



# Understanding Brain Tumours

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

Cancer  
Information

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**13 11 20**



## Understanding Brain Tumours

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

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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

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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. It includes information about both non-cancerous (benign) and cancerous (malignant) tumours. Many people feel shocked and upset when told they have a brain tumour. We hope this booklet will help you, your family and friends understand how brain and spinal cord 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 questions you may want 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.



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13 11 20**

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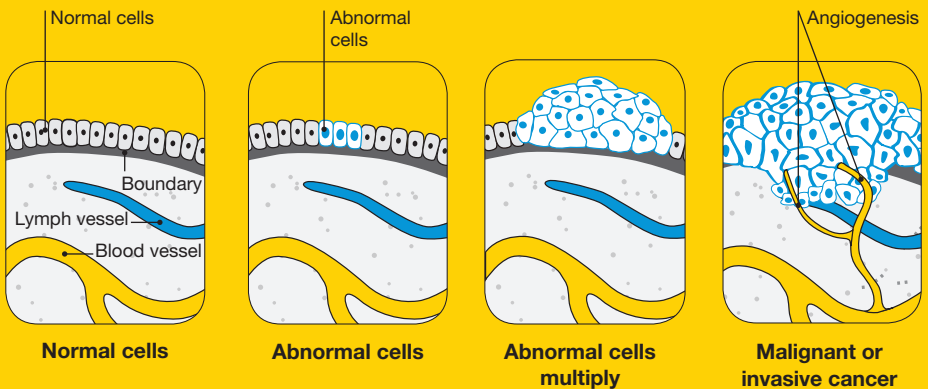
# What is a tumour?

A tumour forms when cells don't grow, divide and die in the usual way. A tumour can be benign or malignant. A benign tumour is non-cancerous. A malignant tumour is cancer.

**Benign tumour** – Cells are confined to one area, grow slowly, and are not able to spread to other parts of the body. Although a benign tumour can cause problems, it is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which in some cases have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid). Most primary tumours of the brain and spine do not spread beyond the central nervous system.

## How cancer starts



Cancer is a disease of the cells, which are the body's basic building blocks. 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. The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, lung cancer that has spread to the brain is still called metastatic lung cancer, even though the person may be experiencing symptoms caused by problems in the brain.

### How cancer spreads

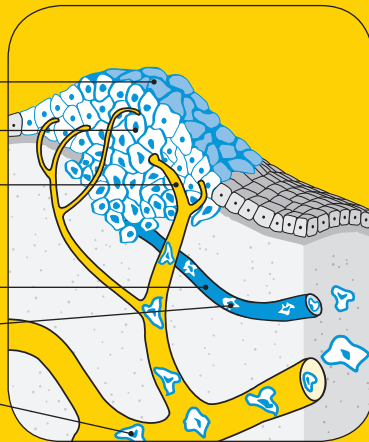
Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

Metastasis –  
cells invade other  
parts of the body via  
blood vessels and  
lymph vessels





# The brain and spinal cord

The brain and spinal cord make up the central nervous system (CNS). The CNS receives messages from cells called nerves, which are spread throughout the body.

The brain interprets information and relays messages through the nerves to muscles and organs. The main sections of the brain are the cerebrum (the largest part of the brain), the cerebellum and the brain stem.

Deep within the brain is the pituitary gland. It controls growth and development by releasing chemical messengers (hormones) into the blood. These chemical messengers signal other hormones to start or stop working.

The spinal cord extends from the brain stem to the lower back. It consists of nerve cells and nerve bundles that connect the brain to all parts of the body through the peripheral nervous system.

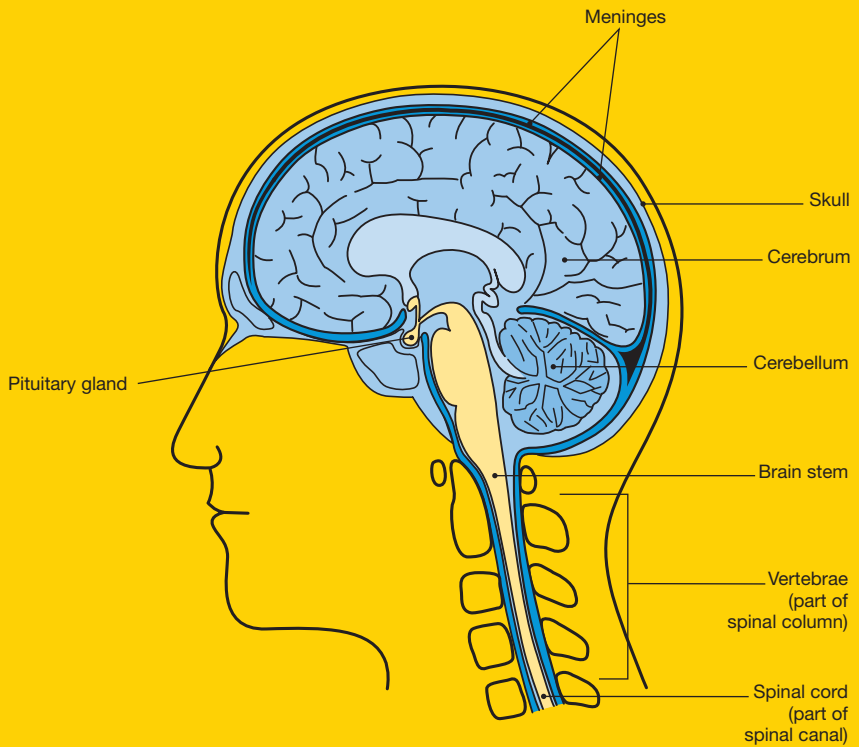
The spinal cord lies in the spinal canal, and is protected by bony vertebrae (spinal column). Both the brain and spinal cord are surrounded by membranes, which is called meninges. Inside the skull and vertebrae, the brain and spinal cord float in liquid. This liquid is called cerebrospinal fluid (CSF).

## Nervous tissue

The brain, spinal cord and nerves consist of billions of nerve cells called neurons or neural cells, which process and send information. Together, this is called nervous tissue.



## The brain and spinal cord



The three main types of neural cells are:

- **sensory neurons** – respond to light, sound and touch
- **motor neurons** – cause muscle contractions
- **interneurons** – connect neurons in the brain and spinal cord.

Glial cells, or neuroglia, are the other main type of cells in the nervous system. There are several different types of glial cells, including astrocytes and oligodendrocytes. Glial cells surround the neurons and hold them in place. The glial cells also supply nutrients to neurons and clear away dead neurons and germs.

## Brain function

The brain plays a unique role in the body's essential functions.

The brain controls all voluntary and involuntary processes, such as moving, learning, sensing, imagining, remembering, breathing, blood circulation and heart rate, body temperature, digestion, and bowel and bladder control (continence).

