

# Understanding Brain Tumours

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



For information & support, call **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.

### Cancer Council

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



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



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# About this booklet

This booklet has been prepared to help you understand more about brain and spinal cord tumours in adults.

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

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 63 for a question checklist).

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 (see page 64). You may also like to pass this booklet to your family and friends for their information.

**How this booklet was developed** – This information was developed with help from a range of health professionals and people affected by cancer. It is based on Australian and international clinical practice guidelines for brain tumours.<sup>1-2</sup>



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).

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### **Key to icons**

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story



Tips

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# What is a tumour?

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

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

## How are brain tumours classified?

Brain tumours are often classified as benign or malignant. These terms are also used for tumours in other parts of the body. But with brain tumours the difference is not as clear.

### Benign tumours

Benign brain tumours usually grow slowly and are unlikely to spread. A benign tumour may grow and affect how the brain works. This can be life-threatening and may need urgent treatment. Sometimes a benign tumour can change over time and become malignant.

### Malignant tumours

A malignant brain tumour may be called brain cancer. Some malignant brain tumours grow slowly, while others grow rapidly (see *Grading tumours*, page 23). They are considered life-threatening because they may grow larger, spread within the brain or to the spinal cord, or come back after treatment.

## Primary cancer

A cancer that starts in the brain is called primary brain cancer. It may spread to other parts of the nervous system. Unlike other malignant tumours that have the potential to spread throughout the body, primary brain cancers usually do not spread outside the brain and spinal cord.

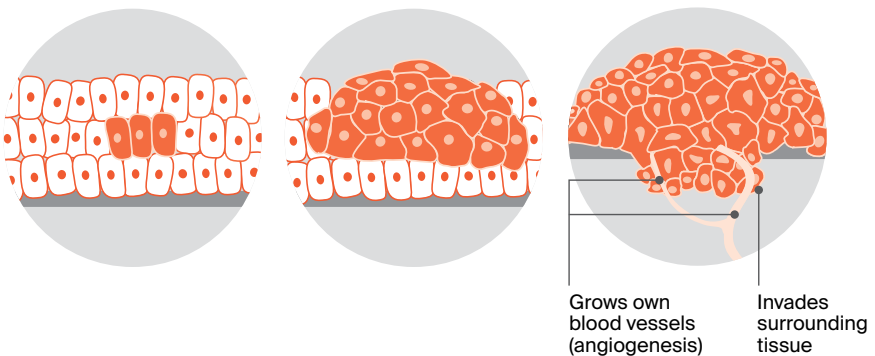
## Secondary cancer

Sometimes cancer starts in another part of the body and then travels through the bloodstream to the brain. This is known as a secondary cancer or metastasis. The cancers most likely to spread to the brain are melanoma, lung, breast, kidney and bowel. A metastasis keeps the name of the original cancer. For example, bowel cancer that has spread to the brain is still called metastatic bowel cancer, even though the person may be having symptoms because cancer is in the brain.

## How cancer starts

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Abnormal cells .....► Abnormal cells multiply .....► Malignant cancer





# The brain and spinal cord

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

**The brain** – The brain receives and interprets information carried to it by nerves from the sensory organs that control taste, smell, touch, sight and hearing. It also sends messages through nerves to the muscles and organs. The brain is responsible for memory, personality and behaviour. The main parts of the brain are the cerebrum, the cerebellum and the brain stem (see pages 8–9 for details).

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

**Meninges** – These are thin layers of protective tissue (membranes) that cover both the brain and spinal cord.

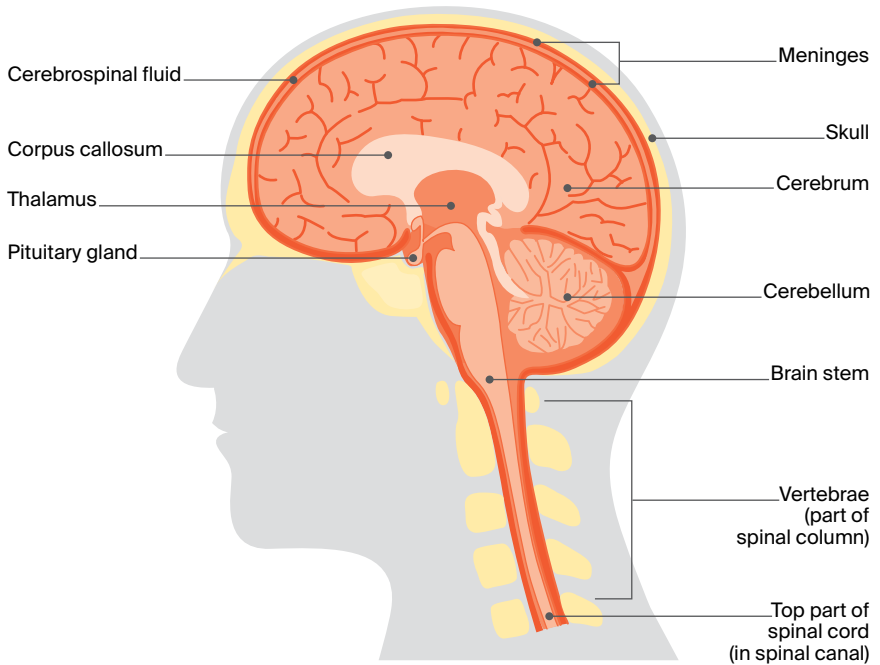
**Cerebrospinal fluid (CSF)** – Found inside the skull and spinal column, CSF surrounds the brain and spinal cord and protects them from injury.

**Pituitary gland** – This is found at the base of the brain and is about the size of a pea. The pituitary gland makes chemical messengers (hormones) and releases them into the blood. These hormones control many body functions, including growth, metabolism and development.



## The central nervous system

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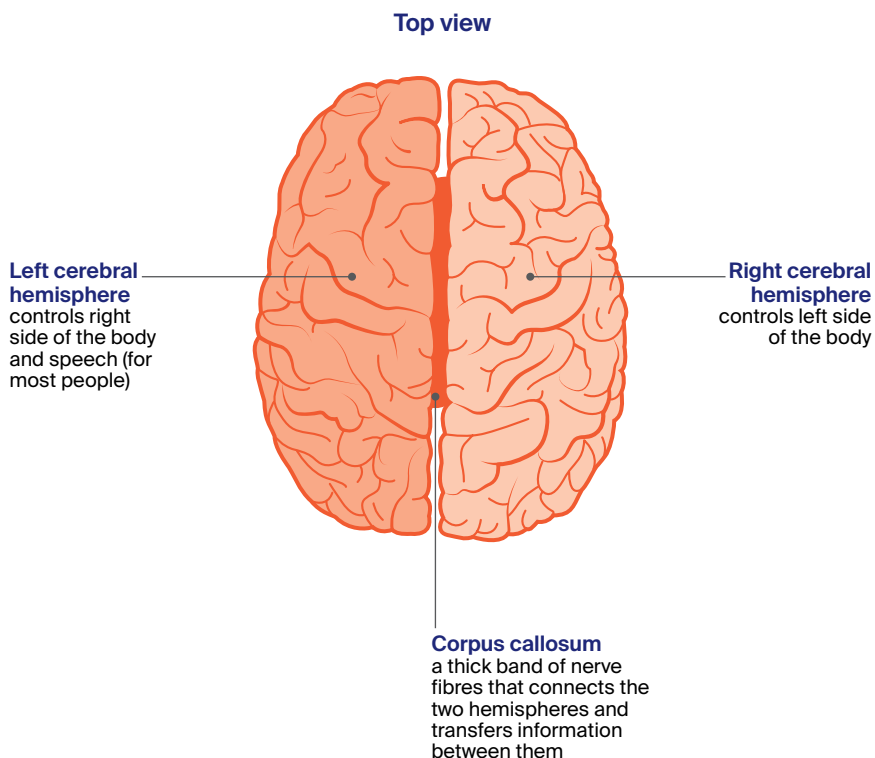
*Cross-section showing the inside of the brain.*

