Cancer Council

CANCER TYPE

Understanding
Brain Tumours

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

For information & support
call **Cancer Connect 13 11 20**

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

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Editor: Wendy Winkler. Designer: Eleonora Pelosi. Printer: IVE Group.

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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 booklet 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 8 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 change the future of cancer, visit cancerconnect.org.au or call 13 11 20.

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

Cancer Council Australia Suite 1202, Level 12, Centennial Place, 300 Elizabeth Street, Sydney NSW 2010
Telephone 02 8256 4100 **Email** info@cancer.org.au **Website** cancer.org.au **ABN** 91 130 793 725

About this booklet

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

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

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

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 64). You may also like to pass this booklet to your family and friends for their information.

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



If you or your family have any questions or concerns, call **Cancer Connect on 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit the Cancer Connect website at cancerconnect.org.au.

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Key to icons

Icons are used throughout this booklet to indicate:


More information


Alert


Personal story


Tips

Is this Cancer Council booklet helpful? Please follow this QR code for a quick 3-minute survey, or call 13 11 20 to provide your feedback.

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What is a tumour?

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

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

How are brain tumours classified?

Brain tumours are often classified as benign or malignant. What it means to have a benign or malignant brain tumour is usually different to what it may mean to have one in another part of the body.

Benign tumours

Many benign brain tumours grow slowly and are less likely to spread or grow back (if all of the tumour can be successfully removed). But a benign tumour may still affect how the brain works. This can be life-threatening and need urgent treatment. Sometimes a benign tumour can change over time and become malignant or more aggressive.

Malignant tumours

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

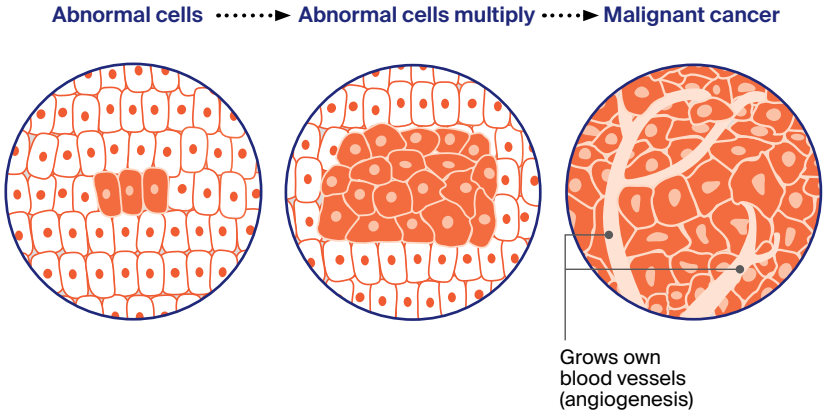
Primary cancer

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

Secondary cancer

Sometimes cancer starts in another part of the body and then travels through the bloodstream or lymphatic system 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



The brain and spinal cord

The brain and spinal cord make up the central nervous system (CNS). This CNS controls how the mind and body work.

The brain – The brain receives and interprets information carried to it by nerves from the sensory organs that control taste, smell, touch, sight and hearing. It also sends messages through nerves to the muscles and organs. The brain controls arm and leg movement and sensations, memory and other thinking skills, personality and behaviour, and balance and coordination. The main parts of the brain are the cerebrum, the cerebellum and the brain stem (see pages 7–9 for details).

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

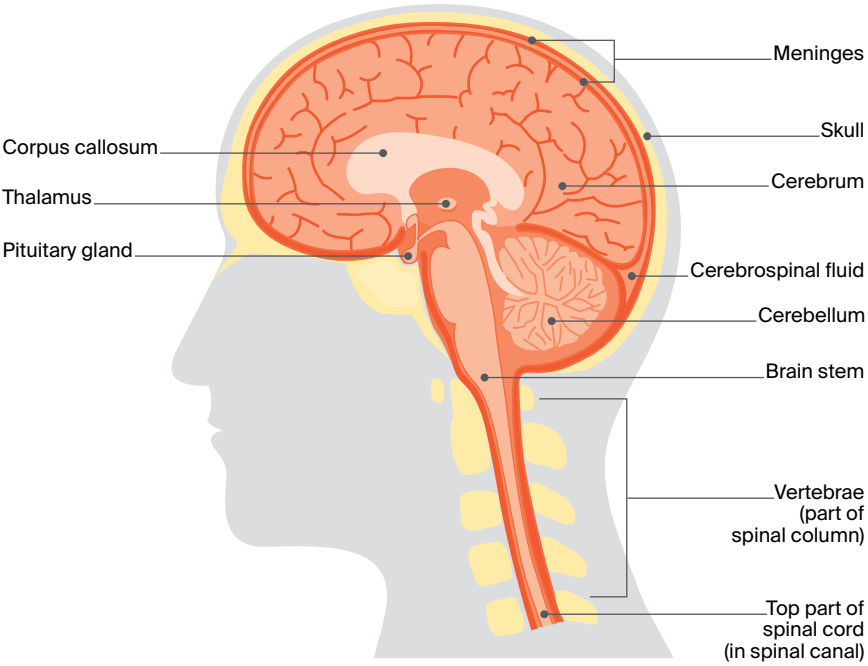
Meninges – These are thin layers of protective tissue (membranes) that cover both the brain and spinal cord.

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

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

The central nervous system

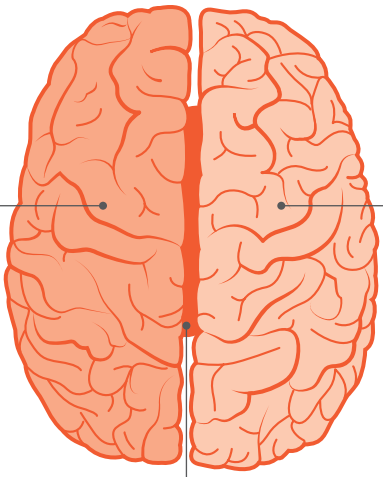
Side view



Cross-section showing the inside of the brain

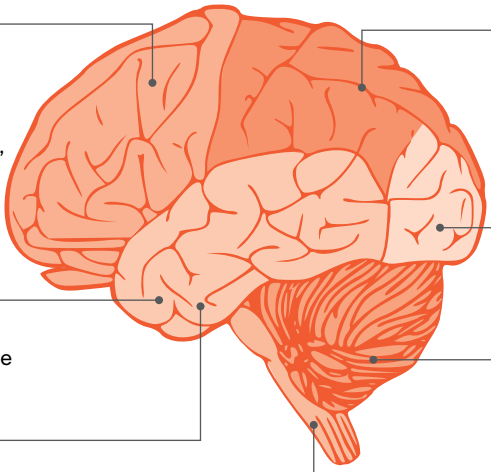
The parts of the brain and their functions

The largest part of the brain is the cerebrum. It is divided into 2 halves called hemispheres. Each hemisphere is divided into 4 main areas – the frontal, parietal, occipital and temporal lobes.



