



Understanding Brain Tumours

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

Cancer
information

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13 11 20



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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 or call your local Cancer Council.



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About this book

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 clinical practice guidelines for brain tumours.¹

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



**Cancer
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13 11 20**

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What is a tumour?

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

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

Tumours in the brain 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. They may also be called low-grade or non-malignant tumours. A benign tumour may grow and affect how the brain works. This can be life-threatening and may require urgent treatment. Sometimes a benign tumour can change over time and become high grade.

Malignant tumours

Malignant brain tumours can grow rapidly. They are considered life-threatening because they may spread within the brain and spinal cord, or come back after treatment. A malignant brain tumour may be called brain cancer.

Unlike malignant tumours in other parts of the body, malignant brain tumours usually do not spread outside the brain and spinal cord.

Primary cancer

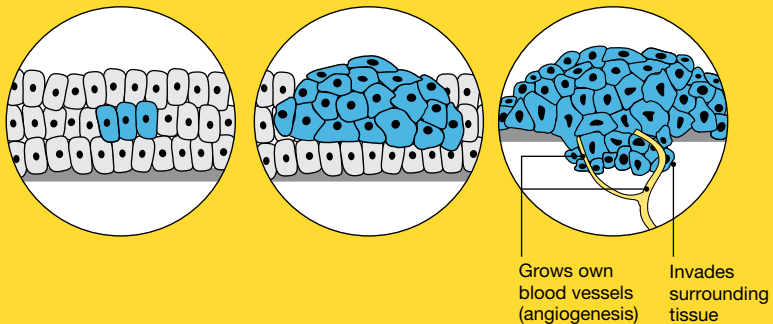
A brain tumour that first develops in the brain is called primary brain cancer. It may spread to other parts of the nervous system, but rarely spreads to other parts of the body.

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

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 the activities of the mind and body.

The brain – The brain receives and interprets information carried to it via nerves from the sensory organs that control taste, smell, touch, sight and hearing. It also sends messages via 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.

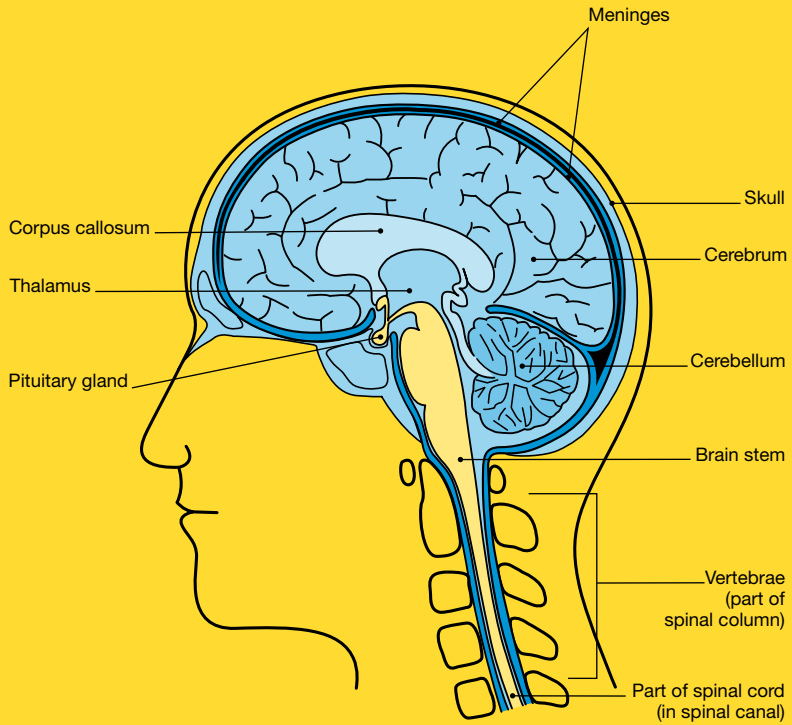
Spinal cord – The spinal cord extends from the brain stem to the lower back. It is made up of nerve tissue that connects the brain to all parts of the body through a network of nerves called the peripheral nervous system. The spinal cord lies in the spinal canal, protected by a series of bony vertebrae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

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

Cerebrospinal fluid – Also known as CSF, cerebrospinal fluid is found inside the skull and spinal column. It surrounds the brain and spinal cord and protects it from injury.

