Understanding Brain Tumours

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

Cancer Council Helpline
13 11 20
www.cancercouncil.com.au
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Note to reader
Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor’s or other health professional’s advice. However, 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.

Cancer Council NSW
Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council’s website at www.cancercouncil.com.au or phone 1300 780 113.

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Introduction

This booklet has been prepared to help you understand more about brain and spinal cord tumours, and what you may experience with either of these diseases. It provides information about both non-cancerous (benign) and cancerous (malignant) tumours, which are diagnosed and treated similarly.

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

We cannot advise you about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some questions and help you think about other questions you want to ask your health carers.

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 at the end of the booklet. You may also like to pass this publication on to your family and friends for their information.

How this booklet was developed

This booklet was developed with help from medical experts and people who have been diagnosed with brain or spinal cord tumours. It is based on clinical practice guidelines for brain and spinal cord tumours.
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Cancer is a disease of the cells, which are the body’s basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury.

Normally cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in abnormal blood cells or may develop into a lump called a tumour.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour is contained in one area and does not spread to other parts of the body. Most benign brain tumours are slow-growing and unlikely to spread, even throughout the brain.
A malignant tumour is made up of cancer cells, which grow out of control and are usually able to spread. However, unlike other types of cancer, malignant tumours of the brain or spinal cord tend not to spread to other parts of the body. Instead, they often are identified as cancer by their rapid growth and tendency to come back (recur) after surgery.

If cancer cells in another part of the body do move away from the original (primary) cancer site and invade other organs, this is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, lung cancer that has spread to the brain is still called lung cancer, even though you may be treated for symptoms caused by a tumour in the brain.
The brain and spinal cord make up the central nervous system (CNS). The CNS receives messages from cells called nerves, which are spread throughout the body (in the peripheral nervous system). The brain interprets information and relays messages through the nerves to muscles and organs.

The brain is the most important organ in the body because it controls all voluntary and involuntary processes, such as learning, sensing, imagining, remembering, breathing, blood circulation and heart rate, body temperature, digestion, and bowel and bladder control (continence).

The main sections of the brain are the cerebrum (the largest part), the cerebellum and the brain stem. These parts play unique roles in the body’s functions, many of which are essential to staying alive. Deep within the brain is the pituitary gland. It controls growth and development by releasing chemical messengers (hormones) into the blood. These signal other hormones to start or stop working.

The spinal cord extends from the brain stem to the lower back. It consists of nerve cells and nerve bundles that connect the brain to all parts of the body through the peripheral nervous system. The spinal cord is part of the spinal canal, along with fat, connective tissue and blood vessels. Bony vertebrae protect the spinal canal.

Both the brain and spinal cord are surrounded by membranes called meninges. Inside the skull and vertebrae (spinal column), the brain and spinal cord float in liquid called cerebrospinal fluid.
The brain and spinal cord

- Meninges
- Skull
- Cerebrum
- Cerebellum
- Brain stem
- Pituitary gland
- Spinal cord (part of spinal canal)
- Vertebrae (part of spinal column)
Nervous tissue
The brain, spinal cord and nerves consist of billions of nerve cells called neurons or neural cells, which process and send information. Together this is called nervous tissue.

The three main types of neural cells are:
- **sensory neurons** – respond to light, sound and touch
- **motor neurons** – cause muscle contractions
- **interneurons** – connect neurons in the brain and spinal cord.

Glial cells, or neuroglia, are the other main type of cell in the nervous system. There are several different types of glial cells, including astrocytes and oligodendrocytes.

Glial cells are the glue of the nervous system because they surround the neurons and hold them in place. The glial cells also supply nutrients and oxygen to neurons and get rid of dead neurons and germs.
Q: What is a brain or spinal cord tumour?

A: A tumour occurs when cells in the central nervous system grow and divide in an uncontrollable way, forming a lump. The lump may press on or grow into different areas of the brain or spinal cord, which can cause various symptoms such as loss of movement. A tumour can be benign or malignant, but sometimes it is difficult to tell the difference between them.

Benign tumours usually have slow-growing cells and clear borders (margins), and they rarely spread. However, they may be found in essential areas of the brain that control vital life functions, which can make them life-threatening.

Malignant tumours usually grow rapidly and spread within the brain and spinal cord. Malignant brain tumours can also be life-threatening. About 40% of brain and spinal cord tumours are malignant.

Q: What types are there?

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

- **Benign tumours** – The most common types are meningiomas, neuromas, cranio-pharyngiomas, pituitary tumours, and cystic astrocytomas.
Benign tumours can cause problems by pressing on the brain and spinal cord. Most of these tumours can be removed by surgery, but if this is not possible, cancer treatments such as radiotherapy may be used.

- **Malignant tumours** – These include high-grade astrocytomas, oligodendrogliomas, ependymomas, glioblastomas and mixed gliomas. In some malignant tumours, the cells are confined to one area. In other tumours, malignant cells are also found in surrounding tissue. Treatments are described on pages 22–36.

- **Metastatic brain tumours** – These begin as cancer in another part of the body before spreading to the brain.

**Q: What are the causes?**

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

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

• **Mobile phones** – Some researchers have studied whether long-term or excessive use of mobile phones increases a person’s risk of developing a brain tumour. It is possible that there may be an increased risk of developing a glioma in people with high levels of mobile phone use (i.e. more than 30 minutes a day). However, there is insufficient scientific evidence to link regular mobile phone use to brain tumours. Research is continuing in this area.

Research shows that exposure to microwave ovens does not cause any type of cancer or tumour.

**Q: What are the symptoms?**

**A:** The symptoms of a brain or spinal cord tumour depend on where it is located and if it is causing pressure in the skull or spinal column. Sometimes, when a tumour grows slowly, symptoms develop gradually or you may not take much notice of them. They may be similar to other illnesses, such as a migraine or a stomach bug (e.g. headaches or nausea).
Brain and spinal cord tumours may cause weakness or paralysis in parts of the body. Some people also have trouble balancing or have seizures (see page 34).

Other symptoms of brain tumours include:
• nausea and/or vomiting
• headaches
• drowsiness
• difficulty speaking or remembering words
• short-term memory problems
• disturbed vision, hearing, smell or taste
• loss of consciousness
• general irritability, depression or personality changes – this is sometimes only noticed by family or friends.

Symptoms of spinal cord tumours include:
• back and neck pain
• numbness or tingling in the arms or legs
• clumsiness or difficulty walking
• loss of bowel or bladder control (incontinence).