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## The parts of the brain

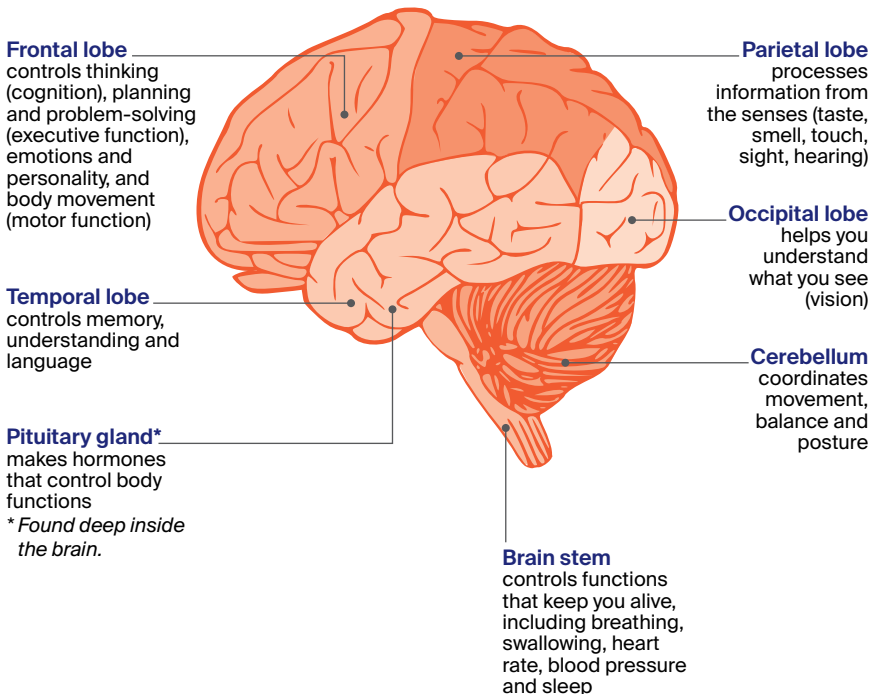
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The largest part of the brain is the cerebrum. It is divided into two halves called hemispheres. Each hemisphere is divided into four main areas – the frontal, parietal, occipital and temporal lobes.



The other main parts of the brain are the cerebellum and the brain stem. The cerebellum is found at the back of the head. The brain stem connects the brain to the spinal cord. Each part of the brain controls different bodily functions.

### Side view



# Key questions

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

**A:** A brain or spinal cord tumour starts when abnormal cells grow and form a mass or a lump. The tumour may be benign or malignant, but both types can be serious and may need urgent treatment. Brain and spinal cord tumours are also called central nervous system or CNS tumours.

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

**A:** Every year an estimated 1900 malignant brain tumours are diagnosed in Australia. They are more common in men than women, and can affect people of any age. About 100 children aged 0-14 are diagnosed each year.<sup>3</sup>

Benign brain and spinal cord tumours are more common than malignant tumours. Data is not collected by every Australian state, but in 2017 there were more than 1200 benign brain and spinal cord tumours in Victoria, Queensland and Western Australia combined.<sup>4</sup>

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

**A:** The brain is made up of different tissues and cells, which can develop into different types of tumours. There are more than 40 types of primary brain and spinal cord tumours. They can start in any part of the brain or spinal cord. Tumours are classified based on the type of cell they start in and how the cells are likely to behave (based on their genetic make-up). Gliomas are the most common type of malignant brain tumour.

## Common types of primary brain tumours

### Glioma tumours

These tumours start in the glial (neuroglia) cells of the brain.

<b>astrocytoma</b>	<ul style="list-style-type: none"><li>• starts in glial cells called astrocytes</li><li>• may be benign or malignant</li></ul>
<b>glioblastoma (GBM)</b>	<ul style="list-style-type: none"><li>• type of malignant astrocytoma</li><li>• may develop from a slow-growing astrocytoma</li><li>• makes up more than half of all gliomas</li><li>• common in both adults and children</li></ul>
<b>ependymoma</b>	<ul style="list-style-type: none"><li>• starts in glial cells called ependymal cells</li><li>• more common in children than adults</li><li>• may be benign or malignant</li></ul>
<b>oligodendroglioma</b>	<ul style="list-style-type: none"><li>• starts in glial cells called oligodendrocytes</li><li>• more common in younger adults</li><li>• malignant; may be slow or fast growing</li></ul>

### Non-glioma tumours

These tumours start in other types of cells found in the brain.

<b>medulloblastoma</b>	<ul style="list-style-type: none"><li>• malignant tumour; starts in the cerebellum</li><li>• more common in children; rare in adults</li></ul>
<b>meningioma</b>	<ul style="list-style-type: none"><li>• starts in the membranes (meninges) covering the brain and spinal cord</li><li>• most common primary brain tumour, usually benign and slow growing</li></ul>
<b>pituitary tumour</b>	<ul style="list-style-type: none"><li>• starts in the pituitary gland</li><li>• usually benign</li></ul>
<b>schwannoma</b>	<ul style="list-style-type: none"><li>• starts in Schwann cells, which surround nerves in the brain and spinal cord</li><li>• usually benign</li><li>• includes vestibular schwannomas (also called acoustic neuromas)</li></ul>

## Q: What are the risk factors?

**A:** The causes of most brain and spinal cord tumours are unknown, but things known to increase a person's risk include:

**Family history** – While it is rare for brain tumours to run in families, some people inherit a gene change from their mother or father that increases the risk of developing a brain tumour. For example, some people have a genetic condition called neurofibromatosis, which can lead to mostly benign tumours of the brain and spinal cord.

**Radiation therapy** – People who have had radiation therapy to the head, particularly to treat childhood leukaemia, may have a slightly higher risk of developing a brain tumour, particularly meningioma.

**Chemical exposure** – A chemical called vinyl chloride, some pesticides, and working in rubber manufacturing and petroleum refining have been linked with brain tumours.

## Mobile phones and microwave ovens

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Many people are concerned that electromagnetic radiation from mobile phones or microwave ovens may cause a brain tumour.

Research has not shown that using a mobile phone causes cancer. Studies are continuing to look at the potential long-term effects of mobile phone use. If you are worried about potential harm from mobile

phones, consider using a hands-free headset, limit the time you spend on your mobile phone, or send a text rather than calling.

Microwave ovens have been in widespread use since the 1980s. There is no evidence that microwave ovens in good condition release electromagnetic radiation at levels that are harmful to people.

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## Q: What are the symptoms?

**A:** Symptoms depend on where the tumour is in the brain and how slowly or quickly the tumour is growing. Symptoms can develop suddenly or gradually over time.

Many symptoms are likely to be caused by other medical conditions, but see your doctor about any new, persistent or worsening symptoms.

**Symptoms caused by the position of the tumour** – see the diagram on the next page.

**General symptoms** – Brain tumours can increase pressure inside the skull (known as intracranial pressure). Pressure can build up because the tumour is taking up too much space, is causing brain swelling or is blocking the flow of cerebrospinal fluid around the brain (see *Having a shunt*, page 33).

Increased pressure inside the skull can lead to symptoms such as:

- headaches – often worse when you wake up
- nausea and vomiting – often worse in the morning or after changing position (e.g. moving from sitting to standing)
- confusion and irritability
- blurred or double vision
- seizures (fits) – might cause some jerking or twitching of your hands, arms or legs, or affect the whole body
- drowsiness
- weakness in parts of the body
- poor coordination
- loss of consciousness
- difficulty speaking or finding the right words.

## Common tumour symptoms

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The symptoms you experience will depend on where the tumour is in the brain or spinal cord. See the previous page for general symptoms caused by pressure in the skull.