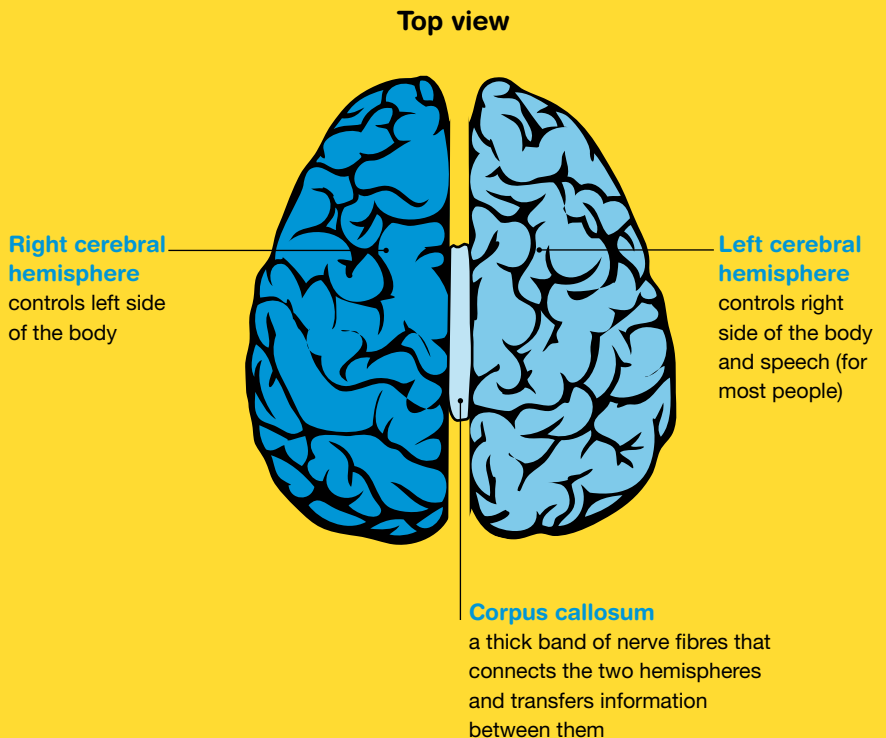
Pituitary gland – This is found at the base of the brain and is about the size of a pea. The pituitary gland releases chemical messengers (hormones) into the blood. These hormones control many body functions, including growth and development, and also tell other glands to start or stop releasing hormones.

The central nervous system

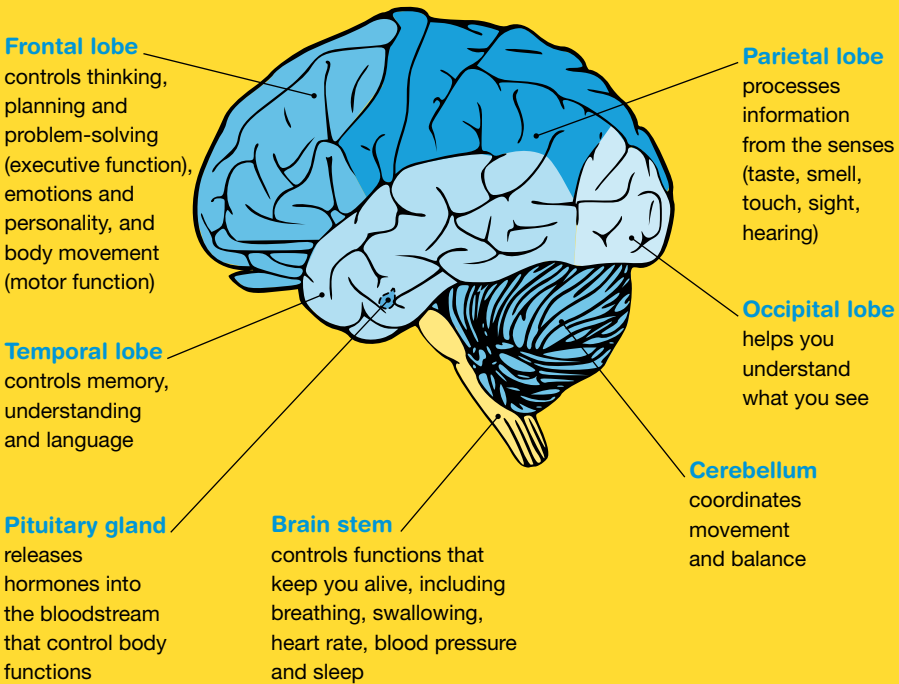


The parts of the brain

The largest part of the brain is the cerebrum, also known as the cerebral cortex. The cerebrum is divided into two halves called hemispheres. Each hemisphere is divided into four main areas. These are called the frontal, parietal, occipital and temporal lobes. Each lobe controls different functions.



Side view





Key questions

Q: What is a brain or spinal cord tumour?

A: A brain or spinal cord tumour occurs when abnormal cells grow and form a mass or a lump. The brain and spinal cord are made up of two main types of cells: neurons and glial cells. The tumour may be benign or malignant, but both types can be serious and may need urgent treatment.

Q: How common are they?

A: Every year an estimated 2000 malignant brain tumours are diagnosed in Australia, and can affect people of any age. About 100 children aged 0–14 are diagnosed each year.²

Benign brain and spinal cord tumours are more common than malignant tumours. Data is not collected by every Australian state, but in 2015, there were more than 1000 benign brain and spinal cord tumours in Victoria, Queensland and Western Australia combined.³

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 (also called central nervous system or CNS 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).