**Hydrocephalus**

A brain tumour can sometimes block the flow of cerebrospinal fluid around the brain and its spaces (cavities). When this happens, fluid can build up and put pressure on the brain. This is called hydrocephalus. The condition is most common in infants but it can occur in some adults. It is usually treated with a shunt (see box on page 26).
Q: How common are brain and spinal cord tumours?

A: Every year about 1,400 malignant brain tumours are diagnosed in Australia. About 100 of these cases are in children.

About 80 people are diagnosed with other malignant central nervous system tumours, including malignant spinal tumours. About one in five of these are in children.

Data about benign brain and spinal cord tumours are not collected, but an estimated 2,000 people – including children – are affected every year.

Children with a brain or spinal cord tumour

Even though they are rare, brain tumours are the second most common cancer in children.

Children with a suspected brain or spinal cord tumour will have the same types of diagnostic tests as adults (see page 14). The treatment offered to children is similar to adults, with the exception of radiotherapy (see page 29).

Many of the side effects and emotional issues for children will also be similar to those experienced by adults.

Most of the information in this booklet applies to children too. There is also a section on caring for a child with a tumour, and talking to a child about having a tumour. See page 57 for more information.
Diagnosis

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

The doctor will take your medical history and ask about your symptoms. After that, you will have a physical examination. Based on those results, the doctor will refer you to have one or more scans of the brain and body, and possibly some other tests, to confirm a diagnosis of a brain or spinal cord tumour.

Physical examination

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

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

The doctor may also test eye and pupil movements, and may look into your eyes using an instrument called an ophthalmoscope. This allows the doctor to see your optic nerve, which sends visual information from the eyes to the brain.
A CT (computerised tomography) scan is a procedure that uses x-ray beams to take pictures of the inside of your body. Unlike a standard x-ray, which takes a single picture, a CT scan uses a computer to compile many pictures of areas of your body.

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

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

The dye that is injected into your veins before a CT scan often contains iodine. If you are allergic to iodine, fish or dyes, let the person performing the scan know in advance.
MRI scan

An MRI (magnetic resonance imaging) scan uses magnetism and radio waves to build up very detailed cross-section pictures of the body. A dye may be injected into your veins before the scan. As the dye may affect the kidneys, your kidney function will be checked.

You will lie on a table in a metal cylinder, which is a large and powerful magnet. Some people feel anxious lying in the narrow cylinder during the MRI. Let your health care team know if you are claustrophobic. It may help to take a mild sedative, or you can talk through an intercom to the person operating the machine. In some hospitals you can listen to music to help you relax.

Although the MRI scanner can feel tightly enclosed and noisy, the test is painless and is usually completed in under an hour. You will be able to go home when your scan is over.

People with a pacemaker or other metallic objects in their body will not be able to have an MRI due to the effect of the magnet.

Further tests

You may also have some of the tests listed on the opposite page. Some tests show how quickly or aggressively a tumour is growing (the grade) or if the cancer has spread (the stage) – see page 18.

If your doctor suggests any of these tests, you can ask for a more detailed explanation of the procedures and any follow-up care. Understanding what will happen may help you feel less anxious.
**Magnetic resonance spectroscopy (MRS) scan** – This scan can be done at the same time as a standard MRI. An MRS scan shows whether the brain's neurons are working properly.

**Single photon emission computerised tomography (SPECT or SPET) scan** – After an injection of a small amount of radioactive fluid, your body is scanned with a machine called a gamma camera. The camera takes three-dimensional (3-D) pictures of your body to assess blood flow in the brain.

**Positron emission tomography (PET) scan** – You are injected with a radioactive glucose solution. This is absorbed by cancer cells at a faster rate than normal cells. The scan shows where these areas of active cancer are.

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

**Surgical biopsy** – If scans show an abnormality that looks like a tumour, your doctor may decide to remove some or all of the tissue for examination (biopsy). In some cases, the neurosurgeon is able to make a small opening in the skull and insert a needle to obtain a sample. In other cases, the neurosurgeon will remove part of the skull to access the tumour.

**Blood tests** – Blood tests may be done to see whether the levels of different hormones in the body are higher or lower than normal. These changes may be due to certain tumours in the brain.
Grading and staging tumours

Grading and staging tumours helps doctors decide on the best treatment for you.

Brain and spinal cord tumours are usually given a grade on a scale of 1 to 4. The grade is worked out by looking at the tumour cells and comparing them to normal cells. The tumour’s rate of growth and likeliness or ability to spread into nearby tissue is also assessed.

<table>
<thead>
<tr>
<th>Grades 1 and 2</th>
<th>These are the slowest-growing tumours. They are called low-grade tumours.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 3</td>
<td>Tumours grow at a moderate rate.</td>
</tr>
<tr>
<td>Grade 4</td>
<td>These are the fastest-growing tumours. They are called high-grade tumours.</td>
</tr>
</tbody>
</table>

Staging shows whether a tumour has spread from its original site, and if so, by how much. The doctor will determine this by doing CT or MRI scans, or by checking the cerebrospinal fluid. However, most CNS tumours don’t spread beyond the central nervous system.

Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis with your doctor if this is something you would like to know. However, it is not possible for any doctor to predict the exact course of your illness.
Both benign and malignant tumours can be life-threatening, but you may have a better prognosis if the tumour is benign, or if a surgeon is able to remove the entire tumour.

Test results, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as age, fitness and your medical history are all important factors in assessing your prognosis. In general, the younger you are, the better the prognosis is.

Some brain or spinal cord tumours can come back (recur), but treatment such as surgery or radiotherapy can often relieve symptoms for some time.

For information about the prognosis of children with brain or spinal cord tumours, see page 57.

**Which health professionals will I see?**

Your GP will probably arrange the first tests to assess your symptoms. This can be a worrying and tiring time, especially if you need several tests. You will usually be referred to a neurologist or a neurosurgeon who will arrange further tests and advise you about treatment options.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. You can ask your doctor or nurse for a referral or access to other services at any time. Your needs may change throughout treatment.
<table>
<thead>
<tr>
<th>Health professional</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>neurologist</td>
<td>diagnoses and treats diseases of the brain and nervous system</td>
</tr>
<tr>
<td>neurosurgeon</td>
<td>diagnoses and treats diseases and injuries in the brain and nervous system, and uses surgery to treat them</td>
</tr>
<tr>
<td>nurses</td>
<td>administer drugs and support you through all stages of your diagnosis and treatment</td>
</tr>
<tr>
<td>care coordinator</td>
<td>provides assistance and information through all stages of diagnosis and treatment</td>
</tr>
<tr>
<td>medical oncologist</td>
<td>prescribes and coordinates chemotherapy treatment</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>prescribes and coordinates radiotherapy treatment</td>
</tr>
<tr>
<td>dietitian</td>
<td>recommends the best eating plan to follow while you’re in treatment and recovery</td>
</tr>
<tr>
<td>social worker, psychologist and pastoral worker</td>
<td>link you to support services and help with emotional or practical issues</td>
</tr>
<tr>
<td>neuropsychologist, physiotherapist, speech therapist and occupational therapist</td>
<td>provide rehabilitation services and help with physical issues</td>
</tr>
</tbody>
</table>
Key points

- Many people diagnosed with a brain or spinal cord tumour have symptoms caused by the tumour, such as dizziness, headaches or difficulty walking.