### Frontal lobe

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

### Temporal lobe

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

### Pituitary gland\*

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

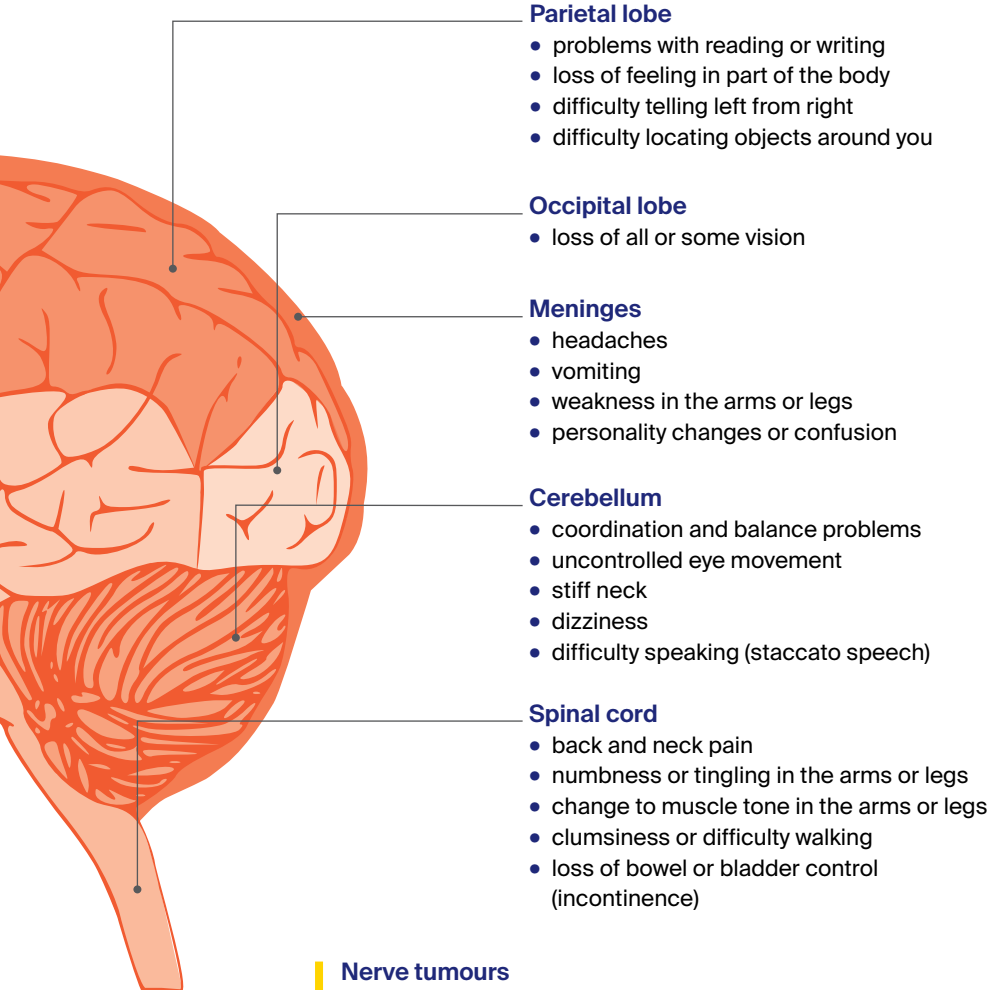
\* Found deep inside the brain.

### Brain stem

- coordination problems
- difficulty swallowing or speaking
- double vision
- weakness and numbness in part of the face
- leg and arm weakness
- fatigue
- changes to sleep/wake patterns







### **Parietal lobe**

- problems with reading or writing
- loss of feeling in part of the body
- difficulty telling left from right
- difficulty locating objects around you

### **Occipital lobe**

- loss of all or some vision

### **Meninges**

- headaches
- vomiting
- weakness in the arms or legs
- personality changes or confusion

### **Cerebellum**

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

### **Spinal cord**

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

### **Nerve tumours**

Symptoms of tumours starting in the nerves in the brain will depend on the affected nerve. The most common nerve tumours are vestibular schwannomas (acoustic neuromas), which cause deafness and loss of balance.

## Q: Which health professionals will I see?

**A:** Your general practitioner (GP) or another doctor will arrange the first tests to assess your symptoms. If these tests do not rule out a tumour, you will usually be referred to a specialist, such as a neurosurgeon or neurologist. The specialist will examine you and arrange further tests.

### Health professionals you may see

<b>neurosurgeon*</b>	diagnoses and treats diseases and injuries of the brain and nervous system; performs surgery
<b>neurologist*</b>	diagnoses and treats diseases of the brain and nervous system, particularly those that do not need surgery; helps people manage cognitive changes and seizures
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy and targeted therapy (systemic treatment)
<b>cancer care coordinator</b>	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>pathologist/ neuropathologist*</b>	analyses blood and tissue from the brain or spinal cord

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

<b>rehabilitation specialist*</b>	recommends and oversees treatment to help you recover movement, mobility and speech after treatment and return to your usual activities
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues
<b>neuropsychologist</b>	assesses people who have problems in thinking or behaviour caused by illness or injury (particularly to the brain) and manages their rehabilitation
<b>psychologist, psychiatrist*</b>	help you manage your emotional response to diagnosis and treatment
<b>physiotherapist, occupational therapist, speech therapist</b>	assist with physical and practical problems, including restoring movement, mobility and speech after treatment, and recommending aids and equipment
<b>exercise physiologist</b>	prescribes exercise to help people with medical conditions improve their overall health, fitness, strength and energy levels
<b>palliative care specialists* and nurses</b>	work closely with the GP and cancer team to help control symptoms and maintain quality of life

*\* Specialist doctor*

## Brain tumours in children

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The information in this booklet is for adults with brain tumours. Brain tumours in children often form in different parts of the brain to adults, and may have different treatments and outlook.

In Australia, about 100 children aged 0–14 are diagnosed with a malignant brain or spinal cord tumour each year.<sup>3</sup>

Children are more likely to develop tumours in the lower part of the brain, which includes the areas that control sleep/wake functions, movement and coordination.

Gliomas and medulloblastomas are the most common types of brain tumours in children.

### Prognosis

In general, children diagnosed with a malignant tumour will have a better outlook than adults. In many children, treatment will cause all signs of the cancer to disappear.

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

### Health professionals to see

Doctors who specialise in treating children and young adults are called paediatricians.

Some hospitals have play, music or art therapists, who can help children cope with the side effects of treatment. Rehabilitation will also be important (see pages 46–47).

### Treatment

Talk to your child's medical team about treatment options, what to expect and your concerns.

### Support

The hospital social worker can link you to support services, and provide practical and emotional support.

Organisations that offer support for families, young adults and children affected by cancer include:

- **Canteen** – call 1800 835 932 or visit [canteen.org.au](http://canteen.org.au)
  - **Camp Quality** – call 1300 662 267 or visit [campquality.org.au](http://campquality.org.au)
  - **Redkite** – call 1800 592 419 or visit [redkite.org.au](http://redkite.org.au)
- See our *Talking to Kids About Cancer* booklet or listen to our podcast episode “Explaining Cancer to Kids”.
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# Diagnosis

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

The doctor will ask you about your symptoms and medical history, and do a physical examination. If they suspect you have a brain or spinal cord tumour, you will be referred for more tests to confirm the diagnosis.

## 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 include:

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

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

## Blood tests

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

## MRI scan

Your doctor will usually recommend an MRI (magnetic resonance imaging) scan to check for brain tumours and to help plan treatment. An MRI scan uses a powerful magnet and a computer to build up detailed pictures of your body. Let your doctor or nurse know if you have a pacemaker or any other metallic object in your body (e.g. surgical clips after heart or bowel surgery). The magnet can interfere with some pacemakers, but newer pacemakers are often MRI-compatible.

For an MRI, you may be injected with a dye (contrast) that highlights any abnormalities in your brain. 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 noisy, narrow machine makes some people feel anxious or claustrophobic. 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 and can press a distress button if you are worried at any time. An MRI takes 30–45 minutes and you will be able to go home afterwards.

The pictures from an MRI scan are generally more detailed than pictures from a CT scan (see opposite).



Before having scans, tell the doctor if you have any allergies or have had a reaction to dyes during previous scans. You should also let them know if you have diabetes or kidney disease, or are pregnant or breastfeeding.

## CT scan

If you are unable to have an MRI, you may have a CT (computerised tomography) scan. This scan uses x-rays and a computer to create detailed pictures of the inside of the body. Sometimes a dye (known as contrast) is injected into a vein before the scan to help make the pictures clearer. The contrast may make you feel hot all over and leave a bitter taste in your mouth. You may also feel a sudden urge to pass urine. These sensations usually ease within minutes.

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

## Further tests

You may have some of the tests listed below to find out more information about the tumour and help your doctor plan treatment.

**MRS scan** – An MRS (magnetic resonance spectroscopy) scan is a specialised type of MRI. It can be done at the same time as a standard MRI. It looks for changes in the chemicals in the brain.

**MR tractography** – An MR (magnetic resonance) tractography scan helps show the message pathways (tracts) within the brain, e.g. the visual pathway from the eye. It can help plan treatment for gliomas.

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

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

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

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

**Surgical removal of tissue (biopsy or resection)** – If scans show an abnormality that looks like a tumour, some tissue may be removed so it can be examined under a microscope. During a biopsy, the neurosurgeon makes a small opening in the skull and inserts a needle to take a small sample. During a resection, the neurosurgeon removes as much of the tumour as possible (see pages 30–31). A specialist doctor called a pathologist will examine the tissue under a microscope for signs of cancer and to work out the type of tumour.

**Molecular testing** – A pathologist will run special tests on the biopsy sample to look for specific mistakes in the structure of the tumour cells (called molecular markers). Some mistakes are found only in cancer



cells (acquired gene changes) and some are passed through families (inherited gene changes, see page 12).

The test results can help identify the features of the tumour so your doctors can recommend the most appropriate treatment. For more information about testing for gene faults (genetic testing), talk to your doctor or call Cancer Council 13 11 20.