The cerebrum is the largest part of the brain. The cerebrum is divided into right and left hemispheres. The right hemisphere controls muscles on the left side of the body, and the left hemisphere controls muscles on the right side. The hemispheres are connected by a band of nerve fibres known as the corpus callosum, which transfers information between the two hemispheres.

Each hemisphere is divided into four main areas, called lobes, which control different functions, as shown in the diagram on the opposite page.

## The brain

### Frontal lobe

Responsible for cognition, executive thinking and memory, including your ability to concentrate, plan, solve problems and some aspects of personality and character. Also responsible for motor function, or body movement. Your ability to change thoughts into words is also stored here.

### Parietal lobe

Responsible for spatial awareness, and integrating senses including speech, visual perception and touch.

### Occipital lobe

Responsible for visual processing, including visual memory.

### Temporal lobe

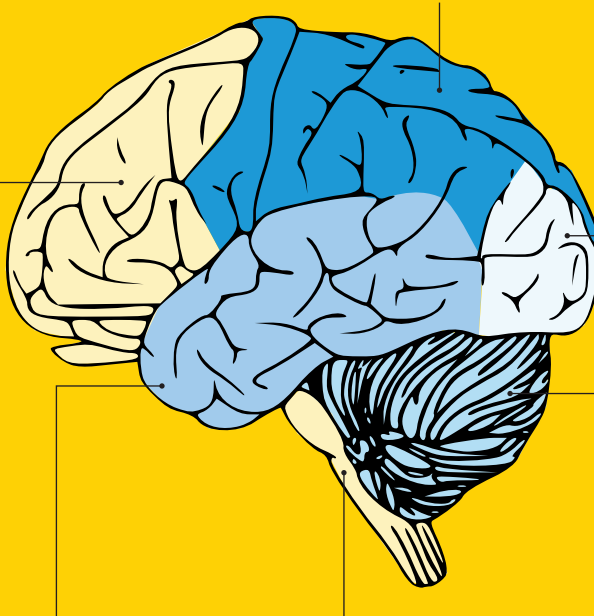
Responsible for auditory perception and language, including recognition of words. Contains the hippocampus, where long-term memories are formed.

### Brain stem

Controls life-supporting functions including alertness, arousal, breathing, temperature, blood pressure and ability to sleep.

### Cerebellum

Responsible for coordination and timing of voluntary movement, as well as balance, standing and walking. Regulates fear, pleasure, attention and language.





## Key questions

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

**A:** A brain or spinal cord tumour occurs when cells in the central nervous system grow and divide to form a lump. Tumours can be benign or malignant.

**Benign (non-cancerous) tumours** – Benign tumours usually have slow-growing cells and rarely spread. However, they may press on the brain, spinal cord, or the cranial nerves, and cause symptoms. Benign tumours may be found in areas of the brain that control vital life functions, and require urgent treatment (see pages 29 – 42).

**Malignant (cancerous) tumours** – These life-threatening tumours often grow rapidly, and may spread within the brain and spinal cord, or reoccur even after treatment. Just over 40% of all brain and spinal cord tumours are malignant.<sup>1</sup>

### Childhood brain tumours

In Australia, about 130 children under 15 are diagnosed with a brain tumour each year. Around 80% of these are cancerous. Children are more likely to develop tumours in the lower parts of the brain, the area that controls movement and coordination.

Glioma and medulloblastoma are the most common types. About 20 children are diagnosed with a spinal cord tumour each year. If your child has a brain tumour, you may find the chapter *Caring for a child with a tumour* helpful – see page 58.

## Q: What types are there?

**A:** There are more than 100 types of brain and spinal cord tumours (also called central nervous system or CNS tumours). They are usually named after the cell type they started in.

**Benign tumours** – The most common types are pituitary tumours (which grow from the pituitary gland), meningiomas (which grow from the meninges), neuromas (which grow from the nerves), and pilocytic astrocytomas.

**Malignant tumours** – The most common type of cancerous brain tumours in adults and children are called gliomas. There are three types of gliomas: astrocytomas, oligodendrogliomas and ependymons. Gliomas can be classified as low or high grade depending on how fast they are growing. A common high grade glioma is glioblastoma (also known as glioblastoma multiforme or GBM), a type of astrocytoma. Medulloblastomas are another type of malignant tumour, which develop in the cerebellum. These are rare in adults but common in children.

**Metastatic brain tumours** – Secondary brain tumours that begin as a primary cancer in another part of the body before spreading to the brain. Cancers that may spread to the brain include melanoma, bowel, breast, kidney and lung cancer.

Not all tumours are easily classified as benign or malignant. Some types of tumours, such as gliomas and ependymomas, may be either.



## Q: How common are they?

**A:** Every year about 1700 malignant brain tumours are diagnosed in Australia.<sup>2</sup> The most common type in adults is a type of glioma called glioblastoma multiforme or GBM. These tumours are generally found in the cerebral hemispheres.

Malignant spinal cord tumours are rare. About 80 people are diagnosed with malignant spinal cord or central nervous system tumours each year.

Data about benign brain and spinal cord tumours is not collected, but they are more common than malignant tumours.<sup>3</sup> In Australia, an estimated 2350 people – including children – are diagnosed with a benign tumour each year.<sup>1</sup>

### Electromagnetic radiation and brain cancer

Many people are concerned that 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. Additionally, you could consider limiting your child's mobile phone use.

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

## Q: What are the symptoms?

**A:** Brain tumour symptoms depend on where it is located and whether it is causing pressure in the skull or on the brain or spinal cord. Sometimes, when a tumour grows slowly, symptoms develop gradually, so you may not be aware of its presence at first.

General symptoms of brain or spinal cord tumours include headaches, seizures, changes in personality, or changes in balance. Increased pressure in the skull can result in nausea, vomiting and confusion. Tumours may also cause weakness or paralysis in parts of the body. Other symptoms might include memory loss, vision loss, hearing difficulties or speech changes. Symptoms may differ depending on where in the brain or spinal cord the tumour is located - see the table on the following pages.