- You will have many tests to diagnose the disease.

- A physical examination checks how different parts of your brain are working.

- Scans, such as CT and MRI, allow the doctor to see inside the brain. Other scans assess the function of neurons, blood flow in the brain, and whether there are active cancer cells in the central nervous system.

- You may also need a blood test to check the levels of hormones, and a biopsy, which removes some tissue for examination under a microscope.

- The tests help doctors diagnose the type of brain or spinal cord tumour you have, as well as its grade and stage.

- The grade shows how abnormal the cells are and how quickly the tumour is growing. The stage shows whether a tumour has spread from its original site.

- Many people want to know the likely outcome of their disease (prognosis). You will need to discuss this with your doctor, as it depends on many factors.

- You will see a range of health professionals who specialise in different areas of your treatment. You will usually be referred to a neurologist or a neurosurgeon.
The main treatments for brain or spinal cord tumours are surgery, radiotherapy and chemotherapy. These treatments may be used alone or in combination. Medication, such as steroids or anti-convulsants, may also be given to reduce symptoms. Treatment cannot begin until the diagnosis is confirmed.

The choice of treatment will depend on:
- the type, size and location of the tumour
- your age, medical history and general state of health
- the types of symptoms and side effects you have.

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

There are also many types of new and experimental treatments, or improvements in existing treatments, that are sometimes used. These are given in clinical trials. For more information about joining a trial, see page 44.

**Surgery**

Surgery in the central and peripheral nervous system is called neurosurgery. In many cases, removing all or part of the tumour may allow you to lead an active life for some time.

Some tumours can be removed completely by neurosurgery. This type of operation is called a gross total resection. In other cases, the surgeon may only be able to remove part of the tumour. This procedure is called a partial resection. This may be
because the tumour is widespread, near major blood vessels, or cannot be removed without damaging other important parts of the brain or spinal cord. A partial resection may improve your symptoms by reducing the pressure on your brain.

Sometimes a tumour cannot be removed because it would be too dangerous. This is called an irresectable or unresectable tumour. In this case, your doctor will talk to you about other treatment options to ease your symptoms.

**Preparing for surgery**
The types of scans used for diagnosing the tumour (e.g. CT, MRI, PET or MRS scans) are often done again to plan surgery by precisely pinpointing the location of the tumour.

You may also have what is called a functional MRI scan to help the doctors work out what areas of your brain control speech and movement. Brain mapping is another way to find these parts of the brain. Tiny electrodes are placed on the outside layer of the brain and stimulated with a low dose of electrical current. This allows doctors to work out where the brain’s sensitive areas are and try to avoid causing damage during surgery.

For one week before surgery, avoid taking any medication, including aspirin, herbal remedies or anti-inflammatory drugs, unless your doctors advise otherwise. Medication may interfere with the anaesthetic you are given during the operation and may cause you to bleed too much.
Surgery for a brain tumour
The surgeon will remove as much of the tumour as possible without damaging healthy parts of your brain. Surgery may be done as open surgery or stereotactic surgery. In open surgery, a relatively large opening needs to be made in the skull to access the tumour. In stereotactic surgery, only a small cut needs to be made (see next page).

Biopsy – A small sample of tumour tissue is removed and examined under a microscope. This is usually a diagnostic procedure but sometimes the entire tumour can be removed.

Craniotomy – The most common type of brain tumour operation. Some hair will be shaved off and you will be given a general anaesthetic. The surgeon will cut through the scalp and move it aside, then remove a piece of skull above the tumour. The bone and scalp are put back once the tumour is taken out.

Craniectomy – This is similar to a craniotomy except that the piece of skull that is removed for the operation is not replaced because the brain may swell. The bone may be replaced in the future when it won’t cause extra pressure.

Awake craniotomy – This operation is done if the tumour is near parts of the brain that control speech or movement. When the brain is exposed, the level of anaesthetic is reduced and the patient awakens (becomes conscious) so they can speak, move and respond. This is not painful because the brain itself does not feel pain, and local anaesthetic is used to numb surrounding tissues.
During the operation, the surgeon asks the patient to speak or move parts of the body so they can identify and avoid certain parts of the brain. Once the tumour is removed, the patient is given general anaesthetic again for the rest of the procedure.

**Endoscopic transnasal brain surgery** – This rarer type of surgery is used if the tumour is near the base of the brain, for example a pituitary gland tumour. The surgeon puts a long tube (endoscope) up the nose, then uses small tools to remove all or part of the tumour through the nostrils. This type of surgery has a faster recovery time and fewer long-term side effects than a craniotomy. You can also have further treatment, if needed.

**Stereotactic surgery**

Often surgery is done using a computer to guide the surgeon. This is called stereotactic surgery. It allows the surgeon to view 3-D images of the brain and tumour. It is safer, more accurate and requires a smaller cut in the skull than in open surgery.

These days, surgery is usually done using small markers called fiducial markers. This is known as a frameless procedure. The markers are taped or glued to the scalp before a scan. The scan shows the brain and tumour in relation to the markers.

The computer also keeps track of where the surgical instruments are, allowing the surgeon to operate precisely.

Less common is the use of a lightweight frame that is screwed to the scalp. The scan shows where the brain, tumour and instruments are in relation to the frame.
**Surgery for a spinal cord tumour**

The main surgery for a spinal cord tumour is called a laminectomy. In this procedure, the surgeon makes an opening through the skin, muscle and a vertebra in the spinal column to remove the tumour that is affecting the spinal cord. Afterwards, the vertebra is replaced. You will have a general anaesthetic for this operation.

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**After your brain or spinal cord operation**

- For the first 12–24 hours after the operation, you will be closely monitored. Nurses will regularly check your breathing, pulse, blood pressure, temperature, pupil size, arm and leg strength and function, and how aware (conscious) you are. These are called neurological observations. They show how your brain and body are recovering from the stress of the surgery.

