which surround nerves in the brain, and is usually low-grade</li><li>• includes acoustic neuromas</li></ul>

## Secondary cancer in the brain

A tumour that begins as a primary cancer in another part of the body before spreading to the brain is known as a secondary cancer or metastasis. The most common cancers to spread to the brain are melanoma, lung, breast, kidney and bowel.

## Q: What are the risk factors?

**A:** The causes of most brain and spinal cord tumours are unknown. However, there are a couple of known risk factors for brain tumours:

- **Family history** – In rare cases, a fault in the genes, usually passed down from one parent, can increase the risk of developing a brain tumour. For example, some people have a genetic condition called neurofibromatosis, which can lead to tumours of the neurons.
- **Radiation therapy** – In rare cases, people who have had radiation therapy to the head, particularly to treat childhood leukaemia, may be at an increased risk of developing a tumour.

### Mobile phones and microwave ovens

Many people are concerned that electromagnetic radiation from mobile phones or microwave ovens may cause brain cancer. Evidence to date does not show that mobile phone use causes cancer. However, if you are concerned about potential harm from mobile phones, you may choose to use a headset,

limit the time you spend on your mobile phone or consider texting rather than calling.

Microwave ovens have been in widespread use since the 1980s. There is no evidence that ovens in good working order release electromagnetic radiation at levels harmful to humans.

## Q: What are the symptoms?

**A:** In some cases, a brain tumour grows slowly and symptoms develop gradually, so you may not be aware that anything is wrong at first. In other cases, symptoms appear suddenly.

Many symptoms of brain tumours are more likely to be caused by other factors. However, any new, persistent or worsening symptoms should be reported to your doctor.

**General symptoms** – Brain tumour symptoms may be caused by increased pressure in the skull (intracranial pressure). Pressure can build up because the tumour itself is taking up too much space or because it is blocking the flow of cerebrospinal fluid around the brain (see page 33).

Intracranial pressure can lead to symptoms such as:

- headaches – often worse when you wake up
- nausea and vomiting – often worse in the morning or after changing position (e.g. moving from sitting to standing)
- confusion and irritability
- blurred or double vision
- seizures (fits) – can be obvious, involving a loss of consciousness, or more subtle, such as “zoning out”
- weakness in parts of the body
- drowsiness – a later symptom.

**Symptoms caused by tumour position** – Other symptoms relate to where in the brain or spinal cord the tumour is located – see the diagram on the next two pages.

## Common tumour symptoms

Some brain tumour symptoms depend on where the tumour is located. See the previous page for general symptoms caused by pressure in the skull.

### Frontal lobe

- difficulty with planning or organising
- changes in behaviour, personality and social skills
- depression or mood swings
- weakness in part of the face, or on one side of the body
- difficulty walking
- loss of sense of smell
- sight or speech problems
- trouble finding the right word

### Temporal lobe

- forgetting events and conversations
- difficulty understanding what is said to you
- trouble learning and remembering new information
- seizures with strange feelings, smells or déjà vu

### Pituitary gland

- headaches
- loss of vision (often peripheral vision)
- nausea or vomiting
- erection problems
- less interest in sex
- thyroid and other hormone changes

### Brain stem

- coordination problems
- difficulty swallowing or speaking
- double vision
- facial weakness and numbness
- weakness and fatigue
- changes to sleep/wake patterns





### Meninges

- headaches
- vomiting
- weakness in arm or leg
- personality changes or confusion

### Parietal lobe

- problems with reading or writing
- loss of feeling in part of the body
- difficulty with spatial awareness, e.g. telling left from right, locating objects

### Occipital lobe

- loss of all or some vision

### Spinal cord

- back and neck pain
- numbness or tingling in the arms or legs
- clumsiness or difficulty walking
- loss of bowel or bladder control (incontinence)

### Cerebellum

- coordination and balance problems
- uncontrolled eye movement
- stiff neck
- dizziness
- difficulty speaking (staccato speech)

## Q: Which health professionals will I see?

**A:** If your general practitioner (GP) or another doctor suspects that you have a brain or spinal cord tumour, they will arrange the first tests to assess your symptoms. You will then be referred to a neurosurgeon, neurologist or neuro-oncologist, who will examine you and may do more tests.

### Health professionals you may see

<b>neurosurgeon*</b>	diagnoses and performs surgery for diseases and injuries of the brain and nervous system
<b>neurologist*</b>	diagnoses and treats diseases of the brain and nervous system that do not need surgery
<b>neuro-oncologist*</b>	diagnoses and treats tumours of the brain and nervous system; a neuro-oncologist may be a neurologist, medical oncologist or neurosurgeon
<b>cancer care coordinator</b>	coordinates your care, liaises with other members of the MDT and is an ongoing contact for you and your family throughout treatment; may also be called a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy

If a tumour is diagnosed, the specialist will consider your treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care.

<b>neuropathologist*</b>	analyses tissue from brain or spinal cord tumours to identify the tumour type
<b>dietitian</b>	recommends an eating plan for you to follow while you are in treatment and recovery
<b>social worker</b>	links you to support services and helps you with emotional, practical or financial issues
<b>neuropsychologist</b>	assesses people with problems in thinking or behaviour caused by illness or injury (particularly to the brain) and manages their rehabilitation
<b>psychologist, psychiatrist*</b>	help you manage your emotional response to diagnosis and treatment
<b>rehabilitation specialist*</b>	recommends and oversees treatment to help you recover movement, mobility and speech after treatment and return to daily life
<b>physiotherapist, occupational therapist, speech therapist</b>	assist with physical and practical problems, including restoring movement, mobility and speech after treatment, and recommending aids and equipment

\* Specialist doctor

## Childhood brain tumours

In Australia, more than 100 children under 15 are diagnosed with a malignant brain or spinal cord tumour each year.<sup>1</sup> Children are more likely to develop tumours in the lower part of the brain, which includes the areas that control sleep/wake functions, movement and coordination. Gliomas and medulloblastomas are the most common types.

In general, children diagnosed with a malignant tumour will have a better outlook than adults. In many children, treatment will cause all signs of the cancer to disappear (remission). Because a child's nervous system is still developing, some children may have a physical, behavioural or learning disability as a result of the tumour or treatment.

Many health care professionals specialise in treating children and young adults (paediatrics). Some hospitals have staff,

such as play therapists, music therapists or art therapists, who can help children cope with the challenges of treatment. Rehabilitation will also be important for your child's recovery (see pages 45–47).

Talk to your child's medical team about treatment options, what to expect, and your concerns. The hospital social worker can provide practical and emotional support.

Organisations like Camp Quality, CanTeen and Redkite (see page 62) offer support for families, young adults and children affected by cancer. Redkite offers a print and online picture book called *Mary has a brain tumour* that you can read with your child.

As a parent, it may be helpful to read Cancer Council's booklet *Talking to Kids About Cancer*. Call **13 11 20** or visit your local Cancer Council website.



# Diagnosis

Many people diagnosed with a brain or spinal cord tumour first go to see their GP because they are feeling unwell. Occasionally a brain tumour will be found during a scan for something unrelated, such as a head injury. Some people have sudden symptoms (such as loss of consciousness, severe headache or a seizure) and go straight to a hospital's emergency department.