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

“ 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*

Part of the brain	Symptom
<b>Frontal lobe</b>	<ul style="list-style-type: none"> <li>● changes in personality, including loss of inhibition</li> <li>● mood swings</li> <li>● difficulty with planning and organising</li> <li>● weakness in part of the face, or on one side of the body</li> <li>● difficulty walking</li> <li>● loss of sense of smell</li> <li>● problems with your sight or speech</li> </ul>
<b>Parietal lobe</b>	<ul style="list-style-type: none"> <li>● difficulty speaking or understanding what is said to you</li> <li>● problems with reading or writing</li> <li>● loss of feeling in part of the body</li> </ul>
<b>Temporal lobe</b>	<ul style="list-style-type: none"> <li>● forgetting words</li> <li>● difficulty finding the correct word</li> <li>● short term memory loss</li> <li>● fits associated with strange feelings, smells or déjà vu</li> <li>● hearing voices in your head</li> </ul>
<b>Occipital lobe</b>	<ul style="list-style-type: none"> <li>● partial or complete loss of vision</li> </ul>
<b>Cerebellum</b>	<ul style="list-style-type: none"> <li>● coordination problems</li> <li>● uncontrolled eye movement</li> <li>● stiff neck</li> <li>● dizziness</li> </ul>



Part of the brain	Symptom
Spinal cord	<ul style="list-style-type: none"> <li>• back and neck pain</li> <li>• numbness or tingling in the arms or legs</li> <li>• clumsiness or difficulty walking</li> <li>• loss of bowel or bladder control (incontinence)</li> </ul>
Pituitary gland	<ul style="list-style-type: none"> <li>• headaches</li> <li>• loss of vision, particularly peripheral vision</li> <li>• nausea or vomiting</li> <li>• sexual problems</li> </ul>
Brain stem	<ul style="list-style-type: none"> <li>• coordination problems</li> <li>• difficulty swallowing or speaking</li> <li>• double vision</li> <li>• drooping eyelid or mouth on one side</li> </ul>
Meninges	<ul style="list-style-type: none"> <li>• headaches</li> <li>• vomiting</li> <li>• weakness in an arm or a leg</li> <li>• personality changes or confusion</li> <li>• seizures (fits)</li> </ul>
Optic nerve	<ul style="list-style-type: none"> <li>• vision problems</li> </ul>
Hearing nerve	<ul style="list-style-type: none"> <li>• hearing problems</li> </ul>

## Q: What are the risk factors?

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

- **Family history** – It is possible to have a genetic predisposition to developing a tumour. This means that you may have a fault in your genes, usually passed down from one of your parents, that increases your risk. For example, some people have a genetic condition called neurofibromatosis, which causes nerve tissue tumours.
- **Radiotherapy** – People who have had radiation to the head, usually to treat another type of cancer, may be at an increased risk of developing a tumour. This may affect people who had radiotherapy for childhood leukaemia.

### Hydrocephalus

A brain tumour can sometimes block the flow of cerebrospinal fluid around the brain and its spaces (cavities). When this happens, fluid can build up and put pressure on the brain. This is called hydrocephalus. The condition is most common in infants, but it can occur in some adults. It is usually treated with a shunt.



# Diagnosis

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

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

Children have the same types of diagnostic tests as adults, however young children may require a general anaesthetic for some of the tests.

## 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.

## CT scan

A CT (computerised tomography) scan is a procedure that uses x-ray beams to take pictures of the inside of your body. Unlike a standard x-ray, which takes a single picture, a CT scan uses a computer to compile many cross-sectional pictures of areas of your body.

A contrast dye may be injected into your veins. This injection will help make the scan pictures clearer. It may make you feel flushed and hot for a few minutes. Rarely, more serious reactions occur, such as breathing difficulties or low blood pressure.

You will be asked to lie still on a table while the CT scanner, which is large and round like a doughnut, slowly rotates around you. It may take about 30 minutes to prepare for the scan, but the actual test is painless and takes less than 10 minutes. You will be able to go home when the scan is complete.



The dye that is injected into your veins before a CT or MRI scan may contain iodine, and may affect your kidneys. Before your scan, tell your doctor if you have any allergies. You may need to have blood tests to check your kidney function.

## MRI scan

An MRI (magnetic resonance imaging) scan uses magnetic waves to create detailed cross-sectional pictures of organs in your brain and spine. You should let your medical team know if you have a pacemaker or another iron-based metallic object in your body, because the scan may damage these devices.

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 noise of the machine can be a source of distress. In addition, some people feel anxious or claustrophobic lying in such a confined space.

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.

“ I found the MRI confronting, going into the cylinder head first and having to hold my breath. But now when I have this scan during check-ups, I count to myself. This helps me feel more in control. ” *Robyn*

## Further tests

You may also have some of the tests below, which show how quickly or aggressively a tumour is growing (the grade) – see page 21. If your doctor suggests any of these tests, you can ask for a more detailed explanation of the procedures and any follow-up care.

**MRS scan** – An MRS (magnetic resonance spectroscopy) scan can be done at the same time as a standard MRI. It detects the chemical make-up of the brain, which may be changed by a brain tumour.

**MR tractography** – An advanced imaging technique that may enable visualisation of the message pathways (tracts) within the brain e.g. the visual pathway (tracts). This can be useful in planning treatment for gliomas.

**MR perfusion scan** – Another advanced imaging technique that shows the amount of blood flow to various parts of the brain. This scan also be used to distinguish between active tumour and treatment effects.

**SPET or SPECT scan** – A SPET or SPECT (single photon emission computerised tomography) scan takes 3D pictures of your body to assess blood flow in the brain. A small amount of radioactive fluid is injected into your body, which is then scanned with a gamma camera. A brain tumour may have higher blood flow than the rest of the brain.

**PET scan** – In a PET (positron emission tomography) scan you are injected with a radioactive tracer solution. This is absorbed

by cancer cells at a faster rate than normal cells and highlights the active cells.

**Lumbar puncture** – A needle is inserted into the spinal column to collect cerebrospinal fluid to see if cancer cells or abnormal substances, such as blood or proteins, are present. Also called a spinal tap.

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

## Grading brain and spinal cord tumours

The grade describes the rate at which tumours grow and the likeliness or ability to spread into nearby tissue. Most brain and spinal cord tumours don't spread in the body. However, your medical team may need to do other tests to check if the cancer has spread (e.g. CT or MRI scans, or checking the cerebrospinal fluid).

Other tests to determine the type of tumour may also be used to predict how a tumour will grow.

Brain and spinal cord tumours are usually given a grade on a scale of 1 to 4. The grade is worked out by looking at the tumour cells and comparing them to normal cells.

## Grading

<b>Grades 1 and 2</b>	These are the slowest-growing tumours. They are called low-grade tumours.
<b>Grade 3</b>	Tumours grow at a moderate rate. They are called high-grade tumours.
<b>Grade 4</b>	These are the fastest-growing tumours. They are also called high-grade tumours.

## 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 any doctor to predict the exact course of your disease.

There are many factors that may affect your prognosis. These include tumour type, location of the tumour, grade, age, family history and your general health.

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

Some brain or spinal cord tumours, particularly gliomas, can come back (recur). In this case, treatments such as surgery, radiotherapy or



chemotherapy may be used to control the growth of the tumour for as long as possible, relieve symptoms, and improve quality of life.

To determine your prognosis, your doctor will consider:

- test results
- the type of cancer you have
- the rate and depth of tumour growth
- how well you respond to treatment
- other factors such as age, fitness and medical history.

For information about the prognosis of children with brain or spinal cord tumours, see page 10.

## Which health professionals will I see?

If your GP or another doctor suspects 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 neurologist, neuro-oncologist or a neurosurgeon, who will examine you and may do more tests and advise you about your treatment options.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team (MDT). The MDT will probably include some or all of the health professionals listed on the next page.