## Grading tumours

The tumour will be given a grade based on how the cells look compared to normal cells. The grade suggests how quickly the cancer may grow. The grading system most commonly used for brain tumours is from the World Health Organization. Brain and spinal cord tumours are usually given a grade from 1 to 4.

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

### Grades of brain and spinal cord tumours

<b>grade 1</b>	These tumours are low grade, slow growing and benign.
<b>grade 2</b>	These tumours are low grade and usually grow slowly. They are more likely to come back after treatment and can develop into a higher-grade tumour.
<b>grades 3 and 4</b>	These tumours are high grade, faster growing and malignant. They can spread to other parts of the brain and tend to come back after treatment.



For an overview of what to expect throughout your cancer care for high-grade glioma, visit [cancer.org.au/cancercareguides/high-grade-glioma](https://cancer.org.au/cancercareguides/high-grade-glioma). This is a short guide to what is recommended, from diagnosis to treatment and beyond.

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease.

Several factors may affect your prognosis, including:

- the tumour type, location, grade and genetic make-up
- your age, general health and family history
- whether the tumour has damaged the surrounding healthy brain tissue
- how well the tumour responds to treatment.

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

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

## Key points about diagnosing brain tumours

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### Symptoms

Many people diagnosed with a brain or spinal cord tumour have symptoms caused by the tumour, such as headaches, nausea and vomiting, confusion and irritability, seizures or weakness in parts of the body.

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### Main tests

- A physical examination checks how different parts of your brain and body are working.
  - You may need a blood test to check your hormone levels and overall health.
  - Imaging scans, such as MRI and CT, allow the doctor to see pictures of the inside of the brain. You may be injected with a dye before these scans to help make the pictures clearer.
  - Other scans assess the brain's chemical make-up, blood flow in the brain and whether there are active tumour cells.
  - You may have surgery to remove a sample of tissue (biopsy) or the whole tumour (resection) so it can be looked at under a microscope.
- 

### Grade

- The tests and scans help doctors diagnose the type of brain or spinal cord tumour you have, as well as its grade.
  - The tumour will be given a grade from 1–4. The grade describes how fast the tumour is growing, and whether it is benign or malignant.
- 

### Prognosis

For information about the expected outcome of the disease (prognosis), talk to your doctor.

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# 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, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a short time. Ask them to explain the options, and take what time you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 17) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

**Record the details** – When your doctor first says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 63 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

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

**It's your decision** – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* booklet.

## Should I join a clinical trial?

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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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

► See our *Understanding Clinical Trials and Research* booklet.

# Treatment

The treatments you are offered for a brain or spinal cord tumour will depend on:

- the type, size, grade, location and genetic make-up of the tumour
- your age, medical history and general state of health
- the types of symptoms you have
- the aim of treatment - whether to remove as much of the tumour as possible; to slow the tumour's growth; or to relieve symptoms by shrinking the tumour and reducing swelling.

For a benign tumour, surgery may be the only treatment needed. For a malignant tumour, treatment can include surgery, radiation therapy and chemotherapy, which may be used alone or together. Medicines, such as steroids or anticonvulsants, may be given to reduce symptoms. You may also be able to have new or modified treatments through a clinical trial (see previous page).

## Surgery

Surgery in the brain or spinal cord is called neurosurgery. You may have surgery to:

- remove the whole tumour (total resection)
- remove part of the tumour (partial resection or debulking)
- help diagnose a brain tumour (biopsy, see page 22).

Removing part of the tumour may be considered when the tumour covers a wider area or is near major blood vessels or other important parts of the brain or spinal cord. This may help reduce the pressure on your brain, which will improve some of the symptoms.

## When surgery is not possible

Sometimes a tumour cannot be safely removed because it is too close to certain parts of the brain and surgery would cause blindness, speech problems or partial paralysis. This is called an inoperable or unresectable tumour.

Your doctor will talk to you about what other treatments you can have and ways to manage symptoms.

## What to expect before surgery

The different scans used to diagnose a brain tumour (such as MRI or CT scans, see pages 20–21) are often done again to help plan surgery.

To help the surgeon avoid damaging the most important areas of the brain, you may have a type of MRI scan called a functional MRI (fMRI). You will be asked to complete brain exercises during the scan to show the exact areas of the brain that are used as you speak or move. These parts of the brain can also be found during surgery with brain mapping (see page 30).

Tell your doctor about any blood-thinning or other medicines you are taking. Some medicines interfere with the anaesthetic used during the operation, so you may need to stop taking them for a while.

If you smoke, it is important to stop before surgery. Continuing to smoke can increase the risk of complications.



Having surgery to the brain can sound frightening and it is natural to feel anxious beforehand. Talk to your treatment team about your concerns or call Cancer Council 13 11 20 for support. You can also listen to our podcast episode “Managing Fear”.

## Types of surgery

Different types of operations may be used to remove brain and spinal cord tumours.

**Removing a brain tumour (craniotomy)** – This is the most common type of brain tumour operation. A craniotomy removes all or part of the tumour (total or partial resection) and may be done while you are asleep under general anaesthetic.

The surgeon cuts an area of bone from your skull to access the brain and cut out the tumour. The bone is then put back. The surgeon will insert small plates and screws to hold the piece of skull in place.

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

**Awake craniotomy** – This operation may be recommended if the tumour is near parts of the brain that control speech or movement. All or part of the operation is done while you are awake (conscious) but relaxed, so you can speak, move and respond.

The surgeon asks you to speak or move parts of your body to identify and avoid damaging those parts of the brain. An electrode is also placed on the outside layer of the brain to stimulate and pinpoint important areas of the brain (known as brain mapping).

You may be worried that an awake craniotomy will be painful, but the brain itself does not feel pain and local anaesthetic is used to numb surrounding tissues.



## Computer-guided surgery

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It is now usual for a craniotomy to be done using a computer system to guide the surgeon. This is known as stereotactic surgery.

During the operation, the computer monitors the position of the surgical instruments, allowing the surgeon to be very precise.

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

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

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**Removing a pituitary tumour (endoscopic transsphenoidal surgery)** – The most common surgery for tumours near the base of the brain (e.g. pituitary gland tumours) is called endoscopic transsphenoidal surgery. To remove the tumour, the surgeon inserts a long, thin tube with a light and camera (endoscope) through the nose and into the skull at the base of the brain. An ear, nose and throat (ENT) surgeon may assist with this type of surgery. You will be given a general anaesthetic for this operation.

**Removing a spinal cord tumour (laminectomy)** – The most common surgery for spinal cord tumours is called a laminectomy. In this procedure, the surgeon makes an opening through the skin, muscle and a vertebra in the spinal column to remove the tumour. A laminectomy is usually performed under general anaesthetic.



You will be given drugs (anaesthetic or anaesthesia) to temporarily block any pain or discomfort during the surgery. For more information about the different types of anaesthetic, see our *Understanding Surgery* booklet.

## What to expect after surgery

You will be closely monitored for the first 12–24 hours after the operation. For the first day or two, you will be in the intensive care or high dependency unit.

### Checks and observations

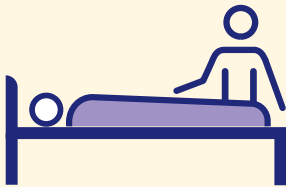


Nurses will regularly check your breathing, blood pressure, pulse, temperature, pupil size, and arm and leg strength and function. You will also be asked questions to assess your level of consciousness. These are called neurological observations. They check how your brain and body are recovering from surgery.

### Pressure stockings



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



### Spinal cord checks

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

### Rehabilitation

The surgery may cause a range of short-term or longer-term side effects (see page 34). Before you can return home, you may need further treatment known as rehabilitation to help you regain your mobility and get back to your daily activities (see pages 46–47).

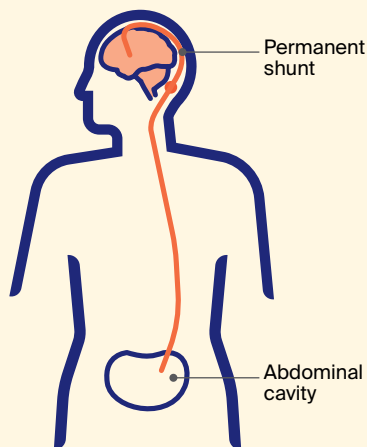
You may stay in hospital for 3–10 days. How long you stay in hospital will depend on whether you have any problems or side effects following surgery.

## Bandages and bruising



The wound will be covered with a dressing, which may vary from a small adhesive pad to bandaging that covers your head. Some or all of your head may have been shaved. After surgery to some parts of the head, your face and eyes may be swollen or bruised: this is normal. It is not usually painful and should ease in about a week.