The doctor will ask you about your symptoms and medical history, and will do a physical examination. You may be referred to have more tests and scans to confirm a diagnosis of a brain or spinal cord tumour.

## Physical examination

Your doctor will assess your nervous system to check how different parts of your brain and body are working, including your speech, hearing, vision and movement. This is called a neurological examination and may cover:

- checking your reflexes (e.g. knee jerks)
- testing the strength in your limb muscles
- walking, to show your balance and coordination
- testing sensations (e.g. your ability to feel pinpricks)
- brain exercises, such as simple arithmetic or memory tests.

The doctor may also test eye and pupil movements, and may look into your eyes using an instrument called an ophthalmoscope. This allows the doctor to see your optic nerve, which sends visual information from the eyes to the brain. Swelling of the optic nerve can be an early sign of raised pressure in the skull.

## Blood tests

You are likely to have blood tests to check your overall health. Blood tests can also be used to check whether the tumour is producing unusual levels of hormones, which could indicate that the pituitary gland is affected (see page 6).

## CT scan

A CT (computerised tomography) scan is a procedure that uses x-rays to take many pictures of the inside of the body and then compiles them into detailed, cross-sectional pictures.

A contrast dye may be injected into a vein to help make the scan pictures clearer. It may make you feel hot all over and leave a bitter taste in your mouth. You may also feel the need to pass urine. These side effects usually ease within minutes.

The CT scanner is a large, doughnut-shaped machine. You will lie on a table that moves in and out of the scanner. It may take about 30 minutes to prepare for the scan, but the actual test is painless and takes about 10 minutes. You will be able to go home when the scan is complete.

“ My doctor thought I had depression but I insisted on a CT scan as I had persistent headaches, felt disorientated and couldn't think clearly. The scan showed that I had a brain tumour. ” *Richard*



The dye used in a CT or MRI scan usually contains iodine. If you have had an allergic reaction to iodine or dyes during a previous scan, tell your medical team beforehand. You should also let them know if you are diabetic, have kidney disease or are pregnant.

## MRI scan

An MRI (magnetic resonance imaging) scan uses a powerful magnet and a computer to make cross-sectional pictures of your body. It may not be safe to have an MRI if you have a pacemaker or any other metallic object in your body. Some types of metal are MRI-compatible, however, so discuss this with your medical team.

For an MRI, you may be injected with a dye that highlights the organs in your body. You will then lie on an examination table inside a large metal tube that is open at both ends.

The test is painless, but the machine can be noisy and some people feel anxious or claustrophobic in the tube. If you think you may become distressed, mention it beforehand to your medical team. You may be given medicine to help you relax or you might be able to bring someone into the room with you for support. You will usually be offered headphones or earplugs. The MRI scan takes 30–90 minutes and you will be able to go home afterwards.

The pictures from an MRI scanner are generally more detailed than pictures from a CT scanner. Many people who first have a CT scan will also need to have an MRI.

## Further tests

You may also have some of the tests below to estimate how quickly the tumour is growing (the grade, see facing page) and whether it has spread into nearby tissue. This information helps your doctor plan treatment.

**MRS scan** – An MRS (magnetic resonance spectroscopy) scan can be done at the same time as a standard MRI. It looks for changes in the chemical make-up of the brain.

**MR tractography** – This MR (magnetic resonance) scan helps show the message pathways (tracts) within the brain, e.g. the visual tracts. It can be useful in planning treatment for gliomas.

**MR perfusion scan** – This type of MR scan shows the amount of blood flowing to various parts of the brain. It can also be used to help identify the type of tumour.

**SPET or SPECT scan** – A SPET or SPECT (single photon emission computerised tomography) scan takes three-dimensional pictures showing blood flow in the brain. You will be injected with a small amount of radioactive fluid and then your body will be scanned with a special camera. Areas with higher blood flow, such as a tumour, will show up brighter on the scan.

**PET scan** – For a PET (positron emission tomography) scan, you will be injected with a small amount of radioactive solution. Cancer cells absorb the solution at a faster rate than normal cells do and show up brighter on the scan.

**Lumbar puncture** – Also called a spinal tap, a lumbar puncture uses a needle to collect a sample of cerebrospinal fluid from the spinal column. The fluid is checked for cancer cells in a laboratory.

**Surgical biopsy** – If scans show an abnormality that looks like a tumour, some or all of the tissue may be removed for examination under a microscope. This is called a biopsy. In some cases, the neurosurgeon makes a small opening in the skull and inserts a needle to take a sample. In other cases, a larger part of the skull has to be removed (craniotomy, see page 30) to get to the tumour.

**Genetic tests** – Every kind of cancer, including brain cancer, changes the genes of the affected cells. These gene faults are not the same thing as genes passed through families. The fault is only in the structure of the tumour cells, not in the normal cells. The study of these gene changes is called cytogenetics or molecular genetics. A pathologist may run special tests on cells from the tumour to look for these gene changes. The results can help your doctors tailor the treatment for that particular tumour.

## Grading tumours

The grade of a tumour describes how quickly it is growing and how it is likely to behave. A specialist doctor called a pathologist examines a sample of tumour tissue under a microscope and looks for several features to work out the grade.

Brain and spinal cord tumours are usually given a grade on a scale of 1 to 4 (often recorded in Roman numerals as I–IV).

Grades 1 and 2 are the slowest-growing tumours. They are considered low-grade and are sometimes called benign. Grades 3 and 4 are fast-growing tumours. They are considered high-grade and often called malignant.

With other types of cancer, doctors give the cancer a stage to describe the extent of the cancer in the body. Primary brain and spinal cord tumours are not staged in this way as most don't spread to other parts of the body.

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease. There are many factors that may affect your prognosis. These include the tumour type, location, grade and genetic make-up; your age, general health and family history; and how well the tumour responds to treatment.

Both low-grade and high-grade tumours can be life-threatening, but the prognosis may be better if the tumour is low-grade, or if the surgeon is able to remove the entire tumour.

Some brain or spinal cord tumours, particularly gliomas, can come back (recur) and may change to a higher grade (progress). In this case, treatments such as surgery, radiation therapy or chemotherapy may be used to control the growth of the tumour for as long as possible, relieve symptoms and maintain quality of life.



## Key points

- Many people diagnosed with a brain or spinal cord tumour have symptoms caused by the tumour, such as dizziness, headaches or difficulty walking.
- You will probably have a number of tests to diagnose the disease.
- A physical examination checks how different parts of your brain are working.
- You may also need a blood test to check your overall health and hormone levels.
- Imaging scans, such as CT and MRI, allow the doctor to see pictures of the inside of the brain. You may be injected with a dye before these scans to help make the pictures clearer.
- Other scans assess the brain's chemical make-up, blood flow in the brain, and whether there are active cancer cells.
- A biopsy removes a sample of tissue for examination under a microscope.
- The tests and scans help doctors diagnose the type of brain or spinal cord tumour you have, as well as its grade. The grade indicates how quickly the tumour is growing.
- Primary brain and spinal cord tumours are not given a stage because they rarely spread to other parts of the body.
- Many people want to know the likely outcome of their disease (prognosis). You will need to discuss this with your doctor, as it depends on many factors.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

## Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want more explanation, you can ask questions – see page 63 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, clinical trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Treatment

The main treatments for brain or spinal cord tumours are surgery, radiation therapy and chemotherapy. These may be used alone or in combination. Medicines, such as steroids or anticonvulsants (anti-seizure medicines), may be given to reduce symptoms. There also could be new, experimental treatments or improvements in existing treatments. These are given in clinical trials – your doctor will tell you if you are eligible to join (see previous page).