Health professional	Role
<b>neurologist</b>	diagnoses and treats diseases of the brain and nervous system, particularly those not requiring surgery
<b>neurosurgeon</b>	diagnoses and surgically treats diseases and injuries of the brain and nervous system
<b>nurses and cancer care coordinators</b>	administer drugs, including chemotherapy, and provide care, information and support throughout your treatment
<b>neuropathologist</b>	pathologist specialising in analysing blood and tissue from the brain and spinal cord
<b>medical oncologist</b>	specialises in diagnosing cancers and treating them using chemotherapy and biological therapies
<b>radiation oncologist</b>	specialist in treating cancers with radiotherapy
<b>dietitian</b>	recommends an eating plan for you to follow while you are in treatment and recovery
<b>social worker, psychologist, neuropsychologist, psychiatrist</b>	help with emotional, spiritual, physical, social or practical and financial issues and link you to support services
<b>physiotherapist, speech therapist and occupational therapist</b>	provide rehabilitation services and help with physical issues



## 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 many tests to diagnose the disease.
- A physical examination checks how different parts of your brain are working.
- Imaging scans, such as CT and MRI, allow the doctor to see pictures of the inside of the brain.
- Other scans assess the chemical make-up of the brain, blood flow in the brain, and whether there are active cancer cells in the central nervous system.
- You may also need a blood test to check hormone levels, and a biopsy, which removes some tissue for examination under a microscope.
- The tests help doctors diagnose the type of brain or spinal cord tumour you have, as well as its grade and if it has spread. The grade shows how abnormal the cells are and how quickly the tumour is growing.
- 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.
- You will see a range of health professionals who specialise in different areas of your treatment. You will usually be referred to a neurologist, neurosurgeon or neuro-oncologist.



# 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 clarification, 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.

“ My husband’s doctor said the tumour was inoperable. We decided to get a second opinion from another neurosurgeon to see if they agreed. ” Judith

## 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, 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)

## Children and clinical trials

When parents discover their child is suffering a brain or spinal cord tumour, they usually want to explore all treatment options. This may include thinking about whether to join a clinical trial. For some parents the decision is easy. Other parents may have mixed feelings.

If you are unsure, discussing the issue in depth with your treatment team before committing may help with any concerns. Or you may wish to call Cancer Council **13 11 20** if you need more information or support when deciding whether or not to join a trial.

Oncologists will quite often prescribe a treatment that is based on clinical trials even if the child is not enrolled in the trial. This is because, in many instances, the treatment protocol follows the best known treatment for a specific tumour at the time. It may be worth considering that today's treatments would not exist without research. Participating in a study means your child also contributes to the improvement of treatments for children affected by all types of cancer.

# Treatment

The main treatments for brain or spinal cord tumours are surgery, radiotherapy and chemotherapy. These treatments may be used alone or in combination. Medication, such as steroids, or anti-convulsants (anti-seizure medication), may also be given to reduce symptoms. Treatment offered to children is similar to adults.

There also may be new and experimental treatments, or improvements in existing treatments. These are given in clinical trials – for more information, see page 27.

The aim of treatment is to remove the tumour, slow its growth, or relieve symptoms by shrinking the tumour and swelling.

Your choice of treatment will depend on:

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

## Surgery

Surgery in the central and peripheral nervous system is called neurosurgery. In many cases, removing all or part of the tumour may allow you to fully recover and return to leading an active life. However, you may also have other treatments, including radiotherapy and chemotherapy.

Some tumours can be removed by neurosurgery. This type of operation is called a gross total resection. In other cases, the surgeon may only be able to remove part of the tumour. This is called a

partial resection or debulking. Partial removal may be because the tumour is widespread, near major blood vessels, or cannot be removed without damaging 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 would cause serious problems. This is called an inoperable or unresectable tumour. Your doctor will talk to you about other ways to try to ease the symptoms.

## 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 to precisely pinpoint the location of the tumour. If a stereotactic surgery is planned, these scans will be imported into a computer and be used to guide the surgeon during the operation (see page 33). You may also have what is called a ‘functional MRI scan’ to help the doctors work out which areas of your brain control speech and movement.

Identifying the brain’s sensitive areas can help the surgeon avoid causing damage during the operation. 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. The night before or on the day of surgery you may be sent for a stereotactic CT or MRI scan. Stereotactic surgery may require the surgeon to use small markers called fiducial markers. See page 33 for more information.





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

## Surgery for a brain tumour

The surgeon will remove as much of the tumour as possible without damaging healthy parts of your brain. Surgery may be done as open surgery (a relatively large opening made in the skull) or a stereotactic surgery (see page 33).

**Biopsy** – A small sample of tumour is removed using a needle and examined under a microscope. A biopsy can also be done at the same time as a craniotomy.


**Craniotomy** – The most common type of brain tumour operation. You are given a general anaesthetic and some hair is shaved off and you are given a general anaesthetic. The surgeon cuts through the scalp and moves it aside, then removes a piece of skull above the tumour. After the tumour is taken out, the bone and scalp are put back. The surgeon uses small plates and screws to hold the piece of skull in place.

Patients with a high grade glioma may be given a solution of Gliolan® (5-ALA) prior to surgery. This makes the tumour glow red under ultraviolet light. It ensures the surgeon is able to remove as much of the tumour as possible, while avoiding normal brain matter.

**Awake craniotomy** – This operation is used 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. This is not painful because 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, so they can identify and avoid certain parts of the brain. An electrode is also used to stimulate and identify the important areas of the brain.

**Endoscopic transphenoidal surgery** – A rarer type of surgery used for tumours near the base of the brain (e.g. a pituitary gland tumour). The surgeon puts a long tube (endoscope) into the nose, then removes all or part of the tumour through the nostrils. Recovery may be faster than a craniotomy. An Ear, Nose and Throat surgeon (ENT) may assist with this type of surgery.

**Craniectomy** – This is similar to a craniotomy, except the piece of skull removed is not replaced. Bone (or a piece of plastic or mesh) may be replaced in the future when it won't cause extra pressure. This procedure is very uncommon.

“ I had a craniotomy for a benign brain tumour but they couldn't take all the tumour out. The risk of paralysis or a stroke was too high because the tumour was wrapped around my carotid artery. Later I had radiotherapy. Part of the tumour is still there, but it is stable, so I have been able to return to full-time work and I can now drive again. ”  Debbie

## Stereotactic surgery

This is when surgery is done using a computer to guide the surgeon. The computer creates 3D images of the brain and tumour and monitors the surgical instruments during the operation, allowing the surgeon to operate precisely.

Stereotactic surgery may require the surgeon to use small markers called fiducial

markers. These are taped or glued to the scalp before a scan. Less commonly, a lightweight frame is screwed to the scalp. The scan shows the brain and tumour in relation to the markers or frame.

Stereotactic surgery is safer, more accurate and requires a smaller cut in the skull than non-computer guided surgery.

## Surgery for a spinal cord tumour

The most common surgery to access a spinal cord tumour 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.