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

Side view



Frontal lobe
controls thinking (cognition), planning and problem-solving (executive function), parts of speech (expression), emotions and personality, and body movement (motor function)

Temporal lobe
controls memory, understanding sounds and language

Pituitary gland*
makes hormones that control body functions
* *Found deep inside the brain.*

Parietal lobe
processes information from the senses (taste, smell, touch, sight, hearing) and spatial perception (e.g. finding an object)

Occipital lobe
helps you understand what you see (vision)

Cerebellum
coordinates movement, balance and posture

Brain stem
controls functions that keep you alive, including breathing, swallowing, heart rate, blood pressure and sleep

Key questions

Q: What is a brain or spinal cord tumour?

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

Q: How common are they?

A: Every year an estimated 2100 malignant brain tumours are diagnosed in Australia. They are more common in men than women. Malignant brain tumours can affect people of any age, but your risk increases with age. About 110 children (aged 0–14) are diagnosed with a malignant brain tumour each year.[3] Other common brain and spinal cord tumours found in the meninges and pituitary gland (see page 7) are usually benign.

Q: What types of tumours are there?

A: The brain is made up of different types of tissues and cells, which can develop into different types of tumours. There are more than 40 main types of primary brain and spinal cord tumours. They can start in any part of the brain or spinal cord.

Tumours are grouped together depending on the type of cell they start in and how the cells behave. This is based on how they look under a microscope and their genomic features (see *Molecular testing*, page 23). Groups include glioma and non-glioma tumours. Gliomas are the most common type of malignant brain tumour.

Common types of primary brain tumours

Glioma tumours

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

glioblastoma	• a fast-growing, high-grade glioma • makes up more than half of all gliomas • affects both adults and children; in adults usually has a certain biomarker (IDH-wildtype)
astrocytoma	• starts in glial cells called astrocytes • may be benign or malignant
oligodendroglioma	• more common in younger adults • malignant, but may be slow or fast growing • has a certain biomarker (1p19q codeletion)
ependymoma	• starts in cells that line the fluid-filled spaces in the brain and spinal cord • more common in children than adults • may be benign or malignant

Non-glioma tumours

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

meningioma	• starts in the membranes (meninges) covering the brain and spinal cord • most common primary brain tumour, usually benign and slow growing
medulloblastoma	• usually starts in the cerebellum; malignant tumour • more common in children; rare in adults
pituitary tumour	• starts in the pituitary gland • most are benign
schwannoma	• starts in Schwann cells, which surround nerves in the brain and spinal cord • usually benign • includes vestibular schwannomas (sometimes called acoustic neuromas)

Q: What are the risk factors?

A: The cause of most brain and spinal cord tumours is unknown. As we get older the risk of developing many cancers, including brain cancer, increases. Other things known to increase a person's risk include:

Family history – It's rare for brain tumours to run in families, though some people inherit a gene change from a parent that increases their risk. For example, a genetic condition called neurofibromatosis can lead to mostly benign tumours of the brain and spinal cord. Having a parent, sibling or child with a primary brain tumour may sometimes mean an increase in risk.

Radiation therapy – People who have had radiation therapy to the head, particularly for childhood leukaemia, may have a slightly higher risk of brain tumours, such as meningioma, many years later.

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

Overweight and obesity – A small number of meningioma brain tumours are thought to be linked to high body weight or obesity.

Mobile phones and microwave ovens

Research has not shown that mobile phone use causes brain cancer, but studies continue into any long-term effects. If you are worried, use a hands-free headset, limit time on your phone, or use messaging. There is no evidence that microwave ovens in good condition release electromagnetic radiation at levels that are harmful to people.

Q: What are the symptoms?

A: Symptoms you may experience depend on where the tumour is, its size and how slowly or quickly it is growing. Symptoms can develop suddenly (in days or weeks) or over time (months or years). Many symptoms are the same as other conditions, but see your doctor about any new, persistent or worsening symptoms.

Brain tumours can increase pressure inside the skull (intracranial pressure). Pressure can build up because the tumour is taking up too much space, is causing brain swelling or is blocking the flow of cerebrospinal fluid around the brain (see *Having a shunt*, page 33). 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 cause some jerking or twitching of your hands, arms or legs, or affect the whole body
- weakness in parts of the body
- poor coordination
- drowsiness or loss of consciousness
- difficulty speaking or finding the right words.

For information about specific symptoms caused by the location of the tumour, see the diagram on the next 2 pages.



Having a brain tumour is stressful and upsetting. Experienced counsellors, psychologists or psychiatrists offer coping strategies and ways to manage any mood swings or behavioural changes. Call Cancer Connect on 13 11 20 for information or support.

Common tumour symptoms

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



Frontal lobe

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

Temporal lobe

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

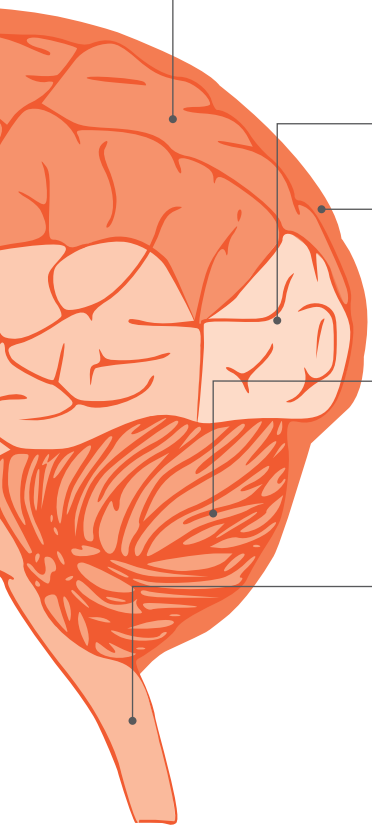
Pituitary gland*

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

**Found deep inside the brain.*

Brain stem

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



Parietal lobe

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

Occipital lobe

- loss of all or some vision

Meninges

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

Cerebellum

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

Spinal cord

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

Nerve and other tumours

Symptoms of tumours starting in the brain's nerves (cranial nerves) depend on the affected nerve. The most common nerve tumours are vestibular schwannomas (acoustic neuromas). They can cause hearing loss, dizziness and balance issues. Vestibular schwannomas are usually benign. Tumours of the pineal gland (deep within the brain) are very rare and usually classified as neuroendocrine tumours.