The aim of treatment may be to remove the tumour completely, slow its growth, or relieve symptoms by shrinking the tumour and reducing swelling. Your choice of treatment will depend on:

- the type, size, grade, location and genetic make-up of the tumour
- your age, medical history and general state of health
- the types of symptoms you have.

## Surgery

Surgery in the brain or spinal cord is called neurosurgery. Removing all or part of the tumour may allow you to return to leading an active life.

Sometimes the entire tumour can be removed in an operation called a total resection. In other cases, the surgeon may be able to remove only part of the tumour. This is called a partial resection or debulking. Partial removal may be chosen because the tumour is widespread, or near major blood vessels or other important parts of the brain or spinal cord. A partial resection may improve your symptoms by reducing the pressure on your brain.

Sometimes a tumour cannot be removed because it is too close to certain parts of the brain and surgery would cause serious problems. This is called an inoperable or unresectable tumour. Your doctor will talk to you about trying to ease the symptoms with other treatments.

## Preparing for surgery

The types of scans used for diagnosing the tumour (e.g. CT, MRI or MRS scans) are often done again when planning surgery.

The surgeon needs to locate the most important areas of the brain to make sure these are not damaged during the operation. A special MRI scan called a functional MRI (fMRI) shows the exact areas of the brain that are used as you speak or move. Brain mapping is another way to find these parts of the brain. A tiny electrode is placed on the outside layer of the brain during the surgery and stimulated with a low dose of electrical current.

Before surgery, talk to your doctor about any medicines you are taking. Some medicines interfere with the anaesthetic used during the operation, so you may need to stop taking them for a while. You may also be advised to stop smoking before surgery.

It is natural to feel anxious before surgery, so talk to your treatment team about your concerns. You can also call Cancer Council **13 11 20** for support and may want to listen to our podcast about overcoming fear, available at [cancercouncil.com.au/podcasts](https://cancercouncil.com.au/podcasts).



## Types of surgery

Different types of operations may be used for brain and spinal cord tumours. You may already have had a biopsy to remove a sample of tissue (see page 23) or the biopsy may be done at the same time as the surgery to remove the brain tumour.

**Craniotomy to remove a brain tumour** – This is the most common type of brain tumour operation. A craniotomy removes all or part of the tumour (total or partial resection) and is done under a general anaesthetic. The surgeon removes part of the skull to access the brain. The tumour is then taken out, and the bone and scalp are put back. The surgeon uses small plates and screws to permanently hold the piece of skull in place.

Patients with a high-grade glioma may be given a solution to drink before surgery that makes the tumour glow under ultraviolet light. This may help the surgeon remove as much of the tumour as possible, while avoiding normal brain tissue.

**Awake craniotomy** – This operation may be recommended if the tumour is near parts of the brain that control speech or movement. All or part of this operation is done with the patient awake (conscious) but relaxed, so they can speak, move and respond. You may be worried that an awake craniotomy will hurt, but the brain itself does not feel pain and local anaesthetic is used to numb surrounding tissues. During the surgery, the surgeon asks the patient to speak or move parts of the body. This helps the surgeon identify and avoid certain parts of the brain. An electrode is also used to stimulate and pinpoint important areas of the brain.

## Computer guidance

It is now usual for craniotomies to be done using a computer navigation system to guide the surgeon.

The computer uses the results of planning scans to create three-dimensional images of the brain and tumour. During the operation, the computer

then monitors the surgical instruments, allowing the surgeon to be very precise.

Surgery that uses computer navigation is known as stereotactic surgery. It is safer, more accurate and requires a smaller cut in the skull than non-computer guided surgery.

**Endoscopic transsphenoidal surgery** – This surgery is used for tumours near the base of the brain (e.g. pituitary gland tumours). To remove the tumour, the surgeon inserts a long, thin tube with a light and camera (endoscope) through the nose and into the skull at the base of the brain. An ear, nose and throat (ENT) surgeon may assist with this type of surgery.

**Laminectomy** – The most common surgery for spinal cord tumours is called a laminectomy. In this procedure, the surgeon makes an opening through the skin, muscle and a vertebra in the spinal column to remove the tumour that is affecting the spinal cord. You will be given a general anaesthetic for this operation.

For more information on surgery, call Cancer Council 13 11 20 and ask for a free copy of *Understanding Surgery*, or visit your local Cancer Council website.

## After brain or spinal cord surgery

You will be closely monitored for the first 12–24 hours after the operation. The length of your hospital stay will depend on whether you have any problems or side effects following surgery. Your doctor will tell you when you can start regular activities again.

### Neurological observations

For the first day or two, nurses will regularly check your breathing, pulse, blood pressure, temperature, pupil size, and arm and leg strength and function. You will also be asked questions to assess your level of consciousness. These neurological observations check how your brain and body are recovering from surgery.



### Pressure stockings

You will need to wear pressure stockings on your legs to prevent blood clots from forming while you are recovering from surgery. Tell your doctor or nurse if you have pain or swelling in your legs or suddenly have difficulty breathing.



### Spinal cord checks

If you have had an operation on your spinal cord, the nurses will regularly check the movement and sensation in your arms and legs. You may need to lie flat in bed for 2–5 days to allow the wound to heal. A physiotherapist will help you learn how to roll over and how to get out of bed safely so the wound is not damaged.

## Headaches and nausea

You may have a headache or nausea after the operation. Both can be treated with medicines.



## Bandages and bruising

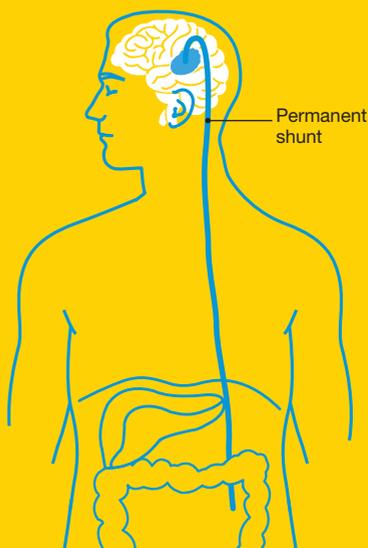
The dressing on your head may vary from a simple bandaid to bandaging that covers your whole head. Some or all of your head may have been shaved. After surgery to certain parts of the head, your face and eyes may be swollen or bruised – this is normal. It is not usually painful and should ease within about a week.

## Rehabilitation

The surgery may cause a range of short-term or longer-term side effects (see next page). Before you can return home, you may require further treatment known as rehabilitation. This may be offered in the same hospital or in a rehabilitation facility.

## Shunting

Some people have a build-up of cerebrospinal fluid in their brain. This is called hydrocephalus and it may occur before surgery as a result of the tumour, but can also happen after surgery. The surgeon may place a long, thin tube called a shunt into your brain to drain out extra fluid. A temporary shunt drains into a bag on the outside of the body. A permanent shunt is completely inside your body. It drains into your abdomen and the fluid is then safely absorbed into the bloodstream.