## Having a shunt



A build-up of cerebrospinal fluid in the brain is called hydrocephalus. It may be caused by the tumour or it can happen after surgery. To drain the extra fluid, you may have a temporary or permanent shunt (a long thin tube placed into your brain). For a temporary shunt (called an external ventricular drain), the tube drains fluid into a bag on the outside of the body. For a permanent shunt, the tube is inserted completely inside your body. It drains into your abdomen and the fluid is absorbed into your bloodstream.

## Headaches and nausea



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

## Side effects of surgery

**Infection** – Although the risk is small, you may develop an infection at the wound site. This can usually be treated with antibiotics. A small number of people may need surgery to have the wound cleaned out.

**Bleeding** – This is a rare but serious side effect. You'll have a CT or MRI scan the day after surgery to check for any bleeding or swelling.

**Swelling** – Surgery can cause swelling in the brain, which increases the pressure inside the skull (intracranial pressure). Your medical team will monitor the swelling and try to reduce it with medicines.

**Other side effects** – You may continue to feel confused and dizzy, and have speech problems, weakness in parts of the body and seizures. You and your family or carers may be surprised that you may feel worse than before the surgery and worry that you aren't recovering well. These side effects are normal and often improve with time.

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

## Rehabilitation after surgery

A range of therapies can help speed up your recovery or show you ways to manage any longer-term changes. These therapies are known as rehabilitation. At first, you may have some rehabilitation therapies in the hospital or a rehabilitation facility. Once you return home, you can continue to have these therapies as an outpatient. You may also be given equipment to use at home. See pages 46–47 for information about some different types of rehabilitation therapies.

## Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill or damage tumour cells in the area being treated. The radiation is usually in the form of x-ray beams.

For gliomas, radiation therapy is typically given after surgery, possibly along with chemotherapy (chemoradiation). Before you start radiation therapy, a radiation therapist will take measurements of your body and do a CT and/or MRI scan to work out the precise area to be treated.

Treatment is carefully planned to do as little harm as possible to the healthy brain tissue near the tumour. Radiation therapy itself is painless, though you may experience some side effects (see pages 38–39). Your treatment team will discuss these with you before you begin treatment.

If you are having radiation therapy for a brain tumour, you will probably need to wear a special plastic mask over your face (see page 37). If you are having radiation therapy for a spinal cord tumour, some small marks may be tattooed on your skin to show the treatment area.

How often you have radiation therapy (the treatment course) will depend on the size and type of tumour. Usually it is given once a day, from Monday to Friday, for several weeks. During treatment, you will lie on a table under a machine called a linear accelerator (LINAC). Most machines use imaging scans to check you are in the correct position for treatment. Each daily treatment will last for about 10–15 minutes.



For glioblastomas (grade 4 cancers), radiation therapy is usually combined with chemotherapy (see page 39). This is called chemoradiation. The chemotherapy drugs make the cancer cells more sensitive to radiation therapy.

## Stereotactic radiosurgery (SRS)

Stereotactic radiosurgery (SRS) is a specialised type of radiation therapy, not a type of surgery, and no cuts are made in the skull.

A specialised radiation machine is used to give very precisely targeted radiation to the tumour. Machine types include LINAC, GammaKnife and CyberKnife. They deliver a high dose of radiation to the tumour while the surrounding healthy brain tissue receives very little.

SRS is not suitable for all types of brain tumours. It may be offered when neurosurgery is not possible or as an alternative to neurosurgery. It is most commonly used for cancers that have spread to the brain from another part of the body. It is also used for some meningiomas, pituitary tumours and schwannomas, and is occasionally used for gliomas that have come back after other treatment.

Often, only 1–5 doses of SRS are needed. A treatment session may last between 15 minutes and two hours, depending on the type of radiosurgery given. You will need to wear a special mask (see opposite) or frame during the treatment. You will usually be able to go home afterwards.

## Stereotactic radiation therapy (SRT)

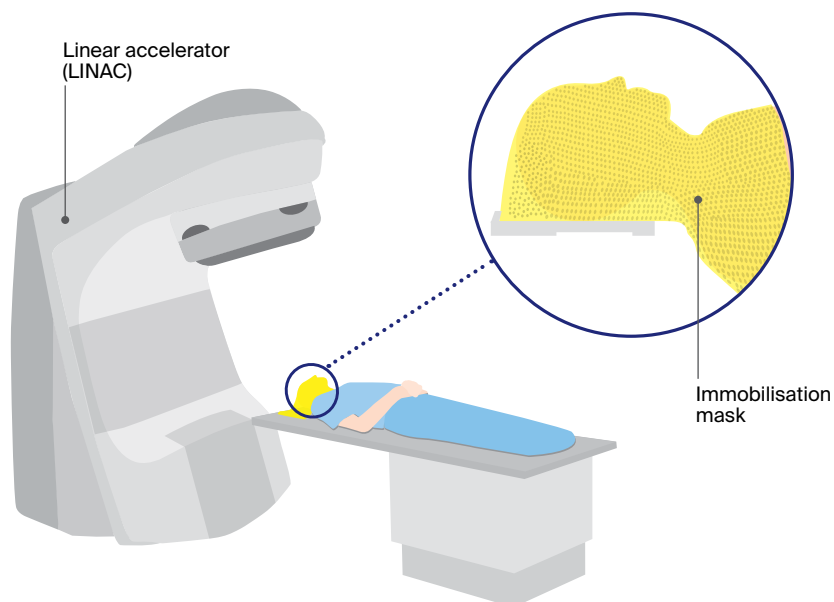
A stereotactic radiosurgery machine may also be used to deliver a longer course of radiation, particularly for benign brain tumours. This is called stereotactic radiation therapy. The treatment is given as multiple small daily doses.



If you feel anxious before your radiation therapy sessions, you may find it helpful to listen to the meditation and relaxation exercises in our *Finding Calm During Cancer* podcast.

## Wearing an immobilisation mask

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You'll need to wear a plastic mask during radiation therapy to the brain. This is known as an immobilisation mask. It will help keep your head still and make sure the radiation is targeted at the same area during each session. The mask is made to fit you. It is fixed to the table while the treatment is delivered.

The mask is made of a tight-fitting mesh, but you will wear it for only

about 10 minutes at a time. You can see, speak and breathe through the mask, but it may feel strange and confined at first. Tell the radiation therapists if wearing the mask makes you feel anxious. With the support of the radiation therapy team, many people find that they get used to wearing the mask. The team may suggest you try breathing or relaxation exercises, or you may be offered medicine to help you relax.

## Proton therapy

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This uses protons rather than x-ray beams. Protons are tiny parts of atoms with a positive charge. Proton therapy is useful for some types of brain and spinal cord tumours, and

tumours near sensitive areas. It is not yet available in Australia (as at mid 2022), but there is funding in special cases to allow Australians to travel overseas for treatment.

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## Side effects of radiation therapy

Radiation therapy side effects generally occur in the treatment area. They are usually temporary, but some may last for a few months or years, or be permanent. The side effects vary depending on whether the tumour is in the brain or spinal cord. They may include:

- **nausea** – can occur several hours after treatment
- **headaches** – can occur during the course of treatment
- **tiredness or fatigue** – worse at the end of the treatment course; can continue to build after treatment, but usually improves over a month or so
- **dry, itchy, red, sore or flaky skin** – may occur in the treatment area; usually happens at the end of the treatment course and lasts 1-2 weeks before going away
- **hair loss** – may occur in a patch in the area of the head receiving treatment; usually temporary but in some cases permanent; if hair grows back, the texture or colour may be different
- **dulled hearing** – may occur if fluid builds up in the middle ear and may be permanent.

Radiation therapy side effects specific for spinal cord tumours include swallowing problems (dysphagia) if the neck is treated and diarrhoea if the lower spine is treated. Both are temporary.



If any side effects develop, talk to your radiation oncology team. They can suggest ways to manage them.

A small number of adults who have had radiation therapy to the brain have side effects that appear months or years after treatment. These are called late effects and can include symptoms such as poor memory, confusion and headaches. The problems that might develop depend on the part of the brain that was treated.

High-dose radiation to the pituitary gland can cause it to produce too little of some hormones. This can affect body temperature, growth, sleep, weight and appetite. The hormone levels in your pituitary gland will be monitored during and after treatment.

▶ See our *Understanding Radiation Therapy* booklet.

## Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells while causing the least possible damage to healthy cells.

You may have chemotherapy after surgery or radiation therapy. Chemotherapy may also be combined with radiation therapy (chemoradiation). You may be given chemotherapy as capsules or tablets that you swallow (orally), or as a liquid through a drip inserted into your vein (intravenously).