Common types of primary brain tumours

Glioma tumours

This is the most common category of brain tumour. Gliomas are tumours that start in the glial (neuroglia) cells of the brain.

astrocytoma	<ul style="list-style-type: none"> • starts in glial cells called astrocytes • most common type of glioma
ependymoma	<ul style="list-style-type: none"> • starts in glial cells called ependymal cells • more common in children than adults
glioblastoma (GBM)	<ul style="list-style-type: none"> • type of high-grade astrocytoma • makes up more than half of all gliomas • common in both adults and children
oligoastrocytoma	<ul style="list-style-type: none"> • mixed glioma tumour; contains both oligodendroglioma and astrocytoma
oligodendroglioma	<ul style="list-style-type: none"> • starts in glial cells called oligodendrocytes • more common in children than adults

Non-glioma tumours

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

Q: What are the risk factors?

A: The causes of most brain and spinal cord tumours are unknown, but factors known to increase the risk include:

Family history – While it is rare for brain tumours to run in families, a fault in the genes, usually passed down from either the mother or father, can increase the risk of developing a brain tumour. For example, some people have a genetic condition called neurofibromatosis, which can lead to tumours of the brain and spinal cord. For more information about genetic testing, talk to your doctor or call Cancer Council 13 11 20.

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.

Mobile phones and microwave ovens

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

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

Evidence to date does not show 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 concerned about potential harm from mobile phones, you

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

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. It can develop suddenly or gradually over time.

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

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

This increased pressure can lead to symptoms such as:

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

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

Common tumour symptoms

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

Frontal lobe

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

Temporal lobe

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

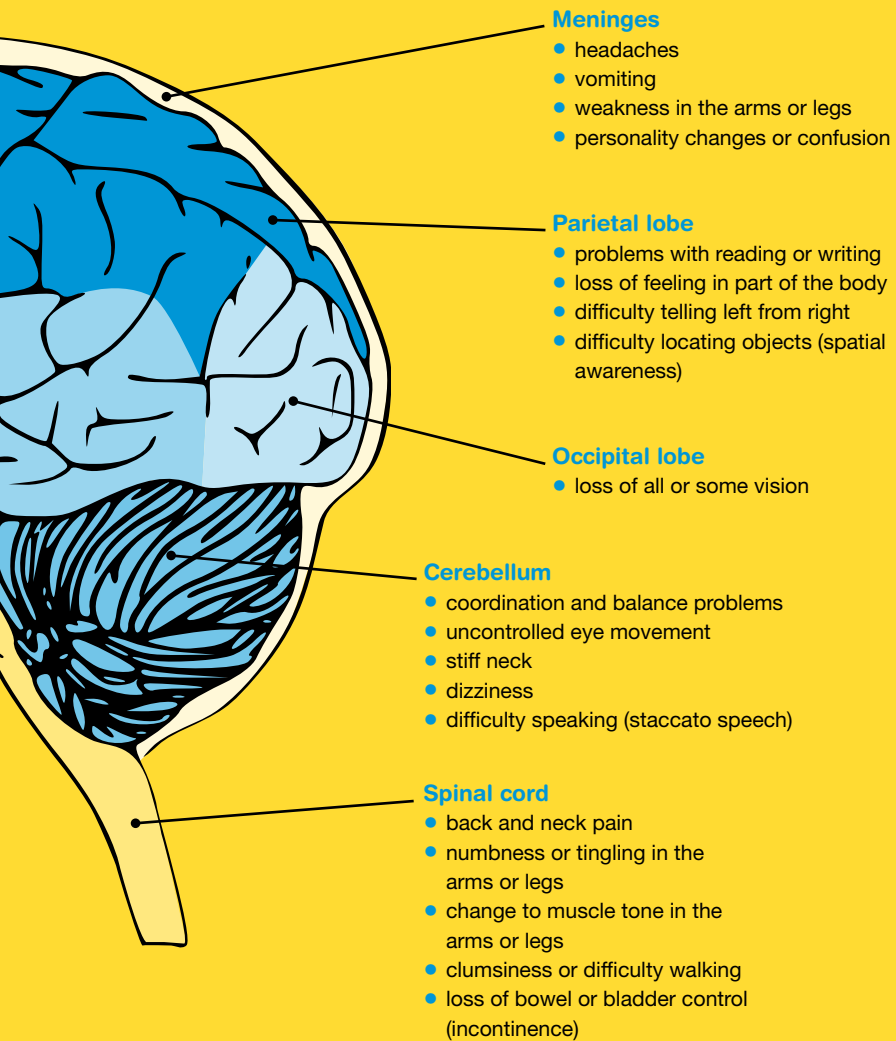
Pituitary gland

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

Brain stem

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





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

neurosurgeon*	diagnoses and surgically treats diseases and injuries of the brain and nervous system
neurologist*	diagnoses and treats diseases of the brain and nervous system, particularly those that do not need surgery
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
cancer care coordinator	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)
nurse	administers drugs and provides care, information and support throughout treatment
neuropathologist*	analyses blood and tissue from 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.

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

* *Specialist doctor*

Brain tumours in children

The information in this booklet is for adults with brain tumours. Brain tumours tend to be different in children. They often form in different areas, and may have different treatment and outlook.