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

- You may need to wear pressure stockings on your legs to prevent blood clots from forming. Tell your doctor if you have pain or swelling in your legs.
• If you are recovering from a craniotomy, your head will be bandaged for the first day and a small tube will drain excess blood from the operation site. Your face and eyes may be swollen or bruised, but this is not usually painful and should ease within about a week.

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

• If you have had an operation on your spinal cord, the nurses will regularly check the movement and sensation in your legs. You may need to rest flat in bed for 3–5 days to allow the wound to heal. A physiotherapist will help you learn how to roll over and how to get out of bed safely so the wound is not damaged further.

• The length of your hospital stay, changes to your speech or movement, and any other side effects will depend on the extent of the operation. Your doctor will tell you when you can start regular activities again. For more information, see the Rehabilitation chapter on page 38.

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

Debbie
Radiotherapy

Radiotherapy is a type of treatment that uses high-energy x-ray beams to kill or damage cancer cells. The radiation is specifically targeted at the treatment site to reduce the risk of damage to healthy cells. The treatment is painless.

Before your treatment begins, you will need to have an appointment to plan it. This is often called a simulation appointment because you will be put in the exact position needed for your treatment.

Your doctor will take measurements of your body, as well as doing an x-ray or CT scan, to work out the precise area to be treated. Several permanent marks (tattoos) the size of a small freckle may be placed on your skin. You may also have a mask made to fit your face. These measures ensure that the same area of your brain or spinal cord is treated every time.

The face mask – also called a cast – helps keep the head in position when treating the head or neck. It is a tight-fitting mesh, but you will have no difficulty breathing or seeing through it and you will only wear it for about 10 minutes at a time during treatment. However, let your doctor know if wearing the mask makes you uncomfortable.

Your radiotherapy treatment will probably start a few days after your planning session. It is usually given once daily, from Monday to Friday, for several weeks. However, the course of your treatment will depend on the size and type of the tumour.
Stereotactic radiosurgery
Stereotactic radiosurgery is a type of radiation therapy, not a type of surgery. It is a non-invasive treatment that uses high doses of precisely targeted radiation to treat a brain tumour in a single hospital visit. The treatment is so accurate that surrounding areas of healthy brain tissue are not affected. The patient is usually able to return home the same day as treatment.

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

Radiotherapy for children
Radiotherapy is rarely used for children under the age of five because high-dose therapy can affect a child’s brain (intellectual) development. If a child receives radiotherapy, it is given at a lower dose than the dose given to adults.

Radiotherapy to the spine and head can slow a child’s physical growth too. It can either reduce the growth of the bones, or affect the work of the pituitary gland, which produces growth hormones. Children may later need hormone therapy to help them grow and develop.

Your child’s health care team will discuss treatment options and possible short- and long-term side effects with you before treatment starts.
Side effects
Radiotherapy causes many possible side effects. Side effects tend to peak about 1–3 weeks after treatment has ended, so it is important to have a follow-up session with your doctor within this time. Most side effects occur in the treatment area and are temporary, but some may be permanent or last for a few months or years. Talk to your doctor before treatment for more information.

Some common short-term side effects include:
- nausea
- headaches
- tiredness or fatigue
- hair loss in the treatment area
- red, sore, inflamed or flaky skin in the treatment area.

Some people experience late-stage side effects, which can occur several years after treatment. These can include confusion or difficulty thinking clearly and remembering things (cognitive impairment) and personality changes. It is not always clear if these changes are caused by radiotherapy or damage in the brain due to the tumour. If you experience these symptoms, you may benefit from rehabilitative therapy (see page 38) or medication.

Many side effects – short-term side effects in particular – can be treated effectively with medication. Talk to your doctor about how to manage side effects.

For more information on coping with side effects from treatment, call 13 11 20 for Cancer Council’s free booklet on radiotherapy.
Chemotherapy

Chemotherapy is the use of cytotoxic drugs to treat cancer. The drugs travel through the blood around the body. The aim is to damage or destroy rapidly dividing cells such as cancer cells while causing the least possible damage to healthy cells. However, some healthy fast-growing cells, such as your hair cells, may also be affected, causing side effects.

It can be difficult to treat brain tumours with chemotherapy drugs because the body has a protection system called the blood-brain barrier. This guards the brain from substances circulating in the blood, such as germs or chemicals, that could harm it. Only certain drugs can get through this barrier.

You may be given chemotherapy through a drip inserted into your vein (intravenously) or by taking an oral capsule. Each treatment session is usually followed by a rest period of a few weeks. This allows your body to recover from any side effects.

Some patients who have a craniotomy have small, dissolvable chemotherapy wafers inserted into their brain during surgery. The wafers release drugs into the brain over a couple of weeks. As the drug is placed directly at the tumour site, it doesn't affect other areas of the body and so reduces the chance of side effects.

Chemotherapy is often combined with radiotherapy for the treatment of some types of brain tumours, such as gliomas. This combination improves the effects of radiotherapy treatment.
Side effects
The way your body reacts to chemotherapy will be monitored carefully through regular blood tests. Your treatment schedule may be changed when your doctor sees how you are responding to the drugs.

There are many possible side effects of chemotherapy. Whether they occur depends on the type of drugs you are given and how you react. Some of these side effects may include:
- tiredness, fatigue and lack of energy
- nausea, vomiting or loss of appetite
- diarrhoea or constipation
- hair loss
- mouth sores and ulcers
- a tingly feeling (nerve or muscle damage)
- breathlessness due to low red blood cells levels (anaemia)
- increased risk of infections.

These problems can be managed. For example, you may be given medication at the same time as chemotherapy to prevent nausea. Ask your doctor what side effects to expect and how to control them. You can also read Cancer Council’s free booklet about chemotherapy, available by calling 13 11 20.

Steroids are made naturally in the body, but they can also be produced artificially and used as drugs. One use is to reduce swelling in the brain. They may be given before, during or after surgery, or during radiotherapy.

The side effects that people get depend on the dose and the length of their treatment. Most side effects are temporary and will disappear as the medication dose is reduced.

Steroids given for a short time may cause increased appetite, weight gain, insomnia, restlessness and mood swings. If you have trouble sleeping, it may help to take the drugs in the morning.

If taken for several months, steroids can cause puffy skin (fluid retention or oedema) in the feet, hands or face; high blood pressure; unstable blood sugar levels; diabetes; or muscle weakness. You are also more likely to get infections.

Your medical team will monitor your treatment, and will change your dose when required. If you are worried about side effects, talk to your doctor.
Seizures
A tumour may cause seizures, which are disruptions to the normal patterns of electrical impulses in the brain. Seizures are sometimes called fits or convulsions. They can often be prevented with anti-convulsant medication (also called anti-epileptic or anti-seizure medication) – see the next page.