## Side effects of surgery

Surgery to remove a brain tumour can cause swelling that leads to pressure inside the skull (intracranial pressure). Your medical team will monitor this and try to reduce it, but you may still experience side effects such as confusion, speech problems, dizziness, weakness and seizures. You and your family or carers may worry that you aren't recovering well, but the side effects often improve over time. Your doctor will explain that such side effects are normal and give you an idea of how long they will last.

In some cases, people recover fully and can gradually return to their usual activities. In other cases, the tumour position may mean that there are longer-term changes to how you speak, move and think.

A range of therapies can speed up recovery or help you learn to manage any changes. These therapies are known as rehabilitation.

At first, you may have some rehabilitation therapies in the hospital or in a rehabilitation facility. Once you return home, you can continue to access these therapies as an outpatient. See pages 46–47 for more information.

“ The most distressing time for me was immediately post op when my side effects were many, varied and quite severe, even though most turned out to be temporary. It was distressing because I wasn't expecting them. ” Ian

## Radiation therapy

Radiation therapy (also called radiotherapy) uses radiation, such as x-ray beams, to kill or damage cancer cells. The radiation is targeted at the treatment site to reduce the risk of damage to healthy cells. The treatment itself is painless, though you may experience side effects afterwards (see pages 38–39).

Before radiation therapy begins, you will go to a planning or simulation appointment to plan the treatment. A radiation therapist will take measurements of your body and do a CT or MRI scan to work out the precise area to be treated. If you are having radiation therapy for a spinal cord tumour, some small tattoos may be marked on your skin to indicate the treatment area. If you are having radiation therapy for a brain tumour, you will probably need to use a face mask (see page 37) or head frame.

Radiation therapy is usually given once daily, from Monday to Friday, for several weeks. However, how often you have the treatment will depend on the size and type of tumour.

## Stereotactic radiosurgery (SRS)

Stereotactic radiosurgery (SRS) is a special type of radiation therapy, not a type of surgery, so no cuts are made in the skull. It is used to treat some small brain tumours. A high dose of radiation is targeted precisely at the tumour, with very little reaching surrounding areas of healthy brain tissue.

Radiosurgery may be offered when neurosurgery is not possible or as an alternative to neurosurgery. It is most commonly used

for metastatic cancers that have spread to the brain from another part of the body. It is also used for some meningiomas, pituitary tumours, and schwannomas, and is occasionally used for gliomas that have come back after other treatment.

Often, only 1–3 doses of SRS are needed. A treatment session may last between 15 minutes and two hours, depending on the type of radiosurgery given, and you will need to wear a face mask (see opposite) during the treatment. You will usually be able to return home afterwards.

### **Stereotactic radiation therapy (SRT)**

A stereotactic radiosurgery machine may also be used to deliver a longer course of radiation, particularly for benign brain tumours. This is called stereotactic radiation therapy. The same precise system is used, but multiple small daily treatments are given.

#### **Proton therapy**

Also known as proton beam therapy, this uses radiation from protons rather than x-rays. Protons are tiny parts of atoms with a positive charge that release most of their radiation within the cancer. This can be important near sensitive areas, such as the brain stem or spinal cord. Special machines, known as cyclotrons and synchrotrons, are used to generate and deliver the protons.

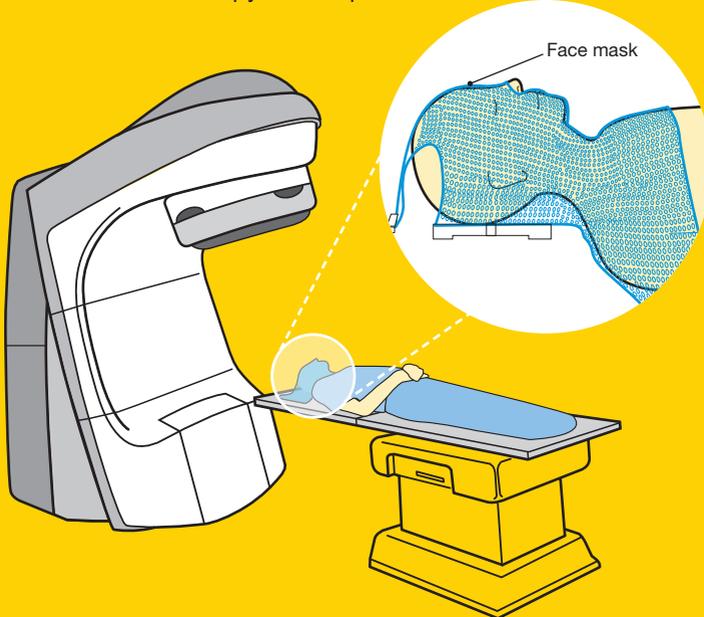
Proton therapy is not yet available in Australia. In specific circumstances, financial assistance may be available from the Australian Government to travel overseas for proton therapy.

## Wearing a face mask

For radiation therapy to the brain, a plastic face mask may be made during the planning sessions. This is known as an immobilisation mask. It will help keep your head still and ensure the radiation is targeted at the same area during each session.

The mask is made of a tight-fitting mesh, but you will wear it for only about 10 minutes at a time. You can see and breathe through the mask, but it may feel strange and claustrophobic at first. The radiation therapist can suggest ways to help you adjust to the mask, so let them know if it is making you feel anxious or uncomfortable.

During treatment, you will lie on a table under a machine called a linear accelerator. Radiation therapy itself is painless.



## Side effects of radiation therapy

Radiation therapy side effects generally occur in the treatment area and are usually temporary, but some may be permanent or last for a few months or years.

The side effects vary depending on whether the tumour is in the brain or spinal cord. They may include:

- **nausea** – often occurs during the course of treatment
- **headaches** – often occur during the course of treatment
- **tiredness or fatigue** – worse at the end of treatment, can continue to build after treatment, but usually fades over time
- **red, sore, inflamed or flaky skin** – may occur in the treatment area, usually happens at the end of treatment and often worsens before improving
- **hair loss** – may occur in the brain tumour treatment area and may be permanent
- **dulled hearing** – may occur if fluid builds up in the middle ear
- **swallowing problems (dysphagia)** – may occur following treatment for spinal cord tumours
- **diarrhoea** – may occur after treatment for spinal cord tumours.

A small number of adults who have had radiation therapy to the brain have side effects that appear months or years later. These are called late effects and can include symptoms such as poor memory, confusion, personality changes and headaches. Rehabilitation therapies (see pages 45–47) or medicines can help with managing late effects. Young children are more likely to have long-term effects from radiation therapy because their nervous system is still developing, so other treatments are used where possible.



Radiation therapy is usually combined with chemotherapy for the treatment of glioblastomas (grade 4 tumours). Compared with radiation therapy alone, this combination leads to better outcomes.

Radiation therapy that affects the pituitary gland can lead to it producing too much or too little of particular hormones. If this is a risk for you, your treatment team will monitor the hormone levels in your pituitary gland.

For a free copy of *Understanding Radiation Therapy*, call Cancer Council 13 11 20 or visit your local Cancer Council website.