In Australia, about 100 children aged 0–14 are diagnosed with a malignant brain or spinal cord tumour each year.² 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 a physical, behavioural or learning disability as a result of the tumour or treatment.

Health professionals to see

Health care professionals who specialise in treating children and young adults are called paediatricians. Some hospitals have play therapists, music therapists or art therapists, who can help children cope with the challenges of treatment. Rehabilitation will also be important for a child's recovery (see pages 46–47).

Treatment

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

Support

Organisations like Camp Quality, CanTeen and Redkite (see page 61) offer support for families, young adults and children affected by cancer. Redkite offers a print and online picture book called *Mary has a brain tumour* that you can read with your child.

> See our *Talking to Kids About Cancer* booklet or listen to the podcast episode.



Diagnosis

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

The doctor will ask you about your symptoms and medical history, and will do a physical examination. If your doctor suspects you have a brain or spinal cord tumour, you will be referred for more tests and scans 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 limb 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 may look into your eyes using an instrument called an ophthalmoscope. This allows the doctor to see your optic nerve, which sends visual information from the eyes to the brain. Swelling of the optic nerve can be an early sign of raised pressure 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

An MRI (magnetic resonance imaging) scan uses a powerful magnet and a computer to make cross-sectional pictures of your body. Let your doctor or nurse know if you have a pacemaker or any other metallic object in your body. The magnet can interfere with some pacemakers, but newer pacemakers are 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 machine can be noisy; some people feel anxious or claustrophobic in the tube. If you think you may become distressed, mention it beforehand to your medical team. You may be given medicine to help you relax or you might be able to bring someone into the room with you for support. You will usually be offered headphones or earplugs and a distress button to press 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 page opposite).



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

CT scan

A CT (computerised tomography) scan uses x-rays to take many pictures of the inside of the body and then compiles them into detailed, cross-sectional pictures. Contrast may be injected into a vein to help make the scan pictures clearer. It may make you feel hot all over and leave a bitter taste in your mouth. You may also feel the need to pass urine. These side effects usually ease within minutes.

The CT scanner is a large, doughnut-shaped machine. You will lie on a table that moves in and out of the scanner. It may take about 30 minutes to prepare for the scan, but the actual test 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 estimate how quickly the tumour is growing (the grade, see page 23) and whether it has spread into nearby tissue. This information helps 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 tracts. 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 the type of 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 from the spinal column. The fluid is checked for cancer cells in a laboratory.

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

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

Grading tumours

The cancer will also be given a grade based on how the cancer cells look compared to normal cells. This 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.

Grade 1 – These tumours are low grade and grow slowly.

Grade 2 – 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.

Grades 3 and 4 – These tumours are high grade and grow faster, and are called malignant. They can spread to other parts of the brain and tend to recur, often as a higher grade.

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.



For an overview of what to expect during all stages of your cancer care, visit cancerpathways.org.au/optimal-care-pathways/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. These include the tumour type, location, grade and genetic make-up; your age, general health and family history; and how well the tumour responds to treatment.

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

Some brain or spinal cord tumours, particularly gliomas, can come back (progress) and may 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

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, or seizures.

Main tests

- A physical examination checks how different parts of your brain are working.
- You may also need a blood test to check your overall health and hormone levels.
- Imaging scans, such as 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 cancer cells.
- A surgical biopsy removes a sample of tissue for examination under a microscope. Sometimes this is done during surgery to remove the brain tumour.

Grade

- The tests and scans help doctors diagnose the type of brain or spinal cord tumour you have, as well as its grade. The grade indicates how quickly the tumour is growing.
- Primary brain and spinal cord tumours are not given a stage because they rarely spread to other parts of the body.

Prognosis

Many people want to know the expected outcome of their disease (prognosis). You will need to discuss this with your doctor.



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 pages 16–17) 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 tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. 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?

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.

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

Treatment

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

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

For a benign tumour, surgery may be the only treatment needed.

For a malignant brain or spinal cord tumour, treatment can include surgery, radiation therapy and chemotherapy, which may be used alone or together. Medicines, such as steroids or anticonvulsants (anti-seizure medicines), may be given to reduce symptoms.

You may be able to access 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).

Partial resection or debulking may be considered because the tumour is widespread, near major blood vessels or near other important parts of the brain or spinal cord. A partial resection may help reduce the pressure on your brain, which will improve some of the symptoms.

Sometimes a tumour cannot be safely removed because it is too close to certain parts of the brain and surgery would cause blindness or partial paralysis. This is called an inoperable or unresectable tumour. Your doctor will talk to you about other ways of easing symptoms.

What to expect before surgery

The different scans used to diagnose a brain tumour (such as CT, MRI or PET scans) are often done again to plan surgery.

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

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 about managing fear, available at cancercouncil.com.au/podcasts.

Types of surgery

Different types of operations may be used for 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 under a general anaesthetic. The surgeon cuts an area of bone from your skull to access the brain. The tumour is then taken out, and the bone is put back. The surgeon holds the piece of skull in place with small plates and screws.