• Generalised seizures – These types of seizure typically affect the whole body. The most common type is called a tonic-clonic seizure (previously known as a grand mal seizure). A seizure often starts with a sudden cry, followed by the person falling down and losing consciousness. The person's muscles may twitch violently and their breath may be shallow for up to two minutes.

First-aid tips to help someone having a seizure

• Remain calm and stay with the person, but do not restrain them or put anything in their mouth.
• Time the seizure.
• Protect the person from injury (e.g. by moving hazards or placing a soft pillow under their head and shoulders).
• Lie the person on their side as soon as possible, or right away if they have vomited. This is important if they are unconscious or have food or fluid in their mouth.
• Call an ambulance (000) if the seizure lasts more than five minutes, if multiple seizures occur, or if anyone is injured.
• Talk to the person and explain what has occurred. In some cases, people are confused after a seizure.
• Observe and reassure the person until they have recovered or the ambulance arrives.
• If the seizure occurs while a person is in a wheelchair or car, support their head and leave them safely strapped in their seat until the seizure is over. Afterwards, remove them from their seat, if possible, and roll them onto their side if there is food, water or vomit in their mouth. If help is needed, call an ambulance immediately.
• For more detailed information about seizures, contact Epilepsy Action Australia on 1300 374 537 or visit www.epilepsy.org.au.

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

After a seizure, a person may be confused and is often very tired. It is important that they are able to rest.

**Anti-convulsant medications**
There are many types of anti-convulsant drugs, which are used to prevent seizures. You may have blood- and liver-function tests while you are taking them. This is to check whether the dose is effective and how your liver is coping with the medication.
Side effects vary and may include tiredness, weight changes, gum problems, tremors, nausea or vomiting, and depression. Some people are allergic to anti-convulsants and may get a rash. Tell your medical team if you have any skin changes or other side effects, or if the medication does not seem to be working for you.

Your doctor can adjust your dose to reduce any side effects, or can give you another type to try. It is important not to stop taking the medicine or change the dose without your doctor’s advice.

**Palliative treatment**

Palliative treatment helps to improve quality of life by controlling the symptoms of a brain or spinal cord tumour. It is not focused on finding a cure. It is particularly important for people with aggressive or advanced tumours, but it isn’t just for end-of-life care. It can be used at different times.

Often treatment is concerned with pain relief and managing other physical symptoms. Treatment may include radiotherapy, chemotherapy or other medication. Palliative care also involves providing emotional support and rehabilitation.

Call the Cancer Council Helpline for more information.
Key points

- The main treatments for brain or spinal cord tumours are surgery, radiotherapy and chemotherapy.

- Some tumours can be completely removed in a gross total resection. Others can only be partially removed. This is a partial resection.

- Different types of surgery are used for different types of tumours. The most common brain surgery is a craniotomy. A laminectomy removes tumours from the spinal cord.

- Stereotactic surgery is when a computer guides the surgeon so the surgery is more precise.

- Radiotherapy uses x-rays to kill cancer cells. It is rarely used for children under five. You will have a simulation appointment so the doctor can work out exactly where to direct the radiation.

- Radiosurgery is a type of radiotherapy that precisely targets the treatment area in a single hospital visit.

- Chemotherapy is the use of drugs to destroy or kill cancer cells. You may be given chemotherapy orally, intravenously, or as wafers that are placed directly in the brain during surgery.

- Other treatments include steroids to reduce brain inflammation, and anti-convulsants to stop seizures occurring.

- Treatments may cause short- and long-term side effects. Talk to your doctors and nurses about managing symptoms and side effects, including getting rehabilitation.
Rehabilitation

A brain or spinal cord tumour – or treatment for it – may affect some of the normal functions of the body and brain, such as speech, personality, memory, movement, balance and coordination. You or your family may notice changes in your thinking and behaviour, such as how easily you can have a conversation or how you respond emotionally in certain situations. If you or your family members have noticed some changes, talk to your doctor, nurse or care coordinator.

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

School-aged children with brain tumours may benefit from tutoring as part of their rehabilitation. Talk to the student welfare coordinator, school counsellor or the principal of your child’s school. You can also ask the medical team for information about how the tumour and treatment may have affected your child’s learning and thinking ability.

Cancer Institute NSW has fact sheets to help people and families affected by a brain tumour. The fact sheets cover a range of topics such as anxiety, anger, social behaviour, thinking problems, memory and concentration. Call (02) 8374 5600 or go to the website www.cancerinstitute.org.au/publications/brochures-and-fact-sheets.
Types of rehabilitation

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

**Physiotherapy** – In some cases, physiotherapy can help you to learn how to move more easily. It can also help you to develop, maintain or regain strength and balance. Moving and strengthening your muscles can help reduce tiredness.

If you can’t move easily, you may be able to learn compensation techniques, such as using a walking stick. You may also be given advice on how to exercise safely and stimulate parts of your body to improve circulation and reduce swelling.

**Speech therapy** – If your ability to talk has been affected, a speech pathologist may be able to help. Speech pathologists also work with people who have difficulty swallowing (dysphagia), which can cause problems with speaking or eating.

**Occupational therapy** – This helps you increase or maintain your independence using your individual abilities.

**Assistance for the vision impaired** – Some people may lose some or all of their sight as a result of a brain tumour or surgery. Vision Australia can help people learn how to live independently with low or no vision. For more information, call 1300 847 466 or go to www.visionaustralia.org.
Driving

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

You must inform your driver licensing authority that you have a tumour, especially if you have had brain surgery or have had seizures in the past six months. The licensing authority will request information from your doctor to help decide if you are medically fit to drive.

You may have an occupational therapy driving assessment. This will help determine the type of difficulties you are experiencing while driving (for example, a slow reaction time). If you hold different classes of licence (e.g. car, motorcycle or truck) you will need to be assessed separately in each of these types of vehicle.

The focus of a driving assessment is not to cancel or suspend your licence. In some cases, an occupational therapist is able to teach you driving techniques to address your weaknesses or instruct you on how to use car modifications (such as additional mirrors). You may also be able to drive with restrictions, such as only in daylight or only short distances from home.

Some people feel upset or frustrated if they are no longer able to drive or they have restrictions placed on their licence. These reactions are natural and understandable.
Changes in your ability to drive can affect your sense of independence and may impact on your family too. However, it may help to remember that the decision is made for your safety and well-being. It is also made for the safety of passengers and other road users. If you have to stop driving, you may want to talk to a counsellor or someone who has been through a similar experience (see page 54).