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 not requiring surgery; helps manage thinking and memory changes and seizures
radiation oncologist	treats cancer by prescribing and overseeing a course of radiation therapy
radiation therapist	plans and delivers radiation therapy
medical oncologist	treats cancer with drug therapies such as chemotherapy and targeted therapy (systemic treatment)
cancer care coordinator, patient navigator	coordinate your care, liaise with other members of the MDT and support you and your family throughout treatment; a clinical nurse consultant (CNC) or clinical nurse specialist (CNS) may also coordinate your care
nurse	administers medicines and drug therapies; provides care, information and support throughout treatment
pathologist, neuropathologist	analyse blood and tissue from the brain and 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 your usual activities
social worker	links you to support services and helps you with emotional, practical and financial issues
neuropsychologist	assesses people who have 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	assist with physical and practical problems, including restoring movement and mobility after treatment, and recommending aids, devices and equipment
speech pathologist, speech therapist	help with communication, swallowing and speech after treatment
exercise physiologist	prescribes safe and effective exercise to help people with medical conditions restore or 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

Brain tumours in children

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

Children are more likely to develop gliomas and medulloblastomas, and tumours in the lower or back part of the brain, which control sleep/wake functions, movement and coordination.

Prognosis

In general, children with a malignant tumour have a better outlook than adults. In many children, treatment will cause signs of the cancer to improve. Because a child's nervous system is still developing, some children may have physical, behavioural or learning difficulties due to the tumour and/or treatment. These may show several years later.

Health professionals to see

Doctors who specialise in treating children with brain and spinal cord tumours are called paediatric oncologists. Older teenagers may have treatment in an adult ward, or be looked after by an adolescent and young adult multidisciplinary team.

Some hospitals have music, play or art therapists, to help children cope with treatment. Most hospitals have occupational therapists, physiotherapists and social workers, and some have a child life therapist.

Treatment

Talk to your child's medical team about treatment and what to expect. The Youth Cancer Service (YCS) is a national network of specialist services for young people aged 15–25 years with cancer. You can call them on 1800 226 833.

Support

The hospital social worker can offer practical and emotional support, and suggest support services.

Cancer Hub can link you to organisations that support families, young adults and children affected by cancer – including Canteen, Camp Quality and Redkite. Call Cancer Hub on 1800 431 312 or visit cancerhub.org.au.

- See our *Talking to Kids About Cancer* booklet or our "Explaining Cancer to Kids" podcast episode.

Diagnosis

The doctor will ask about your symptoms and medical history and do a physical examination. If they suspect a brain or spinal cord tumour, you will be referred for tests. Molecular testing (page 23) is now an important part of diagnosis and treatment planning for many brain tumours.

Physical examination

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

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

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



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

Blood tests

You are likely to have blood tests to check your overall health. Most brain and spinal cord tumours cannot be found or monitored by a blood test. However, blood or special urine tests can be used to check whether the tumour is producing unusual levels of hormones, for example, if the pituitary gland is affected (see page 14).

MRI scan

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

For an MRI, you may be injected with a dye (known as contrast) that highlights any abnormalities in your brain. You will then lie on an examination table inside a large metal tube that is open at both ends.

The test is painless, but the noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may get upset, talk to your medical team before you go for the scan. You may be given medicine to help you relax or be able to bring someone into the room for support. You will have headphones or earplugs and you can press a distress button if you are worried at any time. An MRI takes 30–45 minutes.

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

CT scan

Many people may have a CT (computerised tomography) scan, or it may be used if you are unable to have an MRI. This scan uses x-rays and a computer to create detailed pictures of the inside of the body.

Sometimes a dye (known as contrast) is injected into a vein before the scan to help make the pictures clearer. The contrast may make you feel hot all over and leave a bitter taste in your mouth. You may also feel like you are going to pee. These sensations usually only last a couple of minutes.

The CT scanner is a large, open 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.



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

Further tests

You may have some of the following tests, including molecular tests (sometimes called genomic tests), to find out more information about the tumour. This can then help your doctor plan your treatment.

MRS scan – An MRS (magnetic resonance spectroscopy) scan is a specialised type of MRI that looks for changes in the chemicals in the brain. It may be done at the same time as a standard MRI and helps show the difference between a tumour and other changes in the brain.

MR tractography scan – An MR (magnetic resonance) tractography scan shows the message pathways (tracts) within the brain (e.g. the visual pathway from the eye). It may be used to help plan treatment for gliomas.

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

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

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

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

Biopsy – If scans show an abnormality that looks like a tumour, some tissue may be removed and tested. During a biopsy, the neurosurgeon makes a small opening in the skull and inserts a needle to take a small sample. Or they may take a biopsy through your nose. A biopsy may also be taken during surgery, while the neurosurgeon removes as much of the tumour as possible (see pages 30–31). A specialist doctor called a pathologist will examine the tissue under a microscope for signs of cancer and to work out the specific type of tumour.

Molecular testing – A pathologist will run special tests on the biopsy sample to look for specific changes in the genes of the tumour cells (called molecular biomarkers). This is now an important part of diagnosing many types of brain tumours. The results can identify the type and features of the tumour, which helps your doctors recommend the most appropriate treatment. Ask your doctor about these tests.

Grading tumours

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

Unlike cancers in other parts of the body that are given a stage to show how far they have spread, primary brain and spinal cord tumours are not staged, because most don't spread to other parts of the body.

Grades of brain and spinal cord tumours	
grade 1	These tumours are low grade, slow growing and benign.
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, faster growing and malignant. They can spread to other parts of the brain and tend to come back after treatment.

Prognosis

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

Several factors may affect your prognosis, including:

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

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

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

"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 diagnosing brain tumours

Symptoms

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

Main tests

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

Grade

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

Prognosis

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

Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started.

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

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

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

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

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with 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* fact sheet.

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

Treatments offered for a brain or spinal cord tumour will depend on:

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

The tumour type may not be known for certain until after a biopsy or surgery. Treatment is based on what the surgeon thinks the tumour may be from scans. For a benign tumour, surgery may be the only treatment. For a malignant tumour, treatment may include surgery, radiation therapy, and drug therapies such as chemotherapy or targeted therapy. Medicines, such as steroids or anticonvulsants, may reduce symptoms or manage seizures. You may have a new or modified treatment, such as immunotherapy, on a clinical trial (see previous page).