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

Awake craniotomy – This operation may be recommended if the tumour is near parts of the brain that control speech or movement. All or part of the operation is done with the person awake (conscious) but relaxed, so they 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 used to stimulate and pinpoint important areas of the brain.

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 guidance

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

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

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

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

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 that is affecting the spinal cord. A laminectomy is usually performed under general 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. 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. You may also require rehabilitation (see pages 46–47).

Neurological observations

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



Pressure stockings

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



Spinal cord checks

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

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 require further treatment known as rehabilitation. See pages 46–47.



Bandages and bruising

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

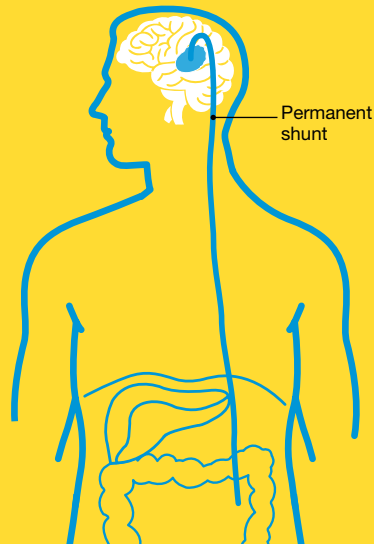


Headaches and nausea

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

Having a shunt

A build-up of cerebrospinal fluid in the brain is called hydrocephalus. It may occur before surgery as a result of the tumour, but can also happen after surgery. To drain the extra fluid you may have a shunt. The surgeon places one end of a long, thin tube into your brain. A temporary tube (called an external ventricular drain, or EVD) drains fluid into a bag on the outside of the body. A permanent shunt is inserted completely inside your body. It drains into your abdomen and the fluid is absorbed into the bloodstream.



Side effects of surgery

Infection – Although the risk is small, you may develop an infection at the surgical 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 scan or MRI the day after surgery to check for any bleeding or swelling.

Swelling – Surgery can cause swelling. This swelling increases the pressure inside the skull (intracranial pressure). Your medical team will monitor the swelling and try to reduce it.

Other side effects – You may continue to feel confused and dizzy, and have speech problems, weakness 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 – A range of therapies can speed up recovery or show you ways to manage any changes. These therapies are known as rehabilitation. At first, you may have some rehabilitation therapies in the hospital or in a rehabilitation facility. You may be given equipment to use at home. Once you return home, you can continue to access these therapies as an outpatient. See pages 46–47 for more information.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill or damage cancer cells in the area being treated. Treatment is carefully planned to do as little harm as possible to the healthy body tissue near the cancer, though you may experience side effects afterwards (see pages 38–39).

Radiation therapy is typically given after surgery and possibly along with chemotherapy. Before you start radiation therapy, a radiation therapist will take measurements of your body and do a CT or MRI scan to work out the precise area to be treated. If you are having radiation therapy for a brain tumour, you will probably need to use a face mask (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 will depend on the size and type of tumour, but 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. Each daily treatment will last for about 10–15 minutes. Radiation therapy itself is painless; however, there are some possible side effects of radiation that will be discussed with you.

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. It is used to treat some brain tumours. A specialised radiation machine is used to give very precisely targeted radiation to the tumour.

This means the tumour gets a high dose of radiation while the surrounding healthy brain tissue gets very little. SRS is not suitable for all brain tumours. It may be offered when neurosurgery is not possible or as an alternative to neurosurgery. It is most commonly used for metastatic cancers that have spread to the brain from another part of the body. It is also used for some meningiomas, pituitary tumours and schwannomas, and is occasionally used for gliomas that have come back after other treatment.

Often, only 1–5 doses of SRS are needed. A treatment session may last between 15 minutes and two hours, depending on the type of radiosurgery given, and you will need to wear a face mask or a frame (see opposite) 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.