Depending on your situation and your ongoing health, you may be able to return to driving at a later stage.

Call the Cancer Council Helpline on 13 11 20 for Cancer Institute NSW’s brochure *Brain Tumours and Driving* or download it from their website, www.cancerinstitute.org.au.

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**If your licence changes**

If your licence has been suspended or cancelled, but you keep driving, you may be fined. If you have an accident whilst driving, you could be charged with a criminal offence and your insurance policy will no longer be valid.

If your license has restrictions but you ignore them or drive unsafely, your licence may then be suspended or cancelled.
Making treatment decisions

Sometimes it is difficult to decide on the right treatment as there are often many factors to consider. You may feel that everything is happening so fast that you don’t have time to think things through properly. Ask your doctor how much time there is for you to decide what kind of treatment to have.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, others want as much information as they can find. Making sure you understand enough about your disease, the treatment and its side effects will help you make your own decisions.

- If you are offered a choice of treatments, you will need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, particularly those that affect your lifestyle.
- If you have a partner, you may also want to talk about options with them. You can also talk to friends and family.
- If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.

You have the right to accept or refuse any treatment.

Some people with more advanced or aggressive tumours will choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects so that they have the best possible quality of life. Some people may choose options that don’t try to cure the disease but make them feel as well as possible.
Talking with doctors

When your doctor first tells you that you have cancer it is very stressful and you may not remember many details about what you are told. You may be able to see the doctor a few times before deciding on treatment. Ask if this is possible.

If your doctor uses medical terms you don’t understand, it’s okay to ask for a simpler explanation. You can also check a word’s meaning in the glossary (see page 63).

Before you see the doctor it may help to write down your questions – see the list of suggested questions on page 62. Taking notes or recording the discussion can also help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor’s recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.
Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You may decide you would prefer to be treated by the doctor who provided the second opinion.

**Taking part in a clinical trial**
Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments to see if they are better than current treatments. Over the years, clinical trials have improved treatment standards and led to better outcomes for patients with CNS tumours. All trials must be approved by an ethics committee before they begin.

If you decide to join a randomised controlled trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other. You may be monitored more frequently than if you were not on a trial.

Being part of a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your treatment. If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

For more information about clinical trials, such as how to find a suitable trial or what questions to ask your doctor, call 13 11 20. You can also visit the website www.australiancancertrials.gov.au.
Having a brain or spinal cord tumour can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and improve well-being. Addressing changes in the way you are feeling and behaving is also important.

**Healthy eating**
Eating nutritious food will help you to keep as well as possible, and cope with having a tumour and any treatment side effects. Depending on how the tumour and treatment has affected you (for example, how easily you can chew and swallow), you may have special dietary needs. A dietitian can help you plan the best foods and supplements for your situation. The Cancer Council Helpline can also send you free information about nutrition and tips for eating during and after treatment.

**Being active**
You will probably find it helpful to stay active and to exercise regularly if you are able to. Physical activity – even if gentle or for a short duration – helps to improve circulation, reduce tiredness and elevate mood.

If you aren’t used to exercise or haven’t exercised for awhile, make small changes to your daily activities. You might be able to walk to the shops, take the stairs, or do some gardening. The amount and type of activity you do will depend on what you are capable of and how well you feel. Ask your doctor, physiotherapist and/or occupational therapist for advice.
Complementary therapies

Complementary therapies are treatments that may help you cope better with side effects such as pain or tiredness. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, including acupuncture, massage, relaxation, meditation and herbal medicine. While some cancer treatment centres offer complementary therapies as part of their services, you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through some different techniques.

Let your doctor know about any complementary therapies you are thinking about trying or that have been recommended by family or friends. While many can be useful during or after cancer treatment, some therapies may not be appropriate, depending on the conventional treatment that you are having.

For example, herbs and nutritional supplements may change the way medication or chemotherapy work, resulting in harmful side effects. Massage, acupuncture and exercise therapies may also need to be modified if you have lowered immunity or low blood platelet levels.

Call the Cancer Council Helpline on 13 11 20 for more information and free complementary therapies resources.
**Relationships with others**

The strong emotions you experience as a result of a brain or spinal cord tumour may affect your relationships. This is particularly so if the tumour has caused behavioural changes that affect your mood, memory or fatigue levels. Having a tumour may also cause you to make some changes in your life or develop a new outlook on your values, priorities and life in general.

Sharing your thoughts and feelings with your family and friends may strengthen your relationships. If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after your treatment. If you find your behaviour causes conflict in your family, it may be beneficial to speak to someone outside the family such as a counsellor or a friend. There are strategies you can use, such as having a routine or going for walks, to reduce your frustrations or difficulties.

While you are giving yourself time to adjust to having a brain or spinal cord tumour, do the same for your friends and family. Everyone will react in a different way – by putting on a happy face, playing down your anxiety, or even ignoring you. They are also adjusting in their own way to changes. It can be helpful to acknowledge that family members are probably feeling considerable stress as well.

If someone’s behaviour upsets you, it may help to discuss how you both feel about the situation.
**Sexuality, intimacy and cancer**

Having a brain or spinal cord tumour can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, and your mood and self-confidence. Talk to your doctor about any possible changes that might be caused by the tumour or treatment, and what can be done about them. Knowing the potential challenges and addressing them as soon as you can will help you adjust to these changes.

Some people with cancer have the support of a partner, while others do not. If you meet a new partner during or after treatment, it can be difficult to talk about having a tumour, as well as any sexuality issues it might have caused. It is probably wise to wait and see if a relationship develops before sharing these personal concerns.

Sexual intercourse may not always be possible during and after treatment, but closeness and sharing are important to a healthy relationship. Call the Cancer Council Helpline for resources about sexuality, intimacy and cancer.

**Contraception**

Depending on the type of tumour and treatment you have, your doctors may advise you to use certain types of contraception, such as condoms, for a period of time during and after treatment. This is both to protect your partner and because of possible harm to the baby if you or your partner were to become pregnant.
Changing body image

Treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not. It may be because you have had to give up work or you can no longer drive. You might feel self-conscious about changes in the way you talk, eat or walk.

Give yourself time to adapt to any changes, and remember that over time and with rehabilitation, you may regain some of your abilities and feel more confident about yourself. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

For practical suggestions about physical changes, such as hair loss and weight changes, call the Cancer Council Helpline.

Look Good… Feel Better program

This free program teaches techniques to help restore appearance and self-esteem during treatment.