## After your brain or spinal cord operation

For the first 12–24 hours after the operation, you will be closely monitored. Nurses will regularly check your breathing, pulse, blood pressure, temperature, pupil size, arm and leg strength and function, and you will be asked questions to assess your level of consciousness. These neurological observations show how your brain and body are recovering from surgery.

Some people have a build-up of fluid in their brain. This is called hydrocephalus. The surgeon may place a long, thin, permanent or temporary tube called a shunt from your brain into your abdomen to drain the extra fluid. The fluid can then be safely absorbed into the bloodstream. A small valve is inserted just under the scalp to make sure the fluid flows away from the brain. You may 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 develop difficulty breathing.

If you are recovering from a craniotomy, your head will be bandaged. Your face and eyes may be swollen or bruised, but this is not usually painful and should ease within about a week.

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

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. Your doctor will tell you when you can start regular activities again.

Your length of stay in hospital will depend on whether you have any problems or side effects following surgery. You may require a period of rehabilitation before you can return home. For more information, see page 44.

## Radiotherapy

Radiotherapy (also called radiation therapy) is a type of treatment that uses high-energy x-ray beams to kill or damage cancer cells. The radiation is specifically targeted at the treatment site to reduce the risk of damage to healthy cells. The treatment itself is usually painless, though you may experience side effects afterwards – see page 37 for more information.

Before your radiotherapy begins, you will need to have a simulation or planning appointment to plan the treatment. A radiation therapist will take measurements of your body, as well as doing a CT scan, to work out the precise area to be treated.

If you are receiving radiotherapy treatment for a spinal cord tumour, some small tattoos may be marked on your skin to indicate the treatment area. If you are having radiotherapy for a brain tumour, a face mask is made before your CT session to keep the head in position.

The face mask is made of a tight-fitting mesh, but you will only wear it for about 10 minutes at a time. You can see and breathe through the mask but it may feel strange and uncomfortable at first. Your treating team can talk to you about techniques to help you manage if you need them.

Radiotherapy treatment is usually given once daily, from Monday to Friday, for several weeks. However, the course of your treatment will depend on the size and type of the tumour.

## Stereotactic radiosurgery

Stereotactic radiosurgery is a specialised type of radiation therapy, not a type of surgery. Stereotactic radiosurgery is sometimes called Gamma Knife® or CyberKnife® treatment, after the machines used to give it.

It is a non-invasive treatment that uses high doses of precisely targeted radiation to treat a brain tumour. Treatment is so accurate that surrounding areas of healthy brain tissue are unlikely to be affected.

A treatment session usually lasts between 15 minutes and two hours, depending on the type of radiosurgery given. You will usually be able to return home afterwards.

Radiosurgery may be offered when traditional surgery is not suitable or as an alternative to open surgery. It is most commonly used for some meningiomas and pituitary tumours, and acoustic neuroma. It is also used for metastatic cancers that have spread from another part of the body.

Stereotactic radiotherapy may also be used to deliver a long course of radiation, particularly for benign brain tumours. The same precise system is used, but several small treatments are given.



Radiosurgery is not usually used for gliomas, as they require a larger treatment area.

## Side effects of radiotherapy

Radiotherapy side effects commonly 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 if you have a brain or spinal cord tumour. 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 for a brain or spinal cord tumour, and fades over time
- **red, sore, inflamed or flaky skin** – may occur in the treatment area, usually happens at the end of treatment for brain tumours, but can and may worsen before improving
- **hair loss** – may occur in the brain tumour treatment area
- **swallowing problems (dysphagia)** – may occur following treatment for spinal cord tumours
- **diarrhoea** – may occur after radiotherapy for spinal cord tumours.

Some people experience similar side effects for several years after treatment. However, it is not always clear if these changes are caused by radiotherapy, the tumour or other treatment. You may benefit from rehabilitation therapy (see page 44) or medication. Your treatment team may also monitor the hormone levels in your pituitary gland.

For more information on radiotherapy treatment, call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*.

## Chemotherapy

Chemotherapy is the use of drugs to treat cancer. Generally, chemotherapy 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 your bone marrow, may also be affected, causing side effects (see the next page).

However, it can be difficult to treat brain tumours with chemotherapy drugs because the body has a protection system called 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 drugs can get through this barrier.

You may be given chemotherapy by taking an oral capsule or through a drip inserted into your vein (intravenously). Each treatment session is usually followed by a rest period of a few weeks.

Oral temozolomide is commonly used to treat gliomas because it is generally effective and well tolerated. If the tumour progresses or recurs while you are taking temozolomide, your oncologist may consider changing the dose or switching to a different chemotherapy drug or combination.



Chemotherapy is often combined with radiotherapy for the treatment of glioblastomas (grade 4 tumours). This combination improves outcomes, compared with radiotherapy alone.



## 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
- diarrhoea or constipation
- breathlessness due to low red blood cell levels (anaemia)
- the feeling of pins and needles (nerve damage known as peripheral neuropathy).

Hair loss is rare with the drugs commonly used to treat brain and spinal cord tumours.

For more information on chemotherapy call Cancer Council 13 11 20 for a free copy of *Understanding Chemotherapy*.

## Steroids

Steroids are made naturally in the body, but they can also be produced artificially and used as drugs. Steroids may help to reduce swelling in the brain, and can be given before, during and after surgery and radiotherapy. Dexamethasone is the most commonly prescribed steroid. It is important to eat some food

before taking steroids. This decreases the likelihood of the steroids irritating your stomach.

The side effects you experience 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, insomnia, restlessness, mood swings, anxiety and very occasionally more serious disturbances of thought and behaviour.

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; or muscle weakness and osteoporosis. You will also be more likely to get infections.

Most side effects are temporary and will fade if your medical team reduces your dose. Short-term side effects can be managed. An experienced counsellor, psychologist or psychiatrist can help you manage mood swings or behavioural changes. A physiotherapist can assist with muscle weakness. If you or your family members are worried about side effects, talk to your doctor, nurse or a counsellor.

“Steroids cause severe mood swings for me. You could tell me I won the lottery and I’d feel like I hated life. I get irritated and cry easily. It’s not rational of course, but I’m aware of how they make me feel and I wait out the feelings.

” *Kate*

## Palliative treatment

Palliative treatment helps to improve people's quality of life by alleviating symptoms of cancer without trying to cure the disease. It is particularly important for people with advanced cancer. However, it is not just for end-of-life care and it can be used at different stages of cancer. Palliative care services can be accessed in the home as well as in a hospital or residential care.

Often treatment is concerned with pain relief and stopping the spread of cancer, but it also involves the management of other physical and emotional symptoms, and psychosocial support for patients and families.

Call Cancer Council 13 11 20 or visit your local Cancer Council website for more information about palliative care and advanced cancer, or to order the *Understanding Palliative Care* booklet.