## Chemotherapy

Chemotherapy is the use of drugs to treat cancer. The drugs travel through the bloodstream and damage or destroy rapidly dividing cells such as cancer cells, while causing the least possible damage to healthy cells. Healthy fast-growing cells, such as bone marrow cells, may also be affected, leading to side effects (see next page).

It can be difficult to treat brain tumours with chemotherapy drugs because the body has a protection system known as the blood–brain barrier. This guards the brain from harmful substances that may be circulating in the blood, such as germs or chemicals. Only certain types of chemotherapy drugs can get through this barrier. Temozolomide is the most commonly prescribed chemotherapy drug for the treatment of brain tumours, although other chemotherapy drugs are also used.

You may be given chemotherapy as capsules or tablets that you swallow, or as a liquid through a drip inserted into your vein (intravenously). Each treatment session is usually followed by a rest period of a few weeks.

## Side effects of chemotherapy

The way your body reacts to chemotherapy will be monitored through regular blood tests. Your treatment schedule may change when your doctor sees how you are responding to the drugs.

There are many possible side effects of chemotherapy, depending on the type of drugs you are given. Side effects may include:

- increased risk of infection
- nausea, vomiting or loss of appetite
- tiredness, fatigue and lack of energy
- mouth sores and ulcers, skin rash
- diarrhoea or constipation
- breathlessness due to low levels of red blood cells (anaemia)
- the feeling of pins and needles and numbness (nerve damage known as peripheral neuropathy)
- damage to ovaries or testicles, which can make you unable to have children naturally (infertile).

It is rare to lose all your hair with the drugs used to treat brain and spinal cord tumours, although in some cases your hair may become thinner.

For a free copy of *Understanding Chemotherapy*, call Cancer Council 13 11 20 or visit your local Cancer Council website.



## Ali's story

Several years ago, I'd been having headaches for a couple of weeks and then one day I collapsed at work. I was rushed off for tests and they found a grade 2 oligodendroglioma.

Within a week, I was having brain surgery. I got over that operation fairly well and didn't need any more treatment at the time.

Last year, I found out that the tumour had returned and now included a new astrocytoma strain. That was a reality check. It had been nine years since the first tumour, and I guess I'd sort of taken my health for granted.

I think I was in denial for a while and I wasn't particularly worried about the second operation, but I got more worried as the date came closer. I had no real problems from the surgery, it was textbook healing really, and the surgeon said they had

got it all. But then he told me I'd need radiation therapy and chemotherapy, just to mop up any stray cells. That floored me – I hadn't needed it the first time, so I thought I'd escaped it.

I had six weeks of radiation therapy, followed by six months of oral chemotherapy, and that knocked everything for six. I developed gastritis – that's an inflamed stomach – and had to go on a very bland diet. I lost so much weight and strength, and I was very vague for a while.

Time has helped, but it has been very gradual. I started off with short walks and short bursts of activity.

I also talked it all through with my local Cancer Council – that kept me afloat. It's been like an oasis and is still a big part of my life.



Anticonvulsant medicines may be given to prevent seizures before and after treatments for brain tumours. See pages 48–50 for more information.

## Steroids

Steroids are made naturally in the body, but they can also be produced artificially and used as drugs. Brain tumours and their treatments can both lead to swelling in the brain. Steroids may help to reduce this swelling, and can be given before, during and after surgery and radiation therapy. The most commonly used steroid for people with brain tumours is dexamethasone.

Side effects depend on the dose and the length of treatment. If you are prescribed steroids for a short period, you may experience increased appetite, weight gain, trouble sleeping, restlessness, mood swings, anxiety and, in rare cases, more serious changes to thought and behaviour. In people with diabetes, steroids can quickly lead to high or unstable blood sugar levels. These short-term side effects can be managed. Eating before taking steroids decreases the likelihood of the steroids irritating your stomach.

If taken for several months, steroids can cause puffy skin (fluid retention or oedema) in the feet, hands or face; high blood pressure; unstable blood sugar levels; diabetes; muscle weakness; and loss of bone density (osteoporosis). You will also be more likely to get infections. Most side effects are temporary and your doctor may adjust your dose to manage them.

An experienced counsellor, psychologist or psychiatrist can help you manage mood swings or behavioural changes. If you or your family are worried about side effects, talk to your doctor or nurse.

## Palliative treatment

Palliative treatment helps to improve quality of life by treating the symptoms of cancer without trying to cure the disease. It can be used at any stage of advanced cancer. As well as slowing the spread of cancer, palliative treatment can relieve pain and help other symptoms. Treatment may include surgery, radiation therapy, chemotherapy or other medicines.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, practical, emotional, spiritual and social needs. Palliative care services can be accessed in the home as well as in a hospital or in residential care. To find out more, call Cancer Council 13 11 20 and ask for free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*, or visit your local Cancer Council website.

“ My wife Robyn was diagnosed with grade 4 brain cancer when she had just turned 50. After getting a diagnosis like that, you just go into shock for a couple of days, then you start thinking about how things will change, you evaluate your life and what you need to do to help. ” Ross



## Key points

- The main treatments for brain or spinal cord tumours are surgery, radiation therapy and chemotherapy.
- Some tumours can be completely removed in a total resection. Others can only be partly removed (partial resection or debulking).
- Different types of surgery are used for different types of tumours. The most common brain surgery is a craniotomy. A laminectomy removes tumours from the spinal cord.
- Stereotactic surgery is when a computer guides the surgeon so the surgery is more precise.
- Radiation therapy uses targeted radiation, such as x-rays, to kill cancer cells. You will have a planning appointment so the doctor can work out exactly where to direct the radiation. It is rarely used for young children.
- Stereotactic radiosurgery is the most precise form of radiation therapy that is used to treat small tumours with high doses.
- Chemotherapy is the use of drugs to destroy or kill cancer cells. You may be given chemotherapy as tablets, or into a vein (intravenously) via a drip.
- Other treatments include steroids to reduce brain swelling, and anticonvulsants to prevent seizures occurring.
- Treatments may cause short-term and long-term side effects. Talk to your doctors and nurses about managing symptoms and side effects, including whether you will need rehabilitation.



# Living with a brain or spinal cord tumour

A brain or spinal cord tumour and its treatment can change how the mind and body work. You or your family members may notice changes in your speech, personality, memory, movement, balance and coordination. If you or your family feel like you are behaving differently, talk to your doctor, nurse or cancer care coordinator. The types of changes will depend on what part of the brain is affected by the tumour and what treatment you have had.

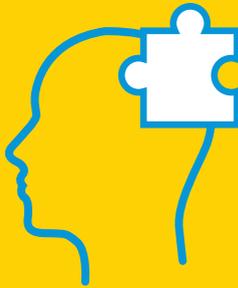
Rehabilitation is treatment designed to help people recover from injury or disease. After brain tumour treatment, most people need rehabilitation assessment and therapies (see next two pages). These can help restore your previous abilities or help you adjust to any changes. The changes may be difficult to cope with emotionally, and you might find that your self-esteem and your relationships are affected. Talking to a counsellor or someone who has had a similar experience may help. Call Cancer Council 13 11 20 to see what support is available close to you.