The brain has a structure known as the blood-brain barrier, which helps protect the brain from substances in the blood, such as germs or chemicals, that may injure the brain. Only certain types of chemotherapy drugs can get through this barrier.

Temozolomide is the most commonly prescribed chemotherapy drug for the treatment of glioma brain tumours. It is given as a capsule you take at home for five days in a row, followed by a rest period of a few weeks. This is called a cycle and each cycle lasts for 28 days. You are likely to have 6–12 cycles of temozolomide, though it may continue for longer.

## Side effects of chemotherapy

There are many possible side effects of chemotherapy, depending on the type of drugs you are given. Talk to your doctor about ways to reduce or manage any side effects you have. Side effects are mostly mild with temozolomide and may include:

- nausea or vomiting
- tiredness, fatigue and lack of energy
- increased risk of infection
- mouth sores and ulcers
- diarrhoea or constipation
- loss of appetite
- skin rash
- liver damage
- damage to ovaries or testicles, which can make you unable to have children naturally (infertile)
- breathlessness due to low levels of red blood cells (anaemia)
- low levels of platelets (thrombocytopenia), increasing the risk of abnormal bleeding
- reduction in the production of blood cells in the bone marrow; you will usually have regular blood tests to monitor your blood levels.

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

▶ See our *Understanding Chemotherapy* booklet.



## Ali's story

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

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

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

*I think I was in denial for a while and I wasn't particularly worried about the second operation, but I got more worried as the date came closer.*

*I had no real problems from the surgery: it was textbook healing really, and the surgeon said they had got it all. But then he told me I'd need radiation therapy and chemotherapy, just to mop up any stray cells. That floored me – I hadn't*

*needed it the first time, so I thought I'd escaped it.*

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

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

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

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



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

## Steroids

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

### Side effects of steroids

The side effects of steroids depend on the dose and length of treatment:

**Short-term use** – If you are prescribed steroids for a short period, you may experience increased appetite, weight gain, trouble sleeping, restlessness, mood swings, anxiety and, in rare cases, more serious changes to thinking and behaviour. In people who have diabetes, steroids can quickly lead to high or unstable blood sugar levels. These short-term side effects can be managed. Eating before taking steroids can reduce the chance of the steroids irritating your stomach.

**Longer-term use** – If steroids are taken for several months, they can cause puffy skin (fluid retention or oedema) in the feet, hands or face; high blood pressure; weight gain; unstable blood sugar levels; diabetes; muscle weakness; and loss of bone density (osteoporosis). You will also be more likely to get infections. Your doctor may change your dose to manage any side effects you have. Most side effects will go away when treatment is over.

An experienced counsellor, psychologist or psychiatrist can help you manage any mood swings or behavioural changes. If you or your family are worried about side effects, talk to your doctor or nurse or call Cancer Council 13 11 20.

## Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. Many people think that palliative treatment is only for people at the end of their life, but it may help at any stage of advanced cancer.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include surgery, radiation therapy, chemotherapy or other medicines or supplements.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, spiritual and social needs. You can have palliative care services in the home as well as in a hospital or in residential care.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

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

## Key points about treating brain tumours

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### Main treatments

The main treatments are surgery, radiation therapy and chemotherapy.

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### Surgery

- Some tumours can be completely removed with surgery (total resection). Others can only be partly removed (partial resection or debulking).
  - The most common brain surgery is a craniotomy.
  - A laminectomy removes tumours from the spinal cord.
- 

### Radiation therapy

- Radiation therapy uses targeted radiation, such as x-rays, to kill cancer cells.
  - Stereotactic radiosurgery is a very precise form of radiation therapy that delivers high doses of radiation. It is used to treat some types of tumours.
- 

### Chemotherapy

- Chemotherapy is the use of drugs to kill cancer cells.
  - You may be given chemotherapy as capsules or tablets, or into a vein (intravenously) through a drip.
- 

### Other treatments

Other treatments include steroids to reduce swelling in the brain, and anticonvulsants to manage seizures (see page 50).

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### Side effects

Treatments may cause short-term and long-term side effects. Talk to your doctors and nurses about ways to manage symptoms and side effects, including whether rehabilitation may help.

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# Living with a brain or spinal cord tumour

A brain or spinal cord tumour and its treatment can change how the mind and body work. You or your family members may notice changes in how you speak and your personality, memory, movement, balance or coordination.

The types of changes you experience will depend on the part of the brain affected by the tumour and what treatment you have had. If you or your family feel like you are behaving differently, talk to your doctor, nurse or cancer care coordinator.

Rehabilitation is treatment designed to help people recover from injury or disease. After treatment for a brain or spinal cord tumour, most people will have a rehabilitation assessment to identify their needs and ways to manage them. A range of therapies (see next two pages) can help restore your previous abilities or help you adjust to any changes.

The changes may be difficult to cope with emotionally, and you might find that your self-esteem and your relationships are affected. Talking to a counsellor or someone who has had a similar experience may help. Call Cancer Council 13 11 20 to see what support is available.

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

## Types of rehabilitation

A range of therapies can support you in your recovery. These may be available at your cancer treatment centre, or through a rehabilitation specialist at a rehabilitation hospital.

### Physiotherapy



Your physical abilities may be affected. Physiotherapy can help you learn how to move more easily, develop muscle strength and improve balance.

Moving and strengthening your muscles can reduce tiredness or weakness related to treatment. If you can't move easily, you may be able to learn techniques, such as using a walking stick, so you can become more independent.

A neurophysiotherapist specialises in treating physical changes caused by damage to the central nervous system.

### Cognitive rehabilitation



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

A neuropsychologist, speech pathologist or occupational therapist can help improve these cognitive skills using memory activities, speech therapy, assistive technology such as diaries and reminder alerts, and word puzzles.

### Exercise



A physiotherapist or an exercise physiologist can give you advice on how to increase physical activity and exercise safely to improve circulation and mobility, reduce swelling, and increase your heart and lung fitness. They will also help you explore ways to return to activities you previously enjoyed.

To find a physiotherapist, visit [choose.physio/find-a-physio](http://choose.physio/find-a-physio) and to find an accredited exercise physiologist, visit [essa.org.au/find-aep](http://essa.org.au/find-aep).



You may also be referred to allied health professionals (e.g. physiotherapist, occupational therapist) in private practice. Ask to see a therapist experienced in working with people after treatment for brain or spinal cord tumours.

## Speech therapy



Your ability to talk may be affected. A speech pathologist could help restore speech.

Speech pathologists also work with people who have difficulty swallowing food and drink (dysphagia).

To find a certified practising speech pathologist, visit [speechpathologyaustralia.org.au](http://speechpathologyaustralia.org.au).

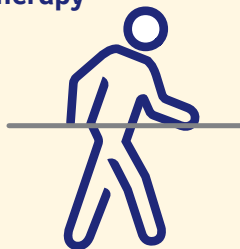
## Sight



You may lose some or all of your sight as a result of a brain tumour or surgery.

Vision Australia can help people learn how to live independently. Call 1300 84 74 66 or visit [visionaustralia.org](http://visionaustralia.org).

## Occupational therapy



If treatment has made it harder to perform everyday personal activities (e.g. showering, dressing, preparing a meal), an occupational therapist can help. A range of strategies and aids can help you manage fatigue and improve or maintain your independence.

To find an occupational therapist, visit [otaus.com.au/find-an-ot](http://otaus.com.au/find-an-ot).

## Managing seizures

A brain tumour or its treatment can sometimes cause seizures (also called fits or convulsions). A seizure is a disruption to the normal patterns of electrical impulses in the brain. Seizures can be divided into two main groups:

**Generalised seizures** – These occur when the whole brain is affected, and typically involve 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 loss of consciousness. The person's muscles may stiffen, their limbs may jerk rhythmically, and their breathing may be shallow for up to two minutes. They may bite their tongue, and lose bladder and bowel control.

**Focal seizures** – Also called partial seizures, these occur when one area (lobe) of the brain is affected. Focal seizures affect one part of the body, such as an arm or leg.

Symptoms of focal seizures depend on the area of the brain involved. They may include twitching; jerking; tingling or numbness; loss of speech; and altered sensations, such as changed vision or hearing, strange tastes or smells, or a feeling of déjà vu. Focal seizures may also cause a brief loss of consciousness, changes in mood, and memory loss just before, during and after the seizure.

## Ways to prevent seizures

Seizures can often be prevented with anticonvulsant medicines (also called anti-epileptic or anti-seizure medicines) – see page 50. Fatigue, or feeling very tired, can also increase your risk of having a seizure. Try to get enough sleep. Limiting alcohol may also help.