“ I've been having palliative care treatment for five years. I'm not trying to get rid of the disease, just keeping it under control – and my quality of life is excellent. ” Cate



## Key points

- The main treatments for brain or spinal cord tumours are surgery, radiotherapy and chemotherapy.
- Some tumours can be completely removed in a gross total resection. Others can only be partially removed. This is a partial resection.
- 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.
- Radiotherapy uses 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 children under five.
- Radiosurgery is a type of radiotherapy that precisely targets the treatment area.
- Chemotherapy is the use of drugs to destroy or kill cancer cells. You may be given chemotherapy orally, into a vein via a drip, or as wafers that are placed directly in the brain during surgery.
- Other treatments include steroids to reduce brain inflammation, and anti-convulsants to prevent seizures occurring.
- Treatments may cause short- and long-term side effects. Talk to your doctors and nurses about managing symptoms and side effects, including if you will need rehabilitation.



# Living with a brain tumour

Many people experience changes in the way their body functions as a result of a brain or spinal cord tumour, or treatment for these tumours. You or your family members may notice changes in your speech, personality, memory, movement, balance and coordination. If you notice some differences in behaviour, talk to your doctor, nurse or care coordinator.

Emotionally, these changes may be difficult to cope with. You might find that your self esteem and your relationships, especially with those close to you, 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.

The brain can sometimes heal itself after treatment, but this can be a slow process. Many patients require some rehabilitation to help restore their abilities or manage changes. The type of therapy you have depends on your needs, choices and what is available.

## Children and brain tumours

School-aged children with brain tumours may benefit from tutoring as part of their rehabilitation. This may be available through children's charities such as Redkite and CanTeen. Ask your child's school if they have a copy of Cancer Council's

*Cancer in the School Community*, or talk to the student welfare coordinator, school counsellor or the principal. You can also ask the medical team for information about how the tumour and treatment may have affected your child.

## Rehabilitation

**Cognitive rehabilitation** – If your memory, language skills or concentration is affected, a neuropsychologist, speech pathologist or occupational therapist may help you to improve your cognitive skills using memory activities, diaries and language puzzles.

**Physiotherapy** – In some cases, physiotherapy can help you to learn how to move more easily. It can also help you to develop, maintain or regain strength and balance. Moving and strengthening your muscles can help reduce tiredness. If you can't move easily, you may be able to learn compensation techniques, such as using a walking stick. You may also be given advice on how to exercise safely and stimulate parts of your body to improve circulation and reduce swelling.

**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).

**Occupational therapy** – Some people find their tumour or their treatment impacts on their ability to perform everyday activities (e.g. preparing a meal). Occupational therapy aims to help you to return to the activities that are important to you. A range of physical or cognitive strategies are used to manage fatigue and improve or maintain your independence.

**Assistance for vision impaired** – 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. For more information, call 1300 847 466 or go to [visionaustralia.org](http://visionaustralia.org).

## Managing seizures

If you are diagnosed with a brain tumour, you may experience seizures, which are disruptions to the normal patterns of electrical impulses in the brain.

Seizures are sometimes called fits or convulsions. They can often be prevented with anti-convulsant medication (also called anti-epileptic or anti-seizure medication). You can minimise 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 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 control of their bladder or bowel and bite their tongue.

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



Grapefruit, Seville oranges and certain herbal medicines may change the way some anti-convulsants work. You should also limit your alcohol intake.



## 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 to floor if possible, loosen clothing, place a soft pillow under their head and shoulders).
- Lie the person on their side to clear their airway. This is particularly important if they have vomited, are unconscious or have food or fluid in their mouth.
- If help is needed, call an ambulance (000).
- Observe the person until they have recovered or the ambulance arrives.
- Time how long the seizure lasts so you can advise 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 after having a seizure as most seizures are exhausting.
- For detailed information about seizures, contact Epilepsy Action Australia on **1300 374 537** or visit **[epilepsy.org.au](http://epilepsy.org.au)**.



## Anti-convulsant medicines

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

Side effects of anti-convulsant drugs vary and may include tiredness, weight changes, gum problems, tremors, nausea, vomiting and depression. 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 your dose to reduce any side effects, or can give you another type to try. It is important not to stop taking the medicine or change the dose without your doctor's advice.

## Driving

Benign and malignant tumours, seizures, and certain treatments and medications (such as anti-convulsants and some pain-killers) can cause changes in vision, mobility, coordination, perception and judgment. These changes can affect a person's driving skills.

If you are diagnosed with any type of brain tumour it is very important to ask your doctor how your condition or treatment will impact on your ability to drive. When you are first diagnosed with a brain tumour your doctor may advise you not to drive for a period of time. You may also be advised not to drive for a period after surgery, radiotherapy and chemotherapy.

Always check with your doctor before resuming driving. Laws in Australia require drivers to report any permanent or long term illness or injury that is likely to affect their ability to drive to their driver licensing authority. Your doctor can advise you if you should report your condition or if there are any temporary restrictions. The licensing authority will request information from your doctor to decide if you are medically fit to drive.

You may be referred to a neurologist to assess your fitness/suitability to return to driving. This may include doing an electroencephalogram (EEG) to assess your seizure risk. You may also have an occupational therapy driving assessment. This can determine the type of difficulties you are experiencing while driving (for example, a slow reaction time).

The focus of a driving assessment is not to suspend or cancel your licence. In some cases, an occupational therapist is able to teach you driving techniques to address your weaknesses or instruct you on how to use car modifications (such as additional 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 are no longer able to drive or they have restrictions placed on their licence. These reactions are natural and understandable.

Changes in your ability to drive can affect your sense of independence and may impact on your family too. However, it

may help to remember that the decision is made for your safety and wellbeing. It is also made for the safety of passengers, pedestrians and other road users who could be injured if your driving is unsafe. If you have to stop driving, you may want to talk to a counsellor or someone who has been through a similar experience (see page 56). Depending on your situation and your ongoing health, it may be possible to return to driving at a later stage.

For more information, talk to your doctor or visit the Frequently Asked Questions under 'Assessing Fitness to Drive' on the Austroads website [austroads.com.au](http://austroads.com.au).

## The impact of licence changes

If your licence has restrictions but you ignore them 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 whilst driving, you could be charged with a criminal offence and your insurance policy will no longer be valid.

“ I was diagnosed with a grade 4 glioblastoma multiforme that couldn't be operated on, so I had radiotherapy and chemotherapy. I needed to stop work and I couldn't drive. I found it all mentally draining, but eventually my scans came back clear. ” *John*



## Key points

- Many people experience changes in the way their body functions as a result of a brain or spinal cord tumour, or treatment for one.
- You or a family member may notice changes to speech, personality, memory, movement, balance and coordination.
- Emotionally, these changes may be difficult to cope with. Talking to a counsellor or someone who has had a similar experience may help.
- Many patients require some rehabilitation to help restore their abilities or manage changes. The type of therapy you have will depend on your needs, choices and what is available.
- If your cognitive function is affected, a neuropsychologist, speech pathologist or occupational therapist may help improve memory, language skills and concentration.
- Physiotherapy can help you to learn how to move more easily, maintain or regain strength and balance.
- Speech therapy may assist if your ability to talk has been affected.
- People living with a brain tumour may experience seizures. Anti-convulsants may be prescribed.
- Living with, or being treated for a brain or spinal cord tumour may affect your ability to drive.
- Laws in Australia require drivers to report any permanent or long term illness or injury that may affect their ability to drive. Ask your doctor how your condition or treatment is likely to affect your driving ability.