Call 1800 650 960 or visit www.lgfb.org.au.
Life after treatment

You may be surprised to find out that life after treatment for a brain or spinal cord tumour can present its own challenges. You will need to take some time to adjust to physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than secure. You might worry about every ache and pain and wonder if the tumour is coming back. It is not uncommon to feel depressed both during and after treatment for a brain tumour.

Although you might feel pressure to get back to your normal life, it’s important to remember you may not want or be able to return your life to how it was before you were diagnosed.

You might find it helpful to:
- re-establish a new daily routine at your own pace
- maintain a healthy diet and lifestyle
- schedule regular checkups with your doctor
- share your concerns with family and friends and tell them how to support you
- call the Cancer Council Helpline on 13 11 20 to find out if you can connect with other people who have had a brain or spinal cord tumour, and for information about life after cancer.

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that
previously gave you pleasure, talk to your doctor. You may be clinically depressed, and counselling or medication may help.

The organisation beyondblue also has information about coping with depression and anxiety caused by a brain tumour. Go to www.beyondblue.org.au or call 1300 224 636 to order a fact sheet.

**After treatment: follow-up**
Depending on the aims and outcome of your treatment, afterwards you will need to have regular checkups to see whether the tumour has come back or grown. You may need blood tests, x-rays or other scans, and physical examinations. Checkups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any health problems.

**What if the tumour returns or grows bigger?**
For some people, a brain or spinal cord tumour does come back or continues growing after treatment. If the tumour returns, this is known as a recurrence. It is important to have regular checkups with your doctor to monitor your health.

If the tumour returns, talk to your doctor about your treatment options. Some people choose to have treatment; others decide not to have any. Your subsequent treatment will depend on your situation and the treatments you have already had. For example, people who have had radiotherapy cannot have this treatment again, whereas they may be able to have surgery more than once.
When you are first diagnosed with a brain tumour, and throughout the different stages of your treatment and recovery, it is normal to experience a range of emotions, such as fear, sadness, anxiety, anger and frustration. If sadness or anxiety is ongoing or severe, talk to your doctor, nurse or care coordinator.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:

- members of your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 54
- the Cancer Council Helpline.

If you need assistance, such as help around the house, it may be hard to tell people what would be useful. Some people prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people you know are supportive, others may not even know what to say to you. Cancer Council has resources about coping with your emotions and communicating about cancer – call 13 11 20.

“Calling the Helpline after I was diagnosed helped me take in the new information. I eventually joined a support group, which was also a great help.”  

Patient
**Practical and financial help**

A serious disease often causes practical, financial and legal issues. This can add to the stress and anxiety you may already be feeling about having a tumour and going through treatment. Many services are available to help so you don't have to face these difficulties alone:

- Financial or legal assistance, through benefits, pensions and programs, can help pay for prescription medicines, transport costs to medical appointments, utility bills or basic legal advice.
- Home nursing care is available through community nursing services or local palliative care services.
- Meals on Wheels, home care services, aids and appliances can make life easier.
- Rural patients may be able to get subsidised travel and accommodation.

To find out more, talk to the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline.

**Learning more about cancer**

If you want to find out more about cancer and coping with it, ask your local Cancer Council or hospital about any education programs or seminars for patients and families.

Programs cover issues such as symptoms, treatment, side effects, diet, palliative care and complementary therapies. Attending a program may also allow you to meet other people with cancer.
**Talk to someone who’s been there**

Getting in touch with other people who have been through a similar experience to you can be beneficial. There are many ways for you and your family members to contact others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Ask your nurse or social worker to tell you about support groups in your area. Call the Helpline to access the Cancer Services Directory and find out how you can connect with others.

**Support services available in your community**

- **Face-to-face support groups** – often held in community centres or hospitals
- **Online discussion forums** – where people can connect with each other any time – see www.cancerconnections.com.au
- **Telephone support groups** – for certain situations or types of cancer, which trained counsellors facilitate
- **Cancer Council Connect** – a confidential peer support telephone service connecting you with a trained volunteer who has had a similar cancer experience.
Cancer Council library*

Following a diagnosis of a brain or spinal cord tumour, or another type of cancer, many people look for information about new types of treatment, the latest research findings and stories about how other people have coped.

Your local library or support group may have some relevant and useful resources. Cancer Council also has a range of books, CDs, DVDs and medical journals that may be helpful for you and your family. The librarian may be able to suggest books from a recommended reading list.

Call the Cancer Council Helpline to find out how to access the library service.

*This service is not available in Victoria and Queensland.

Other resources

Cancer Council Australia and the Clinical Oncological Society of Australia have published a guide for patients and families about adult gliomas (astrocytomas and oligodendrogliomas).

For a copy, call the Cancer Council Helpline on 13 11 20.

Brain Tumour Alliance Australia provides a free copy of the American Brain Tumor Association’s Brain Tumor Primer: a comprehensive introduction to brain tumors to patients and families.

Contact 1800 857 221 to order this detailed resource.
You may be reading this booklet because you are caring for someone with a brain or spinal cord tumour. Being a carer can be very stressful.

Try to look after yourself – give yourself some time out and share your worries with somebody neutral such as a counsellor, your doctor or a close friend. Ask your relatives and friends for help – they may be able to do some shopping or housework, cook some meals, or give you a short break so you can rest or attend to your own health or day-to-day needs.

Many cancer support groups are open to carers as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many organisations and groups that can provide you with information and support, such as Carers Australia. Go to www.carersaustralia.com.au or call 1800 242 636 (free call) for telephone support and information.

Call the Cancer Council Helpline to find out more about different services or to request free information for carers.

“"It was very hard work, but I found caring for my mother at home was one of the best things I could have done for her in her greatest time of need." Carer
Caring for a child

Prognosis

The outcome for your child depends on the type of tumour they have, its location and grade, treatment, and other factors such as their overall health.

A significant number of children with a brain or spinal cord tumour will recover completely. In general, malignant tumours in children have a better outlook than in adults. Other children have treatment that controls their tumour for many years.

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

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

Should I tell my child?

It is natural to want to protect your child from the news of the diagnosis, but children are quick to listen, observe and learn. Doctor’s visits, tests, and absences from school or activities will let them know that something is different.