## Children at school

School-aged children with brain tumours may benefit from tutoring as part of their rehabilitation. This may be available through the Ronald McDonald Learning Program or Redkite (see page 62). Talk to the student welfare coordinator, school counsellor or principal at your child's school and check that they have a copy of Cancer Council's *Cancer in the School Community*. The medical team can provide information on how the tumour and treatment may have affected your child.

## Types of rehabilitation

A range of therapies can support you in your recovery. These may be available at your cancer treatment centre, or you may be referred to a rehabilitation specialist for treatment through a rehabilitation hospital or service team. You may also be referred to individual allied health professionals (e.g. physiotherapists) in private practice.



### Cognitive rehabilitation

Your memory, language skills, concentration, or planning and problem-solving skills (executive function) may be affected.

A neuropsychologist, speech pathologist or occupational therapist can help improve these cognitive skills using memory activities, speech therapy, diaries and language puzzles.



### Exercise

A physiotherapist or an exercise physiologist can give you advice on how to exercise safely and stimulate parts of your body to improve circulation and reduce swelling.

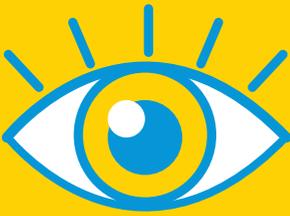
### Physiotherapy

In some cases, physiotherapy can help you learn how to move more easily. It can also help you to develop muscle strength and balance. Moving and strengthening your muscles can reduce tiredness or weakness related to cancer treatment. If you can't move easily, you may be able to learn techniques, such as using a walking stick, so you can become more independent.



### Speech therapy

If your ability to talk has been affected, a speech pathologist may be able to help. Speech pathologists also work with people who have difficulty swallowing (dysphagia).

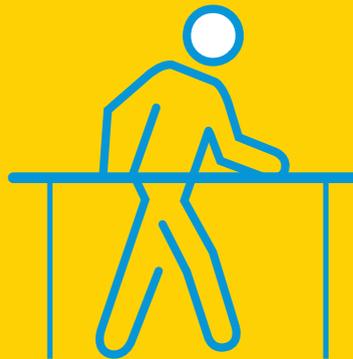


### Help with vision impairment

Some people may lose some or all of their sight as a result of a brain tumour or surgery. Vision Australia can help people learn how to live independently. Call **1300 84 74 66** or go to **[visionaustralia.org](http://visionaustralia.org)**.

### Occupational therapy

Some people find the tumour or its treatment affects their ability to perform everyday personal activities (e.g. showering, dressing, preparing a meal). An occupational therapist can help you to return to the activities that are important to you. A range of strategies and aids can help you manage fatigue and improve or maintain your independence.



## Managing seizures

A brain tumour or its treatment can sometimes cause seizures, which are disruptions to the normal patterns of electrical impulses in the brain. They may also be called fits or convulsions.

Seizures can often be prevented with anticonvulsant medicines (also called anti-epileptic or anti-seizure medicines). You can also reduce your seizure risk by making sure you don't get too tired or fatigued.

**Generalised seizures** – These types of seizures typically affect the whole body. The most common type is called a tonic-clonic



### Ways to help someone having a seizure

- Remain calm and stay with the person while they are having a seizure, but do not restrain them or put anything in their mouth.
- Protect the person from injury (e.g. move hazards, lower them to the floor if possible, loosen clothing, place a soft pillow under their head and shoulders).
- Lie the person on their side to clear their airway
- after jerking stops. This is particularly important if the person has vomited, is unconscious or has food or fluid in their mouth.
- Call **000** for an ambulance if it is the first seizure the person has had; if the person is injured; if there was food or water in the person's mouth; if the seizure lasts longer than five minutes; or if you are in any doubt.

seizure (previously known as a grand mal seizure). A seizure often starts with a sudden cry, followed by the person falling down and losing consciousness. The person's muscles may twitch violently and their breathing may be shallow for up to two minutes. They may lose bladder and bowel control, and bite their tongue.

**Partial seizures** – These affect one part of the body, such as an arm or leg. Symptoms include twitching; jerking; tingling or numbness; and altered sensations (hallucinations), such as changed vision or hearing, strange tastes or smells, or a feeling of déjà vu. Partial seizures may cause a brief loss of consciousness, changes in mood, and memory loss just before, during and after the seizure.

- Observe the person until they have recovered or the ambulance arrives. Time how long the seizure lasts so you can tell the paramedics.
- Talk to the person and explain what has occurred. In many cases, people are confused after a seizure.
- If the seizure occurs while a person is in a wheelchair or car, support their head and leave them safely strapped in their seat until the seizure is over. Afterwards, remove the person from their seat, if possible. Roll them onto their side if there is food, water or vomit in their mouth.
- Allow the person to rest afterwards as most seizures are exhausting.
- For detailed information and an online tool for creating a Seizure Management Plan, visit Epilepsy Action Australia at [epilepsy.org.au](http://epilepsy.org.au) or call **1300 37 45 37**.

## Anticonvulsant medicines

There are many types of anticonvulsant drugs, which are used to prevent seizures. You may require blood tests while you are taking anticonvulsants. This is to check whether the dose is effective and how your liver is coping with the medicine.

Side effects of anticonvulsant drugs vary, but they may include tiredness, gum problems, shakes (tremors), nausea, vomiting, weight changes, depression, irritability and aggression. If you are allergic to the medicine, you may get a rash. Tell your medical team if you have any skin changes or other side effects. Your doctor can adjust the dose or try another anticonvulsant. Do not stop taking the medicine or change the dose without your doctor's advice.

If you are taking anticonvulsants, you may need to avoid eating grapefruit and Seville oranges, and check with your doctor before taking any herbal medicines, as these can change the way some anticonvulsants work. You should also limit your alcohol intake.

## Driving

Tumours, seizures, and certain treatments and medicines (such as anticonvulsants and some pain medicines) can change your vision, mobility, coordination, perception and judgement. These changes can affect driving skills and may make it unsafe for you to drive.

If you are diagnosed with any type of brain tumour, it is very important to ask your doctor how your condition or treatment will affect your ability to drive. When you are first diagnosed with

a brain tumour, your doctor will probably advise you not to drive for a period of time. You probably also won't be able to drive for some time after surgery and possibly after radiation therapy.

Before you start driving again, always check with your doctor. Laws in Australia require drivers to tell their driver licensing authority about any permanent or long-term illness or injury that is likely to affect their ability to drive. Your doctor can advise you if you should report your condition or if there are any temporary restrictions. The licensing authority may request information from your doctor to decide if you are medically fit to drive.

## Returning to driving

You may be referred to an occupational therapist driving assessor or to a neurologist or rehabilitation specialist to check your ability to return to driving. This may include doing an electroencephalogram (EEG) to assess your seizure risk.

An occupational therapy driving assessment can determine the type of problems you may be experiencing while driving (for example, a slow reaction time). The focus of the assessment is not to suspend or cancel your licence – it is to work out if it is possible for you to return to driving safely.

In some cases, an occupational therapist can teach you driving techniques to help with weaknesses or how to make changes to your car (such as extra mirrors). You may also be able to drive with restrictions, such as only in daylight, only in vehicles with automatic transmission, or only short distances from home.