# 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 medical treatments. 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. Your local Cancer Council may also run a counselling program.

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 224 636** to order a fact sheet.

## Follow-up after treatment

After your treatment, you will need regular check-ups – this may include MRI scans, blood tests, scans and physical examinations. 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 after 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 subsequent treatment will depend on your situation and the treatments you've already had.

“ You do get nervous and you tell yourself it's only a check-up – but it becomes this mountain. I have my scans on Monday and see the doctor on Wednesday, because I can't handle having to wait for the results any longer. ” *Mark*





# 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. This includes:

- **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 [cancerconnections.com.au](http://cancerconnections.com.au).

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

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” *Sam*



## Caring for an adult with a tumour

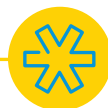
You may be reading this booklet because you are caring for someone with a tumour. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral such as a counsellor or your doctor.

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 Home Help, Meals on Wheels or visiting nurses can help you in your caring role. 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. Phone 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au) for more information and resources.

You can also 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 the website [brainlink.org.au](http://brainlink.org.au).





# Caring for a child with a tumour

## Prognosis

The outcome for your child depends on the type of tumour they have, its location and grade, treatment, and other factors such as their overall health. A significant number of children with a brain or spinal cord tumour will recover completely. In general, children who are diagnosed with a malignant tumour will have a better outlook than adults. Other children have treatment that controls their tumour for many years.

Because a child's nervous system is still developing, some children may develop a physical, behavioural or learning disability as a result of their tumour or treatment.

Talk to your child's medical team about the treatment options, what to expect, and any concerns you have. You may also benefit from talking to a hospital social worker, who can provide practical and emotional support to your family.

## Try to keep things normal

One of your child's most important needs will be for as many things as possible to stay consistent. It is important to continue to show your love and support. It may help to keep rules and discipline as normal as possible. Although you may be tempted to relax the rules, this can lead to confusion over time.

A tumour diagnosis can also be difficult for other children in the family. Their routines may also be disturbed and they may feel left out if parents and visitors show more attention to their sibling.

Try to make time to talk to all your children – ask them how they’re coping and thank them for their patience and help. If your teenager has been diagnosed with a tumour, it can be hard not to be protective at a time when they want to be independent. Talk about finding a balance between maintaining regular activities, going out with friends and staying at home.

## Who can help?

Many hospital staff members specialise in working with children and young adults (paediatrics). Some hospitals employ 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 page 44). Organisations like CanTeen and Redkite offer practical and emotional support for families, young adults and children who are affected by cancer.

## What should I tell my child?

It is natural to want to protect your child from the news of the diagnosis, but children are quick to listen, observe and learn. Doctor’s visits, tests, and absences from school or activities will let them know that something is different. Talking openly about the tumour will help your child to be less anxious and to feel more in control. What you tell your child will depend on their age and knowledge. See tables on the following pages.

For a free copy of *Talking to Kids about Cancer*, call 13 11 20 or visit your local Cancer Council website.



## Newborns, infants and toddlers

Children this young do not understand illness, but will react to being separated from you and changes in routine. They may not be able to talk about it, but they often pick up on physical and emotional changes. Toddlers like to have control over their environment.

- Create a familiar environment that can travel with the child, such as their travel cot and favourite blanket, books and toys.
- Be honest about hospital trips and explain tests that may hurt.
- Give your toddler choices where possible. e.g. “Would you like to wear the red or blue shirt to hospital?”
- If they are in hospital for a period of time, put up some family photographs.



## Preschool children, 3–5 years

Children in this age group are beginning to understand the difference between being well and being sick. They often believe their actions can make things happen.

- Assure your child that their thoughts and behaviour have not caused the illness.
- Be honest when talking about the tests and treatments that they need.
- Reassure your child about your love and care for them.
- Bring familiar toys and books to appointments and the hospital.



## School-age children, 6–12 years

By this age some children know about cancer, but may not know its causes. They may fill in the gaps with their own theories. They can understand what cancer cells are.

- Be open and truthful so they don't assume their own interpretations are correct.
- Tell the school about your child's health and the reasons for any changes in their behaviour or attendance patterns.
- If necessary, seek the support of the student welfare coordinator who may be able to organise extra tutoring or support.



## Teenagers, 13–18 years

Many teenagers have an adult understanding of cancer and often want detailed information. They are starting to separate from the family. This is a vulnerable time, as they don't want to appear different from their peers.

- Provide resources so they can learn more about the diagnosis and treatment of tumours, and get valuable peer and adult support.
- Talk to the school's student welfare coordinator, who may be able to organise or provide extra tutoring or support.
- Encourage teenagers to talk about their feelings but realise they may find it easier to confide in friends, teachers and other trusted people.



# Useful websites

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

## Australian

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Cancer Australia.....	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Cancer Council Australia.....	<a href="http://cancer.org.au">cancer.org.au</a>
beyondblue.....	<a href="http://beyondblue.org.au">beyondblue.org.au</a>
Carers Australia.....	<a href="http://carersaustralia.com.au">carersaustralia.com.au</a>
Brain Foundation.....	<a href="http://brainfoundation.org.au">brainfoundation.org.au</a>
Brain Cancer Action.....	<a href="http://braincanceraction.com.au">braincanceraction.com.au</a>
BrainLink.....	<a href="http://brainlink.org.au">brainlink.org.au</a>
Brain Tumour Alliance Australia.....	<a href="http://btaa.org.au">btaa.org.au</a>
Brain Tumour Australia Information.....	<a href="http://btai.com.au">btai.com.au</a>
CanTeen.....	<a href="http://canteen.org.au">canteen.org.au</a>
Camp Quality.....	<a href="http://campquality.org.au">campquality.org.au</a>
Redkite.....	<a href="http://redkite.org.au">redkite.org.au</a>
Cooperative Trials Group for Neuro-Oncology.....	<a href="http://cogno.org.au">cogno.org.au</a>
Sydney Neuro-Oncology Group.....	<a href="http://snog.org.au">snog.org.au</a>

## International

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American Cancer Society.....	<a href="http://cancer.org">cancer.org</a>
Macmillan Cancer Support (UK).....	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
National Cancer Institute (US).....	<a href="http://cancer.gov">cancer.gov</a>
American Brain Tumor Association.....	<a href="http://abta.org">abta.org</a>
Cancer Research UK.....	<a href="http://cancerresearch.org.uk">cancerresearch.org.uk</a>
National Brain Tumor Society.....	<a href="http://braintumor.org">braintumor.org</a>
Pediatric Brain Tumor Foundation.....	<a href="http://curethekids.org">curethekids.org</a>
Spinal Cord Tumour Forum.....	<a href="http://spinalcortumour.org.uk">spinalcortumour.org.uk</a>





## 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? Is it benign or malignant?
- 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?
- 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

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic puts a person to sleep for some time.