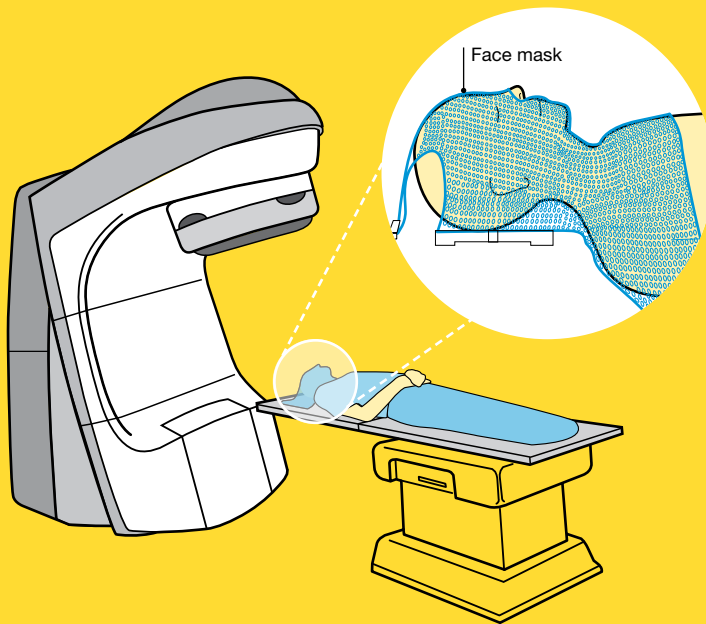
Proton therapy

This uses protons rather than x-ray beams. Protons are tiny parts of atoms with a positive charge. Proton therapy is useful when the cancer is near sensitive areas, such as the brain, eyes and spinal cord. It is not yet available in Australia (as at mid 2020), but there is funding in special cases to allow Australians to travel overseas for treatment.

Wearing a face mask

You'll need to wear a plastic face 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 directed to the same area during each session. It's made especially for you and fixed to the table.

The mask is made of a tight-fitting mesh, but you will wear it for only about 10 minutes at a time. You can see and breathe through the mask, but it may feel strange at first. Let the radiation therapist know if wearing the mask makes you feel anxious, as this can be managed with medicines.





Radiation therapy is usually combined with chemotherapy to treat glioblastomas (grade 4 tumours). This is called chemoradiation, and is better at treating brain tumours than radiation therapy alone.

Side effects of radiation therapy

Radiation therapy side effects generally occur in the treatment area and 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** – often occurs several hours after treatment
- **headaches** – often occur during the course of treatment
- **tiredness or fatigue** – worse at the end of treatment; can continue to build after treatment, but usually 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 treatment and lasts one to two weeks before going away
- **hair loss** – may occur in the brain tumour treatment area and may be permanent
- **dulled hearing** – may occur if fluid builds up in the middle ear and may be permanent.

Side effects specific for spinal cord tumours include swallowing problems (dysphagia) and diarrhoea. Both are temporary.

If any side effects develop, talk to your radiation oncology team.

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 much or too little of particular hormones. This can affect body temperature, growth, sleep, weight and appetite. The hormone levels in your pituitary gland will be monitored during treatment.

➤ See our *Understanding Radiation Therapy* booklet.

Chemotherapy

Chemotherapy is the use of drugs to treat cancer. The drugs travel through the bloodstream and damage or destroy rapidly dividing cells (cells that grow quickly) such as cancer cells, while causing the least possible damage to healthy cells.

You may have chemotherapy after surgery and possibly with radiation therapy (chemoradiation).

The brain has a protection system 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.

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). Temozolomide is the most commonly prescribed chemotherapy drug for the treatment of glioma brain tumours. Temozolomide is given as a capsule that is taken at home. Each treatment session is usually followed by a rest period of a few weeks. You may have chemotherapy for up to six months.

Side effects of chemotherapy

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

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

It is rare to lose all your hair with the chemotherapy drugs used to treat 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 and now included a new astrocytoma strain. That was a reality check. It had been nine years since the first tumour, and I guess I'd sort of taken my health for granted.

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

I had no real problems from the surgery: it was textbook healing really, and the surgeon said they

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

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

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

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



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

Steroids

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

Side effects of steroids

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

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; unstable blood sugar levels; diabetes; muscle weakness; and loss of bone density (osteoporosis). You will also be more likely to get infections. Most side effects are temporary, and your doctor may adjust your dose to manage them.

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

Palliative treatment

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

Main treatments The main treatments are surgery, radiation therapy and chemotherapy.

Surgery

- Some tumours can be completely removed in a 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 the most precise form of radiation therapy. It is used to treat small tumours with high doses of radiation.

Chemotherapy

Chemotherapy is the use of drugs to destroy or 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.

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 you will need rehabilitation.



Living with a brain or spinal cord tumour

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

Rehabilitation is treatment designed to help people recover from injury or disease. After treatment for a brain tumour, most people need to have a rehabilitation assessment and therapies (see next two pages). These can help restore your previous abilities or help you adjust to any changes.

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

Financial support for people with disabilities

The National Disability Insurance Scheme (NDIS) provides Australians aged under 65 and who have a permanent and significant disability with funding for support and services. NDIS can help a person with a brain tumour access services in their community. Call **1800 800 110** or visit [ndis.gov.au](https://www.ndis.gov.au). If your GP refers you to a rehabilitation specialist as part of a Chronic Disease Management plan, you may be eligible for a Medicare rebate for up to five visits each year.

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. You may also be referred to individual allied health professionals (e.g. physiotherapist, occupational therapist) in private practice.

Physiotherapy



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

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 exercise safely and stimulate parts of your body to improve circulation and reduce swelling, and improve your cardiovascular fitness.

To find an accredited exercise physiologist, visit essa.org.au/find-aep; for a physiotherapist, visit choose.physio/findaphysio.

Speech therapy



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

To find a speech pathologist, visit **speechpathologyaustralia.com.au**.