Some people feel upset or frustrated if they have restrictions on their licence or can no longer drive. You may feel that you have lost your independence or be worried about the impact on your family. If you have to stop driving, the occupational therapist can provide you with alternative options. You may also want to talk to a counsellor or someone who has been through a similar experience (see pages 58–59). Depending on your situation and your health, it may be possible to return to driving at a later stage.

For more information about driving assessments, talk to your doctor or visit the “Assessing Fitness to Drive” section on the Austroads website at [austroads.com.au](http://austroads.com.au).

### **Importance of following restrictions**

It is very important to observe any licence restrictions. If your doctor has said you are not safe to drive again, you must not drive unless they change that medical decision. If you ignore the restrictions or drive unsafely, your licence may then be suspended or cancelled. If your licence has been suspended or cancelled, but you keep driving, you may be fined. In addition, if you have an accident while driving, you could be charged with a criminal offence and your insurance policy will no longer be valid.

“ I had a craniotomy for a benign brain tumour but they couldn’t take all the tumour out. Later I had radiation therapy. Part of the tumour is still there, but it is stable, so I have been able to return to work and I can now drive again. ” *Debbie*

🗨️ I was diagnosed with a grade 4 glioblastoma that couldn't be operated on, so I had radiation therapy and chemotherapy. I needed to stop work and I couldn't drive. I found it all mentally draining. 🗨️ *John*

## Working

It can be hard to predict how well you will recover from treatment for a brain tumour, and when and whether you will be able to return to work. This may also depend on the type of work you do.

Some people find it hard to concentrate or make decisions after treatment. At least at first, it may not be safe to operate heavy machinery or take on a lot of responsibility. A rehabilitation specialist can advise you about whether returning to work is safe or possible. They can also give your employer information about whether you could return to work with altered duties or on a part-time basis.

Talk to your employer about adjusting your duties or working part-time until you have recovered. In some cases, it won't be possible to return to your former role. This can be hard to accept and it may help to talk to the hospital social worker, call Cancer Council 13 11 20 or find a brain tumour support group.



## Key points

- Many people experience changes in the way their body works after a brain or spinal cord tumour and its treatment.
- You or your family may notice changes to speech, memory, personality, balance, coordination and movement. Most of these can be improved with rehabilitation therapies.
- These emotional and physical changes may be hard to cope with. Talking to a counsellor or someone who has had a similar experience may help.
- The rehabilitation you have will depend on an assessment of your needs, your choices and what support is available.
- A neuropsychologist, speech pathologist or occupational therapist can offer various strategies to help improve memory, language skills and concentration.
- Physiotherapy can help you learn how to move more easily, and maintain or regain strength and balance.
- Speech therapy may assist if your ability to talk or swallow has been affected.
- Occupational therapy can help you regain independence in tasks such as showering, dressing and meal preparation.
- People living with a brain tumour may experience seizures. Anticonvulsants may be prescribed.
- Living with or being treated for a brain or spinal cord tumour will probably affect your ability to drive and work, at least for a time after treatment.
- Laws in Australia require drivers to report any long-term or permanent illness or injury that may affect their ability to drive safely.



# Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional treatments and medicines. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

## Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life. Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.



Call Cancer Council **13 11 20** for free copies of *Sexuality, Intimacy and Cancer* and *Fertility and Cancer*, or download the booklets from your local Cancer Council website.

## Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”, but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

### Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a

short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to [beyondblue.org.au](http://beyondblue.org.au) or call **1300 22 4636** to order a fact sheet.



# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support setting, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren't trying to protect their loved ones.

## Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as the Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ I looked ahead and knew there would be different stages and tried to work out how to prepare. I found support groups, both over the phone through Cancer Council and a local group. ” *Ross*

## Follow-up appointments

After your treatment, you will need regular check-ups – these will include scans and physical examinations and sometimes blood tests. Depending on the type of tumour you had, check-ups will often become less frequent if you have no further problems and more time passes since you were diagnosed.

## What if the cancer returns?

For some people, a brain or spinal cord tumour does come back or continues growing despite treatment. If the tumour returns, this is known as a recurrence. Your doctor will talk to you about your treatment options. Some people choose to have further treatment; others decide not to have any. Your treatment options will depend on your situation and the treatments you've already had.

“ I’m more aware of my own body and the need to get any changes checked out straightaway. ”  Mark



## Caring for someone with a tumour

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit [carersaustralia.com.au](http://carersaustralia.com.au) or call 1800 242 636 for more information and resources.

You can call Cancer Council 13 11 20 to find out more about carers' services and get a copy of the *Caring for Someone with Cancer* booklet.

BrainLink may also have helpful services for carers of people with brain diseases – visit [brainlink.org.au](http://brainlink.org.au) or call 1800 677 579.



# Useful websites

The internet has many useful resources, although not all websites are reliable. The websites below are good sources of information.

## Australian

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Cancer Council Australia.....	<b>cancer.org.au</b>
Cancer Australia .....	<b>canceraustralia.gov.au</b>
Cancer Council Online Community .....	<b>cancercouncil.com.au/OC</b>
beyondblue.....	<b>beyondblue.org.au</b>
Carers Australia .....	<b>carersaustralia.com.au</b>
Brain Foundation .....	<b>brainfoundation.org.au</b>
BrainLink .....	<b>brainlink.org.au</b>
Brain Tumour Alliance Australia.....	<b>www.btaa.org.au</b>
Brain Tumour Australia Information .....	<b>btai.com.au</b>
Camp Quality.....	<b>campquality.org.au</b>
CanTeen .....	<b>canteen.org.au</b>
Cooperative Trials Group for Neuro-Oncology.....	<b>cogno.org.au</b>
eviQ (cancer treatments online).....	<b>eviq.org.au</b>
Redkite .....	<b>redkite.org.au</b>
Ronald McDonald Learning Program.....	<b>rmhc.org.au</b>
Sydney Neuro-Oncology Group.....	<b>snog.org.au</b>

## International

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American Cancer Society.....	<b>cancer.org</b>
Cancer Research UK.....	<b>cancerresearchuk.org</b>
Macmillan Cancer Support (UK).....	<b>macmillan.org.uk</b>
National Cancer Institute (US) .....	<b>cancer.gov</b>
American Brain Tumor Association .....	<b>abta.org</b>
National Brain Tumor Society (US) .....	<b>braintumor.org</b>
Spinal Cord Tumour Forum (UK) .....	<b>spinalcordtumour.org.uk</b>



## Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of brain or spinal cord tumour do I have?
- How extensive is the tumour? What grade is it?
- What treatment do you recommend and why? Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment? Is there anything I should watch out for?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- When can I drive a car again?
- When can I return to work?
- How frequently will I need check-ups after treatment? Who should I go to for these appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?



# Glossary

## **acoustic neuroma**

See schwannoma.

## **allied health professional**

A tertiary-trained professional who works with others in a health care team to support a person's medical care.

Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

## **astrocytoma**

A brain tumour that starts in the glial cells known as astrocytes.

## **benign**

Not cancerous or malignant. A benign brain tumour is a low-grade tumour that is usually slow-growing. However, it can still be life-threatening and may need urgent treatment.