Surgery

Brain or spinal cord surgery is called neurosurgery. Surgery may:

- remove the whole tumour (total resection)
- remove part of the tumour (partial resection or debulking)
- remove a small piece of the tumour for a biopsy (see page 22).

All of the tumour will be removed if it can be done safely, but this will depend on the type and location of the tumour. Removing only part of the tumour may be considered when the tumour covers a wider area or is near major blood vessels or other important parts of the brain

or spinal cord. Removing some of the tumour may help reduce the pressure on your brain, which may improve some of the symptoms.

When surgery is not possible

Sometimes a tumour is considered unsafe to remove because it is too close to certain parts of the brain, and surgery would cause blindness, loss of speech, paralysis or other serious complications. Sometimes these may be called inoperable or unresectable tumours. A needle biopsy is still often possible and can help to guide treatment options. Your doctor will talk to you about what treatments you can have and ways to manage symptoms.

What to expect before surgery

The different scans used to diagnose a brain tumour (such as MRI or CT scans, see pages 20–21) are often done again to plan surgery. Some people may have a functional MRI (fMRI) to help the surgeon avoid damaging the most important areas of the brain. You will be asked to complete brain exercises during the MRI scan to show the exact areas of the brain that are used as you speak or move. These parts of the brain can also be found during surgery with brain mapping (see the next page).

Tell your doctor about any blood-thinning or other medicines, and any supplements that you take. 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, as smoking can increase the risk of complications.



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

Types of surgery

Different types of surgery are used for brain and spinal cord tumours.

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

The surgeon cuts an area of bone (called the bone flap) from your skull to access the brain and remove the tumour. The bone is then put back and a small plate is screwed on to hold the piece of skull in place.

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

Brain mapping – An electrode is placed on the outside layer of the brain to stimulate and pinpoint important areas of the brain. Brain mapping may be done during surgery, or as part of an awake craniotomy.

Awake craniotomy – This operation may be recommended if the tumour is near parts of the brain that control speech or movement. You are usually put to sleep (general anaesthetic) and are later woken up but relaxed (conscious) for part of the operation. The surgeon asks you to speak or move parts of your body to identify and avoid damaging those parts 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-assisted surgery

It is now usual for a craniotomy to be done using a computer 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, this allows the surgeon to see the scan images at particular places in the head and position the surgical instruments more precisely.

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

Removing a pituitary tumour (endoscopic transsphenoidal surgery) – The most common surgery for pituitary gland tumours (and other tumours located near the base of the brain) is called endoscopic transsphenoidal surgery. To remove the tumour, the surgeon inserts a long, thin tube with a light and camera (called an endoscope) through the nose and into the skull at the base of the brain. An ear, nose and throat (ENT) surgeon may also 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 a laminectomy. The surgeon makes an opening through the skin, muscle and a vertebra in the spinal column to remove the tumour. You usually have a general anaesthetic for this type of surgery.

Some spinal cord tumours may also need surgery to the spinal cord itself. Your surgeon will talk to you about this particular surgery, as it may have a risk of nerve or spinal cord injury.

What to expect after surgery

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

Checks and observations

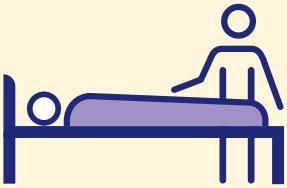


Nurses will regularly check your breathing, blood pressure, pulse, temperature, pupil size, and arm and leg strength and function. You will also be asked questions to assess your level of consciousness. These are called neurological observations, and help to check how your brain and body are recovering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

Pressure stockings



You will need to wear pressure stockings on your legs to prevent blood clots 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. Depending on the operation, you may need to lie flat in bed for a few days so the wound can heal. A physiotherapist will show you how to roll over and get out of bed safely, to avoid damaging the wound.

Rehabilitation

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

You may stay in hospital for only 2 or up to 10 days. How long you stay in hospital will depend on whether you have any problems or side effects after the surgery.

Bandages and bruising



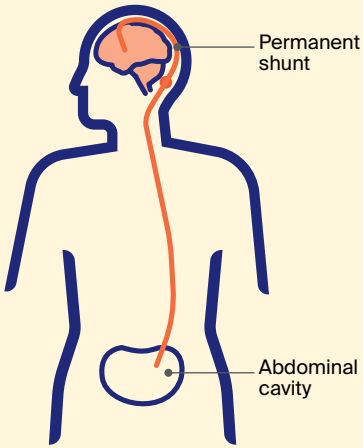
The wound is covered with a dressing, which varies from a small adhesive pad to bandaging covering your head. Some or all of your head may be shaved. After some surgery, your face and eyes may be swollen or bruised. It's not usually painful and should ease in about a week. You may have dissolvable sutures (stitches) that don't need to be removed; they simply fall out. Or you may have sutures or staples that need to be taken out once the wound has healed. You will have a scar, and your hair won't grow in the scar – but it's usually behind the hairline and once the rest of your hair grows back it isn't easily seen.



Headaches and nausea

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

Having a shunt



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

Side effects of surgery

Infection – Although the risk is small, you may develop an infection at the wound site. This can usually be treated with antibiotics. A small number of people may need surgery to have the wound cleaned out and possibly the bone flap removed. Another surgery will usually be done later on to replace the missing area, for safety and to look natural.

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

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

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

Rehabilitation after surgery

Some people recover and can gradually return to their usual activities. For others, there are longer-term changes to speech, movement, behaviour and thinking. A range of therapies can help recovery or show you ways to manage any longer-term changes. These therapies are known as rehabilitation. At first, you may have some rehabilitation therapies in the hospital or a rehabilitation facility. Once you return home, you can continue rehabilitation therapies as an outpatient. You may also be given equipment to use at home. You will have other changes, such as not being able to drive for a while. See pages 46–47 for information about rehabilitation therapies.

Radiation therapy

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

For gliomas, radiation therapy is usually given after surgery, and sometimes with chemotherapy (chemoradiation). Sometimes radiation is given before surgery. 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. Treatment is carefully planned to do as little harm as possible to healthy brain tissue near the tumour. Radiation therapy itself is painless, though you may have side effects (see pages 38–39). Your treatment team will discuss these before treatment.

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

How often you have radiation therapy (the treatment course) will depend on the size and type of tumour. Usually it is given once a day, from Monday to Friday, for several weeks (often 3 or 6 weeks, but this varies from person to person). During treatment, you will lie on a table under a machine called a linear accelerator (LINAC). Most machines use daily imaging scans to check you are in the correct position for treatment. Each treatment will last for about 10–15 minutes.