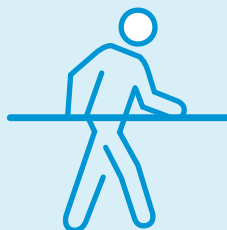
Help with vision impairment



Some people may lose some or all of their sight as a result of a brain tumour or surgery.

Vision Australia can help people learn how to live independently. Call **1300 84 74 66** or visit **visionaustralia.org**.

Occupational therapy



The treatment may mean it's harder to perform everyday personal activities (e.g. showering, dressing, preparing a meal).

An occupational therapist can help you to return to the activities that are important to you. A range of strategies and aids can help you manage fatigue and improve or maintain your independence.

To find an occupational therapist working in private practice, visit **otaus.com.au/find-an-ot**.

Managing seizures

A brain tumour or its treatment can sometimes cause seizures, which are disruptions to the normal patterns of electrical impulses in the brain. They may also be called fits or convulsions. Seizures can 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. The seizure affects one part of the body, such as an arm or leg. The symptoms depend on the area of the brain involved. They may include twitching; jerking; tingling or numbness; and altered sensations, such as changed vision or hearing, strange tastes or smells, or a feeling of déjà vu. Partial seizures may cause a brief loss of consciousness, changes in mood, and memory loss just before, during and after the seizure.

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, and avoid daytime naps if they make sleeping at night difficult. Limiting or cutting down on alcohol may also help.



Ways to help someone having a seizure

- Remain calm and stay with the person while they are having a seizure. If they have one, refer to their Seizure Management Plan.
- 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 **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 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.
- Talk to the person and explain 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.

Anticonvulsant medicines

Many 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 effective and how your liver is coping with the medicine.

Side effects of anticonvulsant drugs vary, but they may include tiredness, gum problems, shakes (tremors), nausea, vomiting, weight changes, depression, irritability and aggression. If you are allergic to the medicine, you may get a rash. Tell your 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.

Driving

Tumours, seizures, and certain treatments and medicines (such as anticonvulsants and some pain medicines) can affect the skills needed to drive safely. These can include:

- having good vision and perception
- being able to concentrate
- being able to remember directions
- good hand-eye coordination.

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 tell their driver licensing authority about any permanent or long-term illness or injury that is likely to affect their ability to drive. Your doctor can advise you if you should report your condition or if there are any temporary restrictions. The licensing authority may request information from your doctor to decide if you are medically fit to drive.

“ 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 evaluation to check your ability to return to driving. This may include doing an off-road assessment, or having an electroencephalogram (EEG) to assess your seizure risk.
- See an occupational therapist driving assessor or a neurologist or rehabilitation specialist to determine the type of problems you may be experiencing while driving (for example, a slow reaction time). The focus of the assessment is not to suspend or cancel your licence: it is to work out if it is possible for you to return safely to driving.
- In some cases, an occupational therapist can teach you some driving techniques to help with weaknesses or how to make changes to your car (such as extra mirrors). You may also be able to drive with restrictions, such as only in daylight, only in vehicles with automatic transmission or only short distances from home.
- Some people feel upset or frustrated if they have restrictions on their licence or can no longer drive. You may feel that you have lost your independence or be worried about the impact on your family. It may help to talk to a counsellor or someone who has been through a similar experience (see pages 59–60). Depending on your situation and your health, it may be possible to return to driving at a later stage.
- 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 or drive unsafely, 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](https://www.austroads.com.au/drivers-and-vehicles/assessing-fitness-to-drive).

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

Working

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

Some people find it hard to concentrate or make decisions after treatment 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.



Key points about living with a brain tumour

Many people experience changes to speech, personality, memory, movement, balance or coordination.

Rehabilitation

- The rehabilitation you have will depend on an assessment of your needs, your choices and what support is available.
- A neuropsychologist, speech pathologist or occupational therapist can offer various strategies to help improve memory, language skills and concentration.
- Physiotherapy can help you learn how to move more easily, and maintain or regain strength and balance.
- Speech therapy may assist if your ability to talk or swallow has been affected.
- Occupational therapy can help you regain independence in tasks such as showering, dressing and meal preparation.
- People living with a brain tumour may experience seizures. A Seizure Management Plan can outline treatment, which may include taking anticonvulsants.
- The National Disability Insurance Scheme (NDIS) can help pay for services and support.

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 and 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 and may prevent successful treatment of the cancer. 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 with a social worker or Cancer Council whether any financial assistance is available to you.

➤ 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. It 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 will 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

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. 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. For 24-hour crisis support, call Lifeline **13 11 14** or visit 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 cancer hasn't come back or spread. During these check-ups, you will usually have a physical examination and you may have blood tests, x-rays or MRI scans.

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

Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

What if the tumour returns?

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

Targeted therapy drugs act on proteins found on cancer cells. Because these proteins are found in small amounts or not at all on normal cells, they tend to cause fewer side effects. Bevacizumab is a targeted therapy drug that works by stopping cancer cells from developing new blood vessels and growing. It is given as a drip into a vein in repeated cycles. Other targeted therapy drugs are being developed.