## Ways to help someone having a seizure

- Remain calm and stay with the person while they are having a seizure. Refer to their Seizure Management Plan, if they have one.
- Do not hold them down or put anything in their mouth.
- Protect the person from injury (e.g. move hazards, lower them to the floor if possible, loosen clothing, cushion their head and shoulders).
- Call Triple Zero (000) for an ambulance if it is the first seizure the person has had; if the person is injured; if there was food or fluid in the person's mouth; if the seizure lasts longer than five minutes; or if you are unsure of what to do.
- Time how long the seizure lasts so you can tell the paramedics.
- After the jerking stops, roll the person onto their side to keep their airway clear. This is particularly important if the person has vomited, is unconscious or has food or fluid in their mouth.
- Watch the person until they have recovered, or the ambulance arrives.
- If the seizure occurs while the 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, fluid or vomit in their mouth.
- Explain to the person what has occurred. In many cases, people are confused after a seizure.
- Allow the person to rest afterwards as most seizures are exhausting.
- For detailed information and an online tool for creating a Seizure Management Plan, contact Epilepsy Action Australia on 1300 37 45 37 or visit [epilepsy.org.au](http://epilepsy.org.au).

## Anticonvulsant medicines

Different types of anticonvulsant drugs are used to prevent seizures. You may need to have blood tests while you are taking anticonvulsants. This is to check whether the dose is working and how your liver is coping with the medicine.

Side effects of anticonvulsant drugs vary, but they may include tiredness, gum problems, shakes (tremors), nausea, vomiting, weight changes, depression, irritability and aggression.

If you are allergic to the medicine, you may get a rash. Tell your treatment team if you have any skin changes or other side effects. Your doctor can adjust the dose or try another anticonvulsant. Do not stop taking the medicine or change the dose without your doctor's advice.



If you are taking anticonvulsants, you may need to avoid eating particular foods. Check with your doctor before taking any herbal medicines, as these can change the way some anticonvulsants work. Talk to your doctor or pharmacist about potential interactions and foods to avoid.

## Driving

Tumours, seizures, brain surgery and medicines (such as anticonvulsants and some pain medicines) can affect the skills needed to drive safely.

These skills include:

- good vision and perception
- ability to concentrate and plan
- ability to remember directions
- good hand-eye coordination
- planning and problem solving.

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

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

If you have had seizures, you will need to be seizure-free for a period of time before you are allowed to drive. If you stop taking your anticonvulsant medicines, you will also need to be seizure-free for a period of time until you are allowed to drive.

Before you start driving again, always check with your doctor. Laws in Australia require drivers to let their driver licensing authority know about any permanent or long-term illness or injury that is likely to affect their ability to drive.

Your doctor can tell you if you should report your condition or if there are any temporary restrictions. The licensing authority may ask for information from your doctor to decide if you are medically fit to drive. See the next page for some things that may help you return to driving.

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



## How to return to driving

- Have a driving assessment to check your ability to return to driving. This may include doing an off-road assessment or having an electroencephalogram (EEG) to assess seizure risk.
- See an occupational therapist driving assessor, a neurologist or rehabilitation specialist to work out the type of problems you may be experiencing while driving (e.g. a slow reaction time). The focus of the assessment is not to suspend or cancel your licence: it is to work out if it is possible for you to safely return to driving.
- An occupational therapist may be able to teach you driving techniques to help with weaknesses or show you how to make changes to your car (such as extra mirrors). You may also be able to drive with restrictions, such as only in daylight, only in automatic cars or only short distances from home.
- Some people feel upset or frustrated if they have licence restrictions or can no longer drive. You may feel that you have lost your independence or be worried about the impact on your family. It may help to talk to a counsellor or someone who has been through a similar experience (see pages 60–61). Depending on your situation and your health, it may be possible to return to driving later on.
- Follow any licence restrictions. If your doctor has said you are not safe to drive, you must not drive unless they change that medical decision. If you ignore the restrictions, your licence may be suspended or cancelled. You may be fined if you drive while your licence has been suspended or cancelled. If you have an accident while driving, you could be charged with a criminal offence and your insurance policy will no longer be valid.
- For more information, talk to your doctor or visit [austroads.com.au/drivers-and-vehicles/assessing-fitness-to-drive](http://austroads.com.au/drivers-and-vehicles/assessing-fitness-to-drive).

## Working

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

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

Talk to your employer about adjusting your duties or working part-time until you have recovered. In some cases, it won't be possible to return to your former role. This can be hard to accept, and it may help to talk to the hospital social worker, call Cancer Council 13 11 20 or join a brain tumour support group. For other sources of support, see pages 60–61.

► See our *Cancer, Work & You* booklet.

## Financial support for people with disabilities

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The National Disability Insurance Scheme (NDIS) provides Australians aged under 65 who have a permanent and significant disability with funding for support and services. The NDIS may be able to help a person whose everyday activities have been impacted by a brain tumour. For more information,

talk with your rehabilitation team, call 1800 800 110 or visit [ndis.gov.au](http://ndis.gov.au).

If your GP refers you to a rehabilitation specialist (see pages 46–47) as part of a GP Management Plan or Team Care Arrangement, you may be eligible for a Medicare rebate for up to five visits each year.

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## Key points about living with a brain tumour

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### Side effects

- A brain or spinal cord tumour and its treatment can cause changes to speech, personality, memory, movement, balance or coordination.
- People living with a brain tumour may have seizures, which can be treated with anticonvulsant medicines.

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### Rehabilitation

Rehabilitation can help you manage any changes. The type of rehabilitation you have will depend on an assessment of your needs, your choices and what support is available:

- A neuropsychologist, speech pathologist or occupational therapist can offer various strategies to help improve memory, language skills and concentration.
- Physiotherapy can help you learn how to move more easily, maintain or regain strength and improve balance.
- Speech therapy may assist if your ability to talk or swallow has been affected.
- Occupational therapy can help you regain independence in tasks such as showering, dressing and making a meal.
- Under a GP Management Plan or Team Care Arrangement, you may be eligible for a Medicare rebate for up to a total of five visits to allied health professionals each year.

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### Driving and working

- Living with or being treated for a brain or spinal cord tumour will probably affect your ability to drive and work, at least for a time after treatment.
- Laws in Australia require drivers to report any illness or injury that may affect their ability to drive safely to their driver licensing authority.



# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more or visit your local Cancer Council website (see back cover).

**Eating well** – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

▶ See our *Nutrition for People Living with Cancer* booklet.

**Staying active** – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

▶ See our *Exercise for People Living with Cancer* booklet.

**Complementary therapies** – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

▶ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested, may prevent successful treatment of the cancer and can be harmful. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. The experience of cancer may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

▶ See our *Emotions and Cancer* booklet.

**Sexuality** – 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.

▶ See our *Sexuality, Intimacy and Cancer* booklet.

**Contraception and fertility** – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

▶ See our *Fertility and Cancer* booklet.

# 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 that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

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.

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

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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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit [beyondblue.org.au](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline 13 11 14 or visit [lifeline.org.au](http://lifeline.org.au).

## Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any long-term side effects and check that the tumour hasn't come back or spread. During these check-ups, you will usually have a physical examination and you may have blood tests or MRI scans.

How often you see your doctor will depend on the type of tumour and treatments you had. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

When a follow-up appointment or test is approaching, you may find that you feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

## What if the tumour returns?

For some people, a brain or spinal cord tumour does come back or keep growing despite treatment. If the tumour returns, this is known as a recurrence. Your treatment options will depend on your situation and the treatments you've already had, but may include surgery, radiation therapy combined with chemotherapy, or targeted therapy.

Targeted therapy drugs attack specific features of cancer cells. Bevacizumab is a targeted therapy drug that can be used to treat advanced brain cancer. It is given through a drip into a vein in repeated cycles. Bevacizumab is most helpful when the tumour is causing brain swelling. Your doctor will talk to you about the risks and benefits.

Other targeted therapy drugs may be available on clinical trials (see page 27). Talk with your doctor about the latest developments and whether you are a suitable candidate.

# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with a brain or spinal cord tumour. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

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

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

▶ See our *Caring for Someone with Cancer* booklet.

# Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free, but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

*“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

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

### Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

### Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

### Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit [cancerCouncil.com.au/OC](http://cancerCouncil.com.au/OC).

## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

### Australian

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Guides to Best Cancer Care	<a href="http://cancer.org.au/cancercareguides">cancer.org.au/cancercareguides</a>
Brain Cancer Group	<a href="http://braincancergroup.com.au">braincancergroup.com.au</a>
Brain Tumour Alliance Australia	<a href="http://btaa.org.au">btaa.org.au</a>
Building the Bridge to Life with Brain Cancer	<a href="http://buildingthebridge.com.au">buildingthebridge.com.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Cooperative Trials Group for Neuro-Oncology	<a href="http://cogno.org.au">cogno.org.au</a>
Cure Brain Cancer Foundation	<a href="http://curebraincancer.org.au">curebraincancer.org.au</a>
eviQ (cancer treatments online)	<a href="http://eviq.org.au">eviq.org.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Services Australia	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>

### International

American Brain Tumor Association	<a href="http://abta.org">abta.org</a>
American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
International Brain Tumour Alliance	<a href="http://theibta.org">theibta.org</a>
The Spinal Cord Tumour Forum (UK)	<a href="http://spinalcordtumour.org.uk">spinalcordtumour.org.uk</a>



# Question checklist

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Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

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## Diagnosis

- What type of brain or spinal cord tumour do I have?
  - Where is the tumour? How extensive is the tumour? How fast is it growing?
  - Will a multidisciplinary team be involved in my care?
  - Are there clinical guidelines for this type of cancer?
- 

## Treatment

- What treatment do you recommend? What is the aim of the treatment?
  - Are there other treatment choices for me? If not, why not?
  - If I don't have the treatment, what should I expect?
  - How long do I have to make a decision?
  - I'm thinking of getting a second opinion. Can you recommend anyone?
  - How long will treatment take? Will I have to stay in hospital?
  - Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the costs be reduced if I can't afford it?
  - How will we know if the treatment is working?
  - Are there any clinical trials or research studies I could join?
- 

## Side effects

- What are the risks and possible side effects of each treatment?
  - Will I have a lot of pain? What will be done about this?
  - Can I work, drive and do my normal activities while having treatment?
  - Will the treatment affect my sex life and fertility?
  - Should I change my diet or physical activity during or after treatment?
  - Are there any complementary therapies that might help me?
  - How can I access rehabilitation services?
  - Who do I contact if I have concerns about side effects?
- 

## After treatment

- How often will I need check-ups after treatment?
  - If the tumour returns, how will I know? What treatments could I have?
-

# Glossary

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## **acoustic neuroma**

See vestibular schwannoma.

## **allied health professional**

A university-qualified professional who works with others in a health care team to support a person's medical care. Examples include psychologists, physiotherapists and dietitians.

## **anaesthetic**

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

## **astrocytoma**

A type of brain or spinal cord tumour that starts in the glial cells known as astrocytes.

---

## **benign**

Not cancerous or malignant. A benign brain tumour is usually slow-growing, but it can still be life-threatening and need urgent treatment.

## **biopsy**

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

## **brain stem**

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

---

## **cells**

The basic building blocks of the body. A human is made up of billions of cells that perform different functions.

## **central nervous system**

The brain and spinal cord.

## **cerebellum**

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

## **cerebrospinal fluid (CSF)**

Clear, watery fluid surrounding the brain and spinal cord.

## **cerebrum**

The largest, upper part of the brain. It is divided into right and left hemispheres, which each have a frontal, parietal, occipital and temporal lobe.

## **chemotherapy**

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

## **cognitive rehabilitation**

Therapies to improve cognitive skills, such as concentration, memory, problem-solving and language skills.

## **corpus callosum**

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

## **craniotomy**

An operation to open the skull to reach the brain.

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

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## **ENT (ear, nose and throat) surgeon**

A doctor who specialises in treating disorders of the ear, nose and throat.

## **ependymoma**

A type of brain or spinal cord tumour that starts in the glial cells called ependymal cells.

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## **frontal lobe**

Part of the cerebrum; responsible for thinking (cognition), planning and problem-solving (executive function), emotions and personality, and body movement (motor function).

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### **glial cell**

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

### **glioblastoma (GBM)**

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

### **glioma**

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

### **grade**

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

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### **high-grade tumour**

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

### **hormones**

Chemicals in the body that send information between cells. Hormones control many of the body's functions, including how people grow, develop and reproduce.

### **hydrocephalus**

A build-up of cerebrospinal fluid in the brain.

---

### **incontinence**

The accidental or involuntary loss of urine (wee or pee) or faeces (poo).

### **inoperable**

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

### **intracranial pressure**

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

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### **laminectomy**

Surgery that involves cutting into the spinal column and removing some bone; allows biopsy or removal of a spinal cord tumour.

### **low-grade tumour**

A slow-growing (grade 1 or 2) brain or spinal cord tumour. Though slow growing, can still be life-threatening.

### **lumbar puncture**

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

---

### **malignant**

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

### **medical oncologist**

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

### **medulloblastoma**

A malignant brain tumour that starts in the cerebellum.

### **meninges**

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

### **meningioma**

A tumour that starts in the meninges of the brain or spinal cord; usually benign.

### **metastasis (plural: metastases)**

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

### **MRI scan**

Magnetic resonance imaging scan. A scan that uses magnetic fields and radio waves to take detailed cross-sectional pictures of the body.

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### **nervous system**

The network of nerves in the body. The two main parts are the central nervous system and the peripheral nervous system.

### **neurologist**

A doctor who specialises in treating diseases of the brain and nervous system, particularly those that do not need surgery.

### **neuron**

The three types of neurons are sensory neurons (transmitting information from the senses), motor neurons (controlling muscle contractions) and interneurons (controlling reflexes). Also called nerve cells.

### **neurophysiotherapist**

A physiotherapist who specialises in treating physical changes caused by damage to the brain, spinal cord and nervous system.

### **neuropsychologist**

A psychologist who specialises in helping people with brain impairments.

### **neurosurgeon**

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

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### **occipital lobe**

Part of the cerebrum; responsible for processing visual information.

### **oligodendroglioma**

A brain tumour that starts in glial cells called oligodendroglia.

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### **palliative care**

The holistic care of people who have a life-limiting illness, their families and carers. Deals with physical, emotional, cultural, spiritual and social needs.

### **palliative treatment**

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

### **parietal lobe**

Part of the cerebrum; responsible for processing information from the senses.

### **peripheral nervous system**

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

### **pituitary gland**

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

### **pituitary tumour**

A brain tumour that starts in the pituitary gland; usually benign.

### **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. Primary brain cancer rarely spreads to other parts of the body but sometimes spreads to other parts of the brain or spinal cord.

### **proton therapy**

A specialised form of radiation therapy that uses radiation from protons rather than x-rays.

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### **radiation therapy**

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

### **rehabilitation**

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

### **resectable**

Able to be surgically removed from the body.

### **resection**

Surgical removal of part or all of a tumour.

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### **schwannoma**

A benign tumour that starts in the Schwann cells, which surround nerves in the brain and spinal cord. A vestibular schwannoma is a type of schwannoma.

### **secondary cancer**

See metastasis.

### **seizure**

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

### **shunt**

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

### **spinal column**

A series of bones or segments (vertebrae) that protect the spinal cord.

### **spinal cord**

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

### **stereotactic radiosurgery (SRS) or stereotactic radiation therapy (SRT)**

Specialised types of radiation therapy that deliver high doses of precise radiation.

### **stereotactic surgery**

Surgery done using a computer to guide the surgeon.

### **steroids**

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

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### **targeted therapy**

Drugs that target specific features of cancer cells to stop the cancer growing.

### **temporal lobe**

Part of the cerebrum; responsible for understanding, language and memory.

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### **vestibular schwannoma**

A slow-growing tumour affecting the nerves between the inner ear and the brain. Also called acoustic neuroma.

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

For more cancer-related words, visit:

- [cancercouncil.com.au/words](https://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](https://cancervic.org.au/glossary)

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## **References**

1. Australian Cancer Network Adult Brain Tumour Guidelines Working Party, *Clinical Practice Guidelines for the Management of Adult Gliomas: Astrocytomas and Oligodendrogliomas*, Cancer Council Australia, Australian Cancer Network and Clinical Oncological Society of Australia Inc., Sydney, 2009.
2. National Comprehensive Cancer Network (US), *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Central Nervous System Cancers*, Version 2.2021.
3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, AIHW, Canberra, 2021, viewed 24 November 2021, available from: [aihw.gov.au/reports/cancer/cancer-data-in-australia](https://aihw.gov.au/reports/cancer/cancer-data-in-australia).
4. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2021*, AIHW, Canberra, 2021.



# How you can help

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

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

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

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

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

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

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



# Cancer Council

## 13 11 20

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

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

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [communications.gov.au/accesshub/nrs](https://communications.gov.au/accesshub/nrs)

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*Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Australia**  
[cancer.org.au](http://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.*