For high-grade glioblastomas, radiation therapy is usually combined with chemotherapy (see pages 39–40). This is called chemoradiation. The chemotherapy drugs make the cancer cells more sensitive to radiation therapy.

Stereotactic radiosurgery (SRS)

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

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

SRS is not suitable for all brain tumours. It may be offered when neurosurgery is not possible, or before or after neurosurgery. It's mostly used for cancers that have spread to the brain from another part of the body. It may also be used for some meningiomas, pituitary tumours, schwannomas, and occasionally gliomas that have come back.

Often, only 2 or 3 doses of SRS are needed (though you may have 1–5 doses as treatment is personalised). A treatment session may last 15–45 minutes, depending on the type of radiosurgery given. You will need to wear a special mask (see opposite) or frame during the treatment. You will usually be able to go home after the session ends.

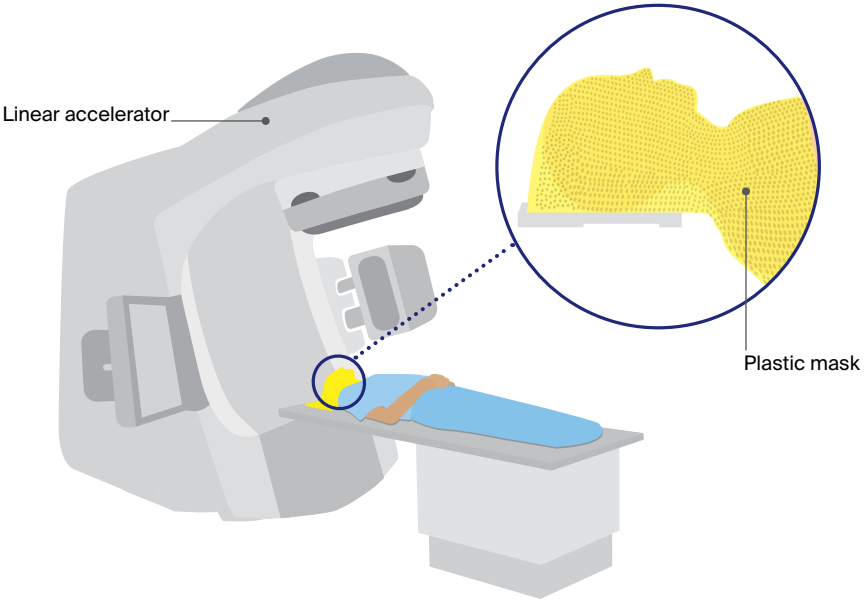
Stereotactic radiation therapy (SRT)

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 or SRT. The treatment is given as multiple small daily doses.



If you feel anxious before your radiation therapy sessions, the meditation and relaxation exercises in our *Finding Calm During Cancer* podcast may help. Or ask to speak to a social worker or psychologist for support.

Wearing an immobilisation mask



You'll need to wear an immobilisation mask during radiation therapy to the brain. It helps keep your head still so that the radiation is targeted at the same area during each session. The mask is made to fit you and fixed to the table when the radiation treatment is given.

The mask is made of a tight-fitting plastic mesh that you can see and breathe through. It may feel strange and confined but you usually only wear it for about 10 or 20 minutes at a time. For some people, especially those with claustrophobia, the thought of wearing the mask can feel overwhelming. The team may suggest that you try relaxation or breathing exercises, or a psychologist can give you strategies to try. You may also be offered medicine to help you relax.

Tell the radiation therapist if wearing the mask makes you feel anxious. With support, many people get used to wearing it.

Proton therapy

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

At the time this booklet was printed (Nov 2026) proton therapy was not available in Australia. However, there is funding in special circumstances to allow Australians to travel overseas for proton therapy.

Side effects of radiation therapy

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

- **nausea** – can occur several hours after treatment
- **headaches** – can occur throughout 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; is usually mild and happens at the end of the treatment course and lasts 1–2 weeks before going away
- **hair loss** – may occur in a patch in the area of the head receiving treatment; usually temporary but in some cases permanent; if hair grows back, the texture or colour may be different
- **dulled hearing** – may occur if fluid builds up in the middle ear and is usually temporary but may be permanent.

Radiation therapy side effects for spinal cord tumours may include a sore or dry throat and swallowing problems (if the neck area is treated) or diarrhoea (if the lower spine is treated). Both are temporary. Talk to your radiation oncology team about how to manage any side effects.

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.

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

▸ See our *Understanding Radiation Therapy* booklet.



Tumour treating fields (TTFields) are low-intensity electric fields given via a wearable device. TTFields usually have a high cost and are only available through clinical trials, special access pathways or overseas treatment.

Chemotherapy

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

You may have chemotherapy after surgery or radiation therapy. Chemotherapy may also be given at the same time as radiation therapy (chemoradiation). For a brain tumour, you usually have chemotherapy as capsules or tablets that you swallow, but you may also have it as a liquid through a drip inserted into your vein (intravenously).

A structure known as the blood–brain barrier helps protect the brain from substances in the blood, such as germs or chemicals. Only certain types of chemotherapy drugs can get through this barrier.

It's common to have chemotherapy as a capsule that you take at home. You take it for a set number of days, which is then followed by a rest period. This is called a cycle. You may have 6 cycles, or more, depending on the chemotherapy drug used. Your doctor may suggest a different dosage or chemotherapy drug.

Side effects of chemotherapy

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

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

In some cases your hair may become thinner or patchy, but it is rare to lose all your hair when you have chemotherapy for brain and spinal cord tumours.

▸ See our *Understanding Chemotherapy* booklet.

Ali's story

I'd been having headaches for a couple of weeks and then one day I collapsed. 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.

Then I found out that the tumour had returned. It had been 9 years since the first tumour. I was in denial and wasn't particularly worried about the second operation, but I got more worried as the date came closer.

I had no real problems and the surgeon said they got it all, but I'd need radiation therapy and chemotherapy, just to mop up any stray cells. That floored me – I hadn't needed them the first time.

I had 6 weeks of radiation therapy, then 6 months of oral chemotherapy, and that knocked everything for six. I developed an inflamed stomach and had to go on a very bland diet. I lost weight and strength, and was very vague. Time has helped, but it's been gradual.

Targeted therapy

This drug therapy targets specific features of cancer cells to stop cancer growing or spreading. The drugs travel through the body and bind to specific molecules in the tumour. They may be given after surgery to delay chemotherapy or radiation therapy, or at other times.

Targeted therapy doesn't work for all tumours. Molecular tests can help show whether a drug may work (see page 23). New targeted therapies are becoming available. However, some drugs may only be available through a clinical trial, and some may have a high cost.