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 depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 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 (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



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.

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.



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	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Brain Tumour Alliance Australia	www.btaa.org.au
Cancer Australia	canceraustralia.gov.au
Camp Quality	campquality.org.au
CanTeen	canteen.org.au
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
Cooperative Trials Group for Neuro-Oncology	cogno.org.au
Cure Brain Cancer Foundation	curebraincancer.org.au
Department of Health	health.gov.au
eviQ (cancer treatments online)	eviq.org.au
NDIS (National Disability Insurance Scheme)	ndis.gov.au
Optimal Care Pathways	cancerpathways.org.au
Redkite	redkite.org.au
Services Australia	servicesaustralia.gov.au
International	
American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov
American Brain Tumor Association	abta.org
National Brain Tumor Society (US)	braintumor.org
Spinal Cord Tumour Forum (UK)	spinalcordtumour.org.uk



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. 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 both 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.

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 Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit 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.



Question checklist

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.

Diagnosis

- What type of brain or spinal cord tumour do I have?
- Where is the tumour? How extensive is the tumour? What grade is it?
- 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?
- What will happen if I don't have treatment, what should I expect?
- How long do I have to decide?
- 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 and after treatment

- 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?
- How often will I need check-ups after treatment?
- If the cancer comes back, how will I know? What treatments could I have?
- Who do I contact if I have concerns about side effects?



Glossary

acoustic neuroma

See schwannoma.

allied health professional

A tertiary-trained professional who works with others in a health care team to support a person's medical care. Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

anaesthetic

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

astrocytoma

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

benign

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

biopsy

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

brain stem

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

cells

The basic building blocks of the body. A human is made 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 and regulating fear, pleasure, attention and language.

cerebrospinal fluid

Clear, watery fluid surrounding the brain and spinal cord.

cerebrum

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

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments.

cognitive rehabilitation

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

continence

Ability to control urination and bowel movements.

corpus callosum

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

craniotomy

An operation to open the skull to access the brain.

CT scan

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

ependymoma

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

frontal lobe

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

glial cell

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

glioblastoma (GBM)

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

glioma

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

grade

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

high-grade tumour

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

hormones

Chemicals in the body that send information between cells to bring about changes in the body. Some hormones control growth, others control reproduction.

hydrocephalus

The build-up of cerebrospinal fluid in the brain.

inoperable

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

intracranial pressure

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

laminectomy

Surgery that involves cutting into the spinal column and removing a spinal cord tumour.

low-grade tumour

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

lumbar puncture

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

malignant

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

medical oncologist

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

medulloblastoma

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

meninges

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

meningioma

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

metastasis (plural: metastases)

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

Also called secondary cancer.

MRI scan

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

neurologist

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

neuron

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

neuropsychologist

A psychologist who specialises in helping people with brain impairments.

neurosurgeon

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

occipital lobe

Part of the brain responsible for processing visual information.

oligodendroglioma

A brain tumour that starts in glial cells called oligodendroglia.

palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to maintain quality of life

by dealing with physical, emotional, cultural, spiritual and social needs. Also known as supportive care.

palliative treatment

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

parietal lobe

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

peripheral nervous system

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

pituitary gland

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

pituitary tumour

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

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

prognosis

The expected outcome of a person's disease.

radiation therapy

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

Also called radiotherapy.

rehabilitation

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

resectable

Able to be removed with surgery.

schwannoma

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

secondary cancer

See metastasis.

seizure

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

shunt

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

spinal cord

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

stereotactic radiosurgery (SRS)

Type of radiation therapy that delivers 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.

temporal lobe

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

vertebrae

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

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary

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2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia, Australian Cancer Incidence and Mortality (ACIM) books: brain cancer*, AIHW, Canberra, 2018.
3. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2019*, AIHW, Canberra, 2019.



How you can help

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

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

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

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

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

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

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



Cancer Council

13 11 20

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

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

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

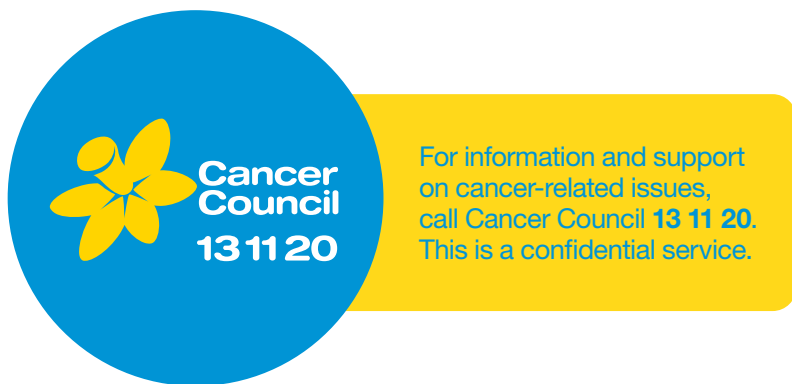
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



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

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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 To support Cancer Council, call your local Cancer Council or visit your local website.*