## **biopsy**

The removal of a sample of tissue from the body for examination under a microscope to help diagnose a disease.

## **brain stem**

Connects the cerebrum and the spinal cord. Controls life-supporting functions.

## **cells**

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

## **central nervous system**

The brain and spinal cord.

## **cerebellum**

The part of the brain responsible for coordinating movement and balance.

## **cerebrospinal fluid**

Clear, watery fluid surrounding the brain and spinal cord.

## **cerebrum**

The largest, upper part of the brain. The cerebrum is divided into right and left hemispheres.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

May be given alone or in combination with other treatments.

## **cognitive rehabilitation**

Therapies to improve cognitive skills, such as concentration, memory, problem-solving and language skills. May be provided by a speech pathologist, neuropsychologist or occupational therapist.

## **continence**

Ability to control urination and bowel movements.

## **corpus callosum**

A band of nerve fibres that transfers information between the left and right hemispheres of the brain.

## **craniotomy**

An operation to open the skull and access the brain.

## **CT scan**

Computerised tomography scan. This scan uses x-rays and a computer to create a detailed, cross-sectional picture of the body.

**ependymoma**

A brain or spinal cord tumour that starts in the glial cells called ependymas.

**frontal lobe**

Part of the brain responsible for thinking, planning and problem-solving, emotions and personality, and body movement.

**glial cell**

A type of nervous system cell that surrounds and holds neurons in place, nourishes them, and gets rid of dead cells and germs. Also called neuroglia.

**glioblastoma (GBM)**

A type of high-grade astrocytoma. Previously known as glioblastoma multiforme.

**glioma**

A brain tumour that begins in the glial cells. Types of glioma include astrocytoma, glioblastoma, oligodendroglioma and ependymoma.

**grade**

A number that describes how similar cancer cells look to normal cells. Indicates how fast the tumour is growing and how it is likely to behave.

**high-grade tumour**

A fast-growing (grade 3 or 4) brain or spinal cord tumour. May be called a malignant tumour or brain cancer.

**hormones**

Chemicals in the body that send information between cells to bring about changes in the body (e.g. growth, reproductive processes).

**hydrocephalus**

The build-up of cerebrospinal fluid in the brain.

**inoperable**

Not able to be removed with surgery. Also called unresectable.

**intracranial pressure**

Increased pressure in the skull caused by a brain tumour taking up too much space or blocking the flow of cerebrospinal fluid, or by swelling after surgery.

**laminectomy**

Surgery that involves cutting into the spinal column and removing the back part of the vertebral column to access a spinal cord tumour.

**low-grade tumour**

A slow-growing (grade 1 or 2) brain or spinal cord tumour. May be called benign, but can still be life-threatening and may need urgent treatment.

**lumbar puncture**

A test in which a needle is inserted into the spinal column to collect a sample of cerebrospinal fluid. Also called a spinal tap.

**malignant**

Cancerous. A malignant brain tumour is a high-grade tumour that tends to grow quickly. It usually needs urgent treatment.

**medical oncologist**

A doctor who treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy.

**medulloblastoma**

A high-grade brain tumour that starts in the cerebellum.

**meninges**

The thin layers of protective tissue (membranes) that surround the brain and spinal cord.

**meningioma**

A low-grade brain or spinal cord tumour that starts in the meninges.

**metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

**MRI scan**

Magnetic resonance imaging scan. It uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

**neurologist**

A doctor who specialises in the brain and nervous system, and treats tumours that do not need surgery.

**neuron**

A cell that transmits electrical impulses that carry information from one part of the body to the other.

**neuro-oncologist**

Neurologist, oncologist or surgeon who specialises in the management of tumours of the brain and nervous system.

**neuropsychologist**

A psychologist who specialises in helping people with brain impairments.

**neurosurgeon**

A surgeon who specialises in surgery on the brain and nervous system.

**occipital lobe**

Part of the brain responsible for processing visual information.

**oligodendroglioma**

A brain tumour that starts in glial cells called oligodendroglia.

**palliative care**

The holistic care of people who have a life-limiting illness, their families and carers. It aims to maintain quality of life by addressing physical, practical, emotional, spiritual and social needs. Also known as supportive care.

**palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer.

**parietal lobe**

The part of the brain responsible for processing information from the senses.

**peripheral nervous system**

The system of nerves extending outside the central nervous system to the limbs and organs.

**pituitary gland**

A gland in the brain that produces hormones. These hormones control many of the body's functions, including growth, metabolism and production of sex hormones.

**pituitary tumour**

A low-grade brain tumour that starts in the pituitary gland.

**primary cancer**

The original cancer. Cells from the primary cancer may break away and

be carried to other parts of the body, where secondary cancers may form.

### **prognosis**

The expected outcome of a person's disease.

### **radiation therapy**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

### **rehabilitation**

A program to help a person recover and regain function, or adapt to changes, after illness or injury.

### **resectable**

Able to be removed with surgery.

### **schwannoma**

A tumour that starts in the Schwann cells that surround nerves in the brain. Usually low-grade. An acoustic neuroma is a type of schwannoma.

### **secondary cancer.**

See metastasis.

### **seizure**

A disruption of the normal electrical impulses in the brain, causing fits (convulsions) or other symptoms.

### **shunt**

A thin tube to drain fluid build-up in the brain. May be temporary or permanent.

### **spinal cord**

The portion of the central nervous system enclosed in the spinal column, consisting of nerve cells and bundles of nerves that connect all parts of the body with the brain.

### **stereotactic radiosurgery (SRS)**

A type of radiation therapy that delivers a few high doses very precisely.

### **stereotactic surgery**

Surgery done using a computer to guide the surgeon.

### **steroids**

A class of drugs used to reduce swelling in the brain caused by a tumour or surgery.

### **temporal lobe**

The part of the brain responsible for understanding, language and memory.

### **vertebrae**

The bones or segments of the spinal column that protect the spinal cord.

### **Can't find a word here?**

For more cancer-related words, visit:

- [cancerCouncil.com.au/words](http://cancerCouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## **Reference**

1. Australian Institute of Health and Welfare (AIHW), *Brain and other central nervous system cancers*, AIHW, Canberra, 2017.



# How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council

## 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

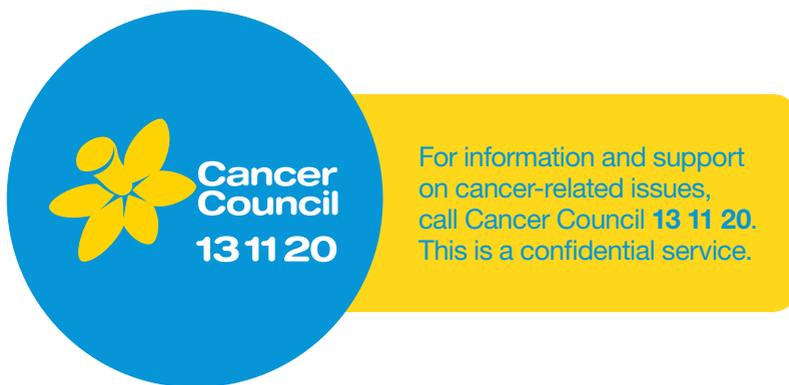
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

**Cancer Council Australia**  
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*