Immunotherapy and brain tumours

Immunotherapy is not currently a standard treatment for primary brain tumours. However, it may be available for certain immunotherapy-sensitive cancers that have spread to the brain from other parts of the body (called advanced or metastatic cancers). Ask your doctor whether immunotherapy may be an option for you and how much it would cost.

New immunotherapy drugs are also being tested in clinical trials (see page 27). These trials include treatments to help the immune system better recognise cancer cells, vaccines against cancer cells, viruses to infect cancer cells, and treatments that change the patient's own immune cells (e.g. CAR T-cell therapy).

Treatments to control symptoms

Steroids

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

Side effects of steroids

The side effects you may experience with steroids depend on the dose and length of treatment:

Short-term use – You may experience increased appetite and weight gain; trouble sleeping; restlessness; mood swings; anxiety; and, in rare cases, more serious changes to thinking and behaviour. In people who have diabetes, steroids can quickly lead to high or unstable blood sugar

levels. These short-term side effects can be managed. Eating before taking steroids can reduce the chance of them irritating your stomach.

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

Anticonvulsants

Taking anticonvulsants may help to control seizures (see page 50), but they can also affect your mood and energy. An experienced counsellor, psychologist or psychiatrist can help you manage any mood swings or behavioural changes. If you or your family are worried about side effects, talk to a doctor or nurse, or call Cancer Connect on 13 11 20.

Palliative treatment

Palliative treatment helps to improve quality of life by managing the symptoms when a brain tumour is no longer curable. As well as slowing the spread of cancer, palliative treatment can relieve pain and help with other symptoms. Treatment may include surgery, radiation therapy, chemotherapy or other medicines.

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

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

Key points about treating brain tumours

Main treatments	The main treatments are surgery, radiation therapy and chemotherapy.
Surgery	• Some tumours can be completely removed with surgery (total resection). Others can only be partly removed (partial resection or debulking). • The most common brain surgery is a craniotomy. • A laminectomy is surgery to remove tumours from the spinal cord.
Radiation therapy	• Radiation therapy uses targeted radiation, such as x-ray beams, to kill cancer cells. • Stereotactic radiosurgery (SRS) is a very precise form of radiation therapy that delivers high doses of radiation. It is used to treat some tumours.
Chemotherapy	• Chemotherapy uses drugs to kill cancer cells. • You may be given chemotherapy as capsules or tablets, or sometimes into a vein (intravenously) through a drip.
Targeted therapy	Targeted therapy uses drugs to target specific features of cancer cells to stop them growing.
Treatments to control symptoms	Other treatments include steroids to reduce swelling in the brain, and anticonvulsants to manage seizures (see page 50).
Side effects	Treatments may cause short-term and long-term side effects. Talk to your doctors and nurses about ways to manage symptoms and side effects, including whether rehabilitation may help.

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 and other thinking skills, movement, balance or coordination.

It's common to feel very tired. An occupational therapist can help you to manage the effects of this fatigue and give you strategies to cope.
▸ See our *Understanding Fatigue and Cancer* fact sheet.

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

The changes may be difficult to handle, and they could affect how you feel about yourself and your relationships. Talking to a counsellor or someone who has had a similar experience may help. Call Cancer Connect on 13 11 20 to see what support is available.

Rehabilitation

Rehabilitation is treatment designed to help people recover from or adjust to injury or disease. After treatment for a brain or spinal cord tumour, most people will have a rehabilitation assessment to identify what they need help with and ways to manage changes. A range of health professionals offer various therapies (see the next 2 pages) to help restore your previous abilities or help you adjust to changes or long-term effects.

Types of rehabilitation

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

Physiotherapy



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

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

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

Cognitive rehabilitation



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

A neuropsychologist, speech pathologist or occupational therapist can help improve these cognitive skills. They may use memory strategies, speech therapy, technology such as calendars and reminder alerts, and word puzzles.

Exercise



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

To find a physiotherapist in your area, visit choose.physio/find-a-physio, and to find an accredited exercise physiologist, visit essa.org.au/find-aep.

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

Speech therapy



Your ability to talk may be affected, which is often called aphasia. A speech pathologist could help to restore speech.

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

To find a certified practising speech pathologist, visit speechpathologyaustralia.org.au.

Sight



You may lose some or all of your sight as a result of a brain tumour, depending on what part of the brain is affected.

Vision Australia can teach you tips and strategies to live independently. Call 1300 84 74 66 or visit visionaustralia.org.

Occupational therapy



If you are finding it harder to do everyday personal activities (e.g. showering, dressing, preparing a meal) or more complex activities (e.g. work and driving), an occupational therapist may be able to help. They can offer a range of strategies and aids to help you manage fatigue as well as physical and cognitive changes so you can improve or maintain your independence.

To find an occupational therapist near you, visit otaus.com.au/find-an-ot.

Managing seizures

A brain tumour or its treatment can sometimes cause seizures (fits or convulsions). A seizure is a disruption to the normal patterns of electrical impulses in the brain. There are 2 main groups of seizures:

Generalised seizures – These occur when all of the 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 2 minutes. They may bite their tongue, and lose bladder and bowel control.

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

Symptoms of focal seizures depend on the area of the brain involved. They may include twitching; jerking; tingling or numbness; not being able to speak; and changes in vision or hearing, strange tastes or smells, or a feeling of deja vu. Focal seizures may also cause a brief loss of consciousness, changes in mood, and memory loss just before, during and after the seizure.

Ways to prevent seizures

Seizures can often be prevented with anticonvulsant medicines (also called anti-epileptic or anti-seizure medicines) – see page 50. Feeling overstimulated or very tired can also increase your risk of having a seizure. Try to get 6–8 hours of sleep each night. Drinking less alcohol may also help.



How to help someone having a seizure

- Remain calm and stay with the person while they are having a seizure. Refer to their Seizure Management Plan (see last tip in this list), if they have one.
- Do not hold them down or put anything in their mouth.
- Protect the person from injury (e.g. move hazards, lower them to the floor if possible, loosen their clothing, cushion their head and shoulders).
- Call Triple Zero (000) for an ambulance if it is the first seizure the person has had; if the person is injured; if there was food or fluid in the person's mouth; if the seizure lasts longer than 5 minutes; or if you are unsure of what to do.
- Time how long the seizure lasts so you can tell the paramedics.
- After the jerking stops, roll the person onto their side to keep their airway clear. This is particularly important if the person has vomited, is unconscious or has food or fluid in their mouth.
- Watch the person until they have recovered, or the ambulance arrives.
- If the seizure occurs while the person is in a wheelchair or car, support their head and leave them safely strapped in their seat until the seizure is over. Afterwards, remove the person from their seat, if possible. Roll them onto their side if there is food, fluid or vomit in their mouth.
- Explain to the person what has occurred. In many cases, people are confused after a seizure.
- Allow the person to rest afterwards as most seizures are exhausting.
- For detailed information and an online tool for creating a Seizure Management Plan, contact Epilepsy Action Australia on 1300 37 45 37 or visit epilepsy.org.au.