## **astrocyte**

A type of glial cell.

## **astrocytoma**

A type of malignant brain tumour.

## **benign**

Not cancerous or malignant.

## **biopsy**

The removal of a small 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.

## **central nervous system**

The brain and spinal cord.

## **cerebellum**

Part of the brain responsible for the coordination of voluntary movements, as well as balance, standing and walking.

## **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**

The use of drugs to treat cancer

by killing cancer cells or slowing their growth.

## **continence**

Ability to control urination and bowel movements.

## **corpus callosum**

Transfers information between the left and right hemispheres of the brain.

## **craniectomy**

An operation to open the skull by removing some bone in order to access the brain. The bone is not replaced due to swelling.

## **cranio-pharyngioma**

A type of benign brain tumour.

## **craniotomy**

An operation to open the skull and access the brain.

## **CT scan**

A computerised tomography scan. This scan uses x-rays to build a picture of the body.

## **ependymoma**

A type of tumour that can develop in the brain or spinal cord.

## **fiducial markers**

Small markers that are taped or glued to the scalp before the brain is scanned for stereotactic surgery.

## **frontal lobe**

Part of the brain responsible for cognition, executive thinking and memory.

## **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**

A type of glioma. Also known as glioblastoma multiforme or GBM.

### **glioma**

A common type of brain tumour that begins in the glial cells.

### **grade**

The degree of abnormality of cancer cells.

### **hydrocephalus**

The build-up of cerebrospinal fluid in the brain.

### **inoperable**

Not able to be surgically removed. Also called unresectable.

### **interneuron**

A type of neuron that connects other neuron cells in the brain and spinal cord.

### **laminectomy**

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

### **lumbar puncture**

A test where a needle is inserted into the spinal column to collect fluid. Also called a spinal tap.

### **malignant**

Cancerous. Malignant cells spread and can eventually cause death if they are not treated.

### **malignant transformation**

When a benign tumour becomes a rapidly growing, cancerous tumour.

### **medulloblastoma**

A type of malignant brain tumour.

### **meninges**

The membranes surrounding the brain and spinal cord.

### **meningioma**

A type of benign brain tumour.

### **metastasis**

A cancer that has spread from another part of the body. Also called a secondary cancer.

### **motor neuron**

A type of neuron that causes muscle contractions.

### **MRI scan**

A magnetic resonance imaging scan.

This scan uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

### **neurologist**

A doctor who specialises in the structure, function and diseases of the nervous system (including the brain, spinal cord and peripheral nerves).

### **neuroma**

A type of benign brain tumour.

### **neuron**

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

The three types of neurons are sensory neurons, motor neurons and interneurons.

### **neuro-oncologist**

Neurologist or oncologist who specialises in the management of brain tumours and the neurologic side effects of cancer and its therapies.

**neuropsychologist**

A psychologist who specialises in helping people with brain impairments.

**neurosurgeon**

A surgeon who specialises in operations on the nervous system.

**occipital lobe**

Part of the brain responsible for visual processing.

**oligodendrocyte**

A type of glial cell.

**oligodendroglioma**

A type of brain tumour.

**oncologist**

A doctor who uses drugs, including chemotherapy, to treat cancer.

**palliative care**

The holistic care of people who have a life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, emotional, spiritual, social and practical needs. It is not just for people who are about to die, although end-of-life care is a part of palliative care.

**palliative treatment**

Medical treatment to help people with cancer manage pain and other physical and emotional symptoms.

**parietal lobe**

Part of the brain responsible for spatial awareness and integrating senses.

**peripheral nervous system**

The system of nerves extending

outside the central nervous system to the limbs and organs.

**pilocytic astrocytoma**

A type of brain tumour.

**pituitary tumour**

A type of benign brain tumour.

**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 likely outcome of a person's disease.

**psycho-oncologist**

A psychologist or psychiatrist who has special training and experience in the treatment of psychosocial aspects of cancer.

**radiotherapy**

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

**rehabilitation**

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

**resectable**

Able to be surgically removed.

**schwannoma**

A type of benign brain tumour. secondary cancer. See metastasis.

**seizure**

A disruption of the normal electrical impulses in the brain, causing a person to convulse or have other symptoms.

### **sensory neuron**

A type of neuron that responds to light, sound and touch.

### **shunt**

A small, permanent tube used to drain fluid build-up in the brain.

### **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.

### **spinal tap**

See lumbar puncture.

### **stereotactic radiosurgery**

Highly-focused, precisely-targeted radiotherapy done as a single day treatment.

### **stereotactic surgery**

Surgery done using a computer to guide the surgeon.

### **steroids**

Hormones used to reduce swelling in the brain caused by a tumour.

### **temporal lobe**

Part of the brain responsible for auditory perception and language.

### **vertebrae**

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

## **References**

1. Australian Institute of Health and Welfare (AIHW) 2015. Australian Cancer Incidence and Mortality (ACIM) books: Brain cancer. Canberra: AIHW.
2. 2011 Australian Cancer Database, Australian Institute of Health and Welfare.
3. Martin Dobes, Bruce Shadbolt, Vini G. Khurana, Sanjiv Jain, Sarah F. Smith, Robert Smee, Mark Dexter, and Raymond Cook 'A multicenter study of primary brain tumor incidence in Australia (2000-2008)' *Neuro-Oncology* 13(7):783-790, 2011.

### **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).



# 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 Pink Ribbon Day, 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.

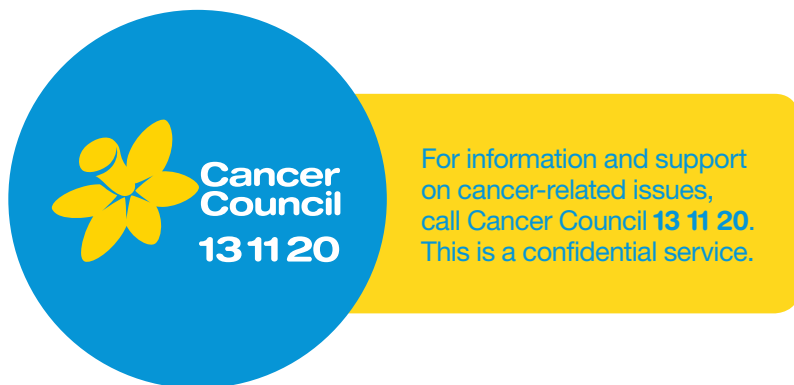
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**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, 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.*