Anticonvulsant medicines

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

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

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



If you take anticonvulsants, you may need to avoid some foods. Check with your doctor before taking any herbal medicine, as it can change how some anticonvulsants work. Ask your doctor or pharmacist about potential interactions and foods to avoid.

Driving

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

These skills include:

- good vision and perception
- ability to concentrate and plan
- processing speed and reaction time
- ability to remember directions
- good hand–eye coordination
- planning and problem-solving.

When 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.

Your doctor will usually advise you not to drive for a while. You will probably need to wait for some time before you drive again after surgery and possibly after radiation therapy.

There are also some set exclusion periods your doctor will follow after certain treatments or events such as seizures. If you have had seizures, legally you will need to be seizure-free for a period of time before you are allowed to drive. If you stop taking your anticonvulsant medicines, you will also need to be seizure-free for a period of time until you are allowed to drive.

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

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

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



How to return to driving

- Have a driving assessment to check your ability to return to driving. This may include doing an off-road assessment or having an electroencephalogram (EEG) to assess seizure risk.
- See an occupational therapist driving assessor, a neurologist or rehabilitation specialist to work out the type of problems you may experience while driving (e.g. a slow reaction time). The focus of the assessment is not to suspend or cancel your licence: it is to work out if it is possible for you to safely return to driving.
- An occupational therapist may be able to teach you driving techniques to help with weaknesses or show you how to make changes to your car (such as extra mirrors). You may also be able to drive with restrictions, such as only in daylight, only in automatic cars or only short distances from home.
- Some people feel upset or frustrated if they have licence restrictions or can no longer drive. You may feel that you have lost your independence or worry about the impact on your family. It may help to talk to a counsellor or someone who has been through a similar experience (see page 57). Depending on your situation and your health, it may be possible to return to driving later on.
- Follow any licence restrictions. If your doctor says you are not safe to drive, you must not drive unless they change that medical decision. If you ignore the restrictions, your licence may be suspended or cancelled. You may be fined if you drive while your licence has been suspended or cancelled. If you have an accident while driving, you could be charged with a criminal offence and your insurance policy will no longer be valid.
- Talk to your doctor or visit austroads.com.au/drivers-and-vehicles/assessing-fitness-to-drive.

Working

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

Some people find it hard to concentrate or make decisions after they have treatment for a brain tumour. At least at first, it may not be safe to operate heavy machinery or take on a lot of responsibility. Your doctors and an occupational therapist can tell you whether it's okay to return to work.

Talk to your employer about adjusting your duties or hours until you have recovered. In some cases, it won't be possible to return to your former role. It may help to talk to a social worker, occupational therapist or psychologist, call Cancer Connect on 13 11 20 or join a brain tumour support group to try and come to terms with these changes. For other sources of support, see pages 60–61.

▸ See our *Cancer, Work and You* booklet.

Financial support for people with disabilities

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

For more information, talk with your GP or rehabilitation team, call 1800 800 110 or visit ndis.gov.au.

If your GP refers you to a rehabilitation specialist (see pages 34 and 45–47) as part of a chronic condition management plan, you may be eligible for a Medicare rebate for up to 5 visits each year.

Key points about living with a brain tumour

Side effects

- A brain or spinal cord tumour and its treatment can cause changes to speech, personality, memory and thinking skills, movement, balance or coordination.
- People living with a brain tumour may have seizures, which can be treated with anticonvulsant medicines.
- Fatigue can be a long-term symptom of brain cancer. An occupational therapist can help you manage the effects of this fatigue.

Rehabilitation

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

- A neuropsychologist, speech pathologist or occupational therapist can suggest strategies to improve memory, language skills and concentration.
- Physiotherapy can help you learn how to move more easily, maintain or regain strength and improve balance.
- Speech therapy may assist if your ability to talk or swallow has been affected.
- Occupational therapy can help you regain independence in daily activities such as showering, dressing, making a meal or leisure interests.
- Under a chronic condition management plan, you may be eligible for a Medicare rebate for up to 5 visits to allied health professionals each year.

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 Cancer Connect on 13 11 20 or visit cancerconnect.org.au.

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

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.
▸ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.
▸ See our *Understanding Complementary Therapies* booklet.

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

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

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

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

▸ See our *Emotions and Cancer* booklet.

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

▸ See our *Sex, Intimacy and Cancer* booklet.

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

▸ See our *Fertility and Cancer* booklet.

Life after treatment

Some people continue to have regular treatment, but for those who finish their treatment, the cancer experience doesn't usually end there. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry about the cancer 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 Connect can help you connect with other people who have had cancer and with information about living well after cancer. Call 13 11 20 or visit cancerconnect.org.au.

▸ 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 you used to enjoy, 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. You may be eligible for Medicare-rebated sessions with a psychologist. Cancer Council may run a counselling program in your area.

Call Beyond Blue 1300 22 4636 or visit beyondblue.org.au for help with depression and anxiety. For 24-hour 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 tumour hasn't come back or spread. During these check-ups, you will usually have a physical examination and you may have blood tests or MRI scans. How often you see your doctor will depend on the type of tumour and treatments you had. Between follow-up appointments, let your doctor know immediately of any new or changing symptoms or health problems.

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

What if the tumour returns?

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

Targeted therapy drugs attack specific features of cancer cells (see page 41). Bevacizumab is a targeted therapy drug that can be used to treat advanced brain cancer. Bevacizumab is most helpful when the tumour is causing swelling in the brain. Your doctor will talk to you about the benefits and possible risks. Other targeted therapy drugs and immunotherapy may be available on clinical trials (see page 27). Talk with your doctor about the latest developments and whether you are a suitable candidate.

Caring for someone with cancer

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

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

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

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

Carers Australia – Carers Australia provides information and advocacy for carers. Visit carersaustralia.com.au.

Cancer Council – You can call Cancer Connect on 13 11 20 or visit cancerconnect.org.au to find out more about carers' services.

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

Seeking support

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

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

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

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

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre. You can also call Cancer Connect on 13 11 20 or visit cancerconnect.org.au.

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

Support from Cancer Council

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

Cancer Connect by Cancer Council



Call 13 11 20 to talk to a qualified professional. We can answer questions you have about your situation and link you to local services (see inside back cover).

Legal and financial support



If you need advice on legal or financial issues, we may be able to refer you to appropriate professionals. These services may be free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Connect on 13 11 20.

Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. We can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancercouncil.com.au/OC.

Information resources



Cancer Council produces booklets and fact sheets on more than 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit cancerconnect.org.au.

Practical help



Cancer Connect can help you find ways to manage the practical impacts of cancer. This can include connecting you with services, such as accommodation and transport services.

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 Connect	**cancerconnect.org.au**
Cancer Council Online Community	**cancercouncil.com.au/OC**
Cancer Council podcasts	**cancercouncil.com.au/podcasts**
Guides to Best Cancer Care	**cancer.org.au/cancercareguides**
Brain Cancer Group	**braincancergroup.com.au**
Brain Tumour Alliance Australia	**btaa.org.au**
Building the Bridge to Life with Brain Cancer	**buildingthebridge.com.au**
Cancer Australia	**canceraustralia.gov.au**
Carer Gateway	**carergateway.gov.au**
Cooperative Trials Group for Neuro-Oncology (COGNO)	**cogno.org**
Cure Brain Cancer Foundation	**curebraincancer.org.au**
eviQ (cancer treatments online)	**eviq.org.au**
Healthdirect Australia	**healthdirect.gov.au**
Peace of Mind Foundation (brain cancer support)	**peaceofmindfoundation.org.au**
Services Australia (including Centrelink and Medicare)	**servicesaustralia.gov.au**
International	
American Brain Tumor Association	**abta.org**
American Cancer Society	**cancer.org**
Cancer Research UK	**cancerresearchuk.org**
International Brain Tumour Alliance	**theibta.org**
The Spinal Cord Tumour Forum (UK)	**spinalcordtumour.org.uk**

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? How fast is it growing?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

Treatment

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

Side effects

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

After treatment

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

Glossary

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

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

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

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

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

brain stem
Connects the cerebrum and the spinal cord. It controls functions that keep you alive.

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

central nervous system (CNS)
The brain and spinal cord.

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

cerebrospinal fluid (CSF)
Clear, watery fluid surrounding the brain and spinal cord.

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

chemotherapy
A cancer treatment that uses drugs to kill cancer cells or slow their growth. It may be given alone or in combination with other treatments such as radiation therapy.

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

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

craniotomy
An operation to open the skull to reach the brain and remove, or biopsy, the tumour.

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

endoscopic surgery
A type of surgery for cancers that can be reached through the nose or mouth. Tissue is removed using a thin tube with a fine cutting instrument and a camera on the end (endoscope).

ENT (ear, nose and throat) surgeon
A doctor who specialises in treating disorders of the ear, nose and throat.

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

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

glial cell
A type of nervous system cell. Also called neuroglia.

glioblastoma
A type of malignant astrocytoma. Previously known as glioblastoma multiforme (GBM).

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

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

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

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

hydrocephalus
A build-up of cerebrospinal fluid in the brain.

incontinence
The accidental or involuntary loss of urine (wee/pee) or faeces (poo). Also known as urinary or faecal incontinence or leakage.

inoperable
Not able to be safely 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 some bone; allows biopsy or removal of a spinal cord tumour.

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

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

lymphatic system
A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

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 (systemic treatment).

medulloblastoma
A type of brain tumour that starts in the cerebellum; usually malignant.

meninges
Thin layers of protective tissue (membranes) that cover the brain and spinal cord.

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

metastasis (plural: metastases)
Cancer that has spread from a primary cancer in another part of the body.
Also called secondary or advanced cancer.

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

nervous system
The network of nerves in the body. The 2 main parts are the central nervous system and the peripheral nervous system.

neurologist
A doctor who specialises in diagnosing and treating diseases of the brain and nervous system, including seizures.

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

neuropsychologist
A psychologist who specialises in helping people who have cognitive and behavioural changes from brain injury or disease.

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

occipital lobe
Part of the cerebrum; responsible for processing visual information.

oligodendroglioma
A type of brain tumour that starts in the glial cells called oligodendroglia.

palliative care
The holistic care of people with a life-limiting illness, their families and carers. It aims to maintain quality of life by addressing 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
Part of the cerebrum; responsible for processing information from the senses.

peripheral nervous system
The system of nerves beyond the central nervous system going to the limbs and organs.

pineal gland
A gland in the brain that helps to control your body clock. It makes hormones including melatonin, which helps you sleep. Tumours of the pineal gland are rare and are usually classified as neuroendocrine tumours.

pituitary gland
A gland in the brain that produces hormones to control bodily functions, including growth, metabolism and production of sex hormones.

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

primary cancer
The original cancer. Cells from the primary cancer may spread to other parts of the body, where secondary cancers may form. Primary brain cancers usually do not spread outside the brain or spinal cord.

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

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

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

resectable
Able to be surgically removed from the body.

resection
Surgical removal of part or all of a diseased organ or tumour.

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

seizure
A disruption of the normal electrical impulses in the brain, causing a person to have fits (convulsions) or other symptoms.

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

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

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

stereotactic radiosurgery (SRS) or stereotactic radiation therapy (SRT)
Types of external beam radiation therapy that deliver high doses of precise radiation.

stereotactic surgery
Surgery that uses a computer to guide the surgeon.

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

systemic treatment
Cancer drugs that spread throughout the whole body. Includes chemotherapy, targeted therapy and immunotherapy.

targeted therapy
Drugs targeting specific features of cancer cells to stop cancer growing and spreading.

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

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

Can't find a word here?

For more cancer-related words, visit connect.cancer.org.au/glossary.

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3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, AIHW, Canberra, 2026, viewed 21 September 2026, available from: aihw.gov.au/reports/cancer/cancer-data-in-australia.

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.

The right support.

cancer connect
Cancer Council

Cancer is never one story. Every diagnosis, every person, and every path is different. You don't have to figure it out alone.

Cancer Connect can help you find the information and support that are right for you.

You can explore trusted information on our Cancer Connect website at your own pace, or call 13 11 20 to talk to our qualified professionals. We will listen to your concerns, answer your questions, and connect you with support.

Wherever you are on your path, Cancer Connect can help make the next step feel clearer.

Right when you need it.

Call 13 11 20

Visit cancerconnect.org.au

TIS TRANSLATING AND INTERPRETING SERVICE

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

National Relay Service

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

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



For information & support,
call **Cancer Connect 13 11 20**
or visit **cancerconnect.org.au**

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Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancer.org.au/tas

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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