Talking openly about the tumour will help your child to be less anxious and to feel more in control of the situation. What you tell your child will depend on their age and knowledge.
Newborns, infants and toddlers

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

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

Preschool children, 3–5 years

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

- Assure your child that their thoughts and behaviour have not caused the illness.
- Be honest when talking about the tests and treatments that they need.
- Reassure your child about your love and care for them.
- Bring familiar toys and books to appointments and the hospital.
### School-age children, 6–12 years

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

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

### Teenagers, 13–18 years

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

- Provide resources so they can learn more about the diagnosis and treatment of tumours, and get valuable peer and adult support.
- Talk to the school’s student welfare coordinator, who may be able to organise or provide extra tutoring or support.
- Encourage teenagers to talk about their feelings but realise they may find it easier to confide in friends, teachers and other trusted people.
Try to keep things normal
One of your child’s most important needs will be for as many things as possible to stay normal and consistent. It is important to continue to show your love and support. It may help to keep rules and discipline as normal as possible. Although you may be tempted to relax the rules, this can lead to confusion over time.

A tumour diagnosis can also be difficult for other children in the family. They may feel left out, as parents are constantly caring for the sick child, and visitors may show more attention to their sibling. Their routines are disturbed and they may be cared for by other people while their parents are at the hospital. Try to make time to talk to all your children – ask them how they’re coping and thank them for their patience and help.

If your teenager has been diagnosed with a tumour, it can be hard not to be protective at a time when they want to be independent. Talk about finding a balance between maintaining regular activities, going out with friends and staying at home.

Who is available to help?
Many hospital staff members specialise in working with children and young adults (paediatrics). Some hospitals employ play therapists, music therapists or art therapists who can help children cope with the challenges of treatment. Rehabilitation will also be important for your child’s recovery (see page 38).

CanTeen and Redkite offer practical and emotional support for families and children. See the next page for website details.
The Internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

### Australian

<table>
<thead>
<tr>
<th>Website</th>
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<tbody>
<tr>
<td>Cancer Council Australia</td>
<td><a href="http://www.cancer.org.au">www.cancer.org.au</a></td>
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<tr>
<td>Brain Australia</td>
<td><a href="http://brainfoundation.org.au">http://brainfoundation.org.au</a></td>
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<tr>
<td>Brain Cancer Action</td>
<td><a href="http://www.braincanceraction.com.au">www.braincanceraction.com.au</a></td>
</tr>
<tr>
<td>Brain Tumour Alliance Australia</td>
<td><a href="http://www.btaa.org.au">www.btaa.org.au</a></td>
</tr>
<tr>
<td>Brain Tumour Australia Information</td>
<td><a href="http://www.btai.com.au">www.btai.com.au</a></td>
</tr>
<tr>
<td>Cooperative Trials Group</td>
<td><a href="http://www.cogno.org.au">www.cogno.org.au</a></td>
</tr>
<tr>
<td>Cancer Institute NSW</td>
<td><a href="http://www.cancerinstitute.org.au">www.cancerinstitute.org.au</a></td>
</tr>
<tr>
<td>Can Assist</td>
<td><a href="http://www.canassist.com.au">www.canassist.com.au</a></td>
</tr>
<tr>
<td>CanTeen</td>
<td><a href="http://www.canteen.org.au">www.canteen.org.au</a></td>
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<tr>
<td>Camp Quality</td>
<td><a href="http://www.campquality.org.au">www.campquality.org.au</a></td>
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<tr>
<td>Redkite</td>
<td><a href="http://www.redkite.org.au">www.redkite.org.au</a></td>
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<tr>
<td>beyondblue</td>
<td><a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a></td>
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### International

<table>
<thead>
<tr>
<th>Website</th>
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<tbody>
<tr>
<td>American Brain Tumor Association</td>
<td><a href="http://www.abta.org">www.abta.org</a></td>
</tr>
<tr>
<td>American Cancer Society</td>
<td><a href="http://www.cancer.org">www.cancer.org</a></td>
</tr>
<tr>
<td>National Brain Tumor Society</td>
<td><a href="http://www.braintumor.org">www.braintumor.org</a></td>
</tr>
<tr>
<td>Macmillan Cancer Support</td>
<td><a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a></td>
</tr>
<tr>
<td>Spinal Cord Tumour Forum</td>
<td><a href="http://www.spinalcordtumour.co.uk">www.spinalcordtumour.co.uk</a></td>
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</table>
You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don’t understand, it is okay to ask for clarification.

- What type of brain or spinal cord tumour do I have? Is it benign or malignant?
- How extensive is the tumour?
- What treatment do you recommend and why?
- Are the latest tests and treatments for this type of tumour available in this hospital?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take?
- How much will treatment cost? Can I get any financial support? Is there any practical assistance for people living in rural areas?
- Will I have a lot of pain with the treatment? What will be done about this?
- How will the treatment affect what I can do? Will the treatment affect my sex life?
- Are there any precautions I need to take while having treatment, for example, if I have chemotherapy?
- Are there any clinical trials of new treatments?
- How frequently will I have checkups?
- What can I expect in the future?
- Are there any complementary therapies that might help me?
- What do you think about these complementary or alternative treatments that friends or relatives have told me about?
You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words on Cancer Council’s website at www.cancercouncil.com.au/words.

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

**astrocyte**
A type of glial cell.

**astrocytoma**
A type of malignant brain tumour.

**benign**
Not cancerous or malignant.

**biopsy**
The removal of a small sample of tissue from the body to examine under a microscope to help diagnose a disease.

**central nervous system**
The brain and spinal cord.

**cerebellum**
The largest part of the brain. It is responsible for the coordination of voluntary movements.

**cerebrospinal fluid**
Clear, watery fluid surrounding the brain and spinal cord.

**cerebrum**
The front part of the upper brain.

**chemotherapy**
The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

**continence**
Ability to control urination and bowel movements.

**cranio-pharyngioma**
A type of benign brain tumour.

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

**craniotomy**
Similar to a craniectomy but the bone is replaced afterwards.
CT scan
A computerised tomography scan. This scan uses x-rays to build a picture of the body.

Cystic astrocytoma
A type of benign brain tumour.

ependymoma
A type of malignant brain tumour.

glioblastoma
A type of malignant brain tumour.

Grade
The degree of abnormality of cancer cells.

Hydrocephalus
The build-up of cerebrospinal fluid in the brain.

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

Irresectable
Not able to be surgically removed. Also called unresectable.

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

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

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

Malignant transformation
When a benign tumour is damaged and becomes a rapidly growing, cancerous tumour.

Meninges
The membranes surrounding the brain and spinal cord.

Meningioma
A type of benign brain tumour.
metastasis
A cancer that has spread from another part of the body. Also called a secondary cancer.

mixed glioma
A type of malignant brain tumour.

motor neuron
A type of neuron that causes muscle contractions.

MRI scan
A magnetic resonance imaging scan. This scan uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

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

neuroma
A type of benign brain tumour.

neuron
A cell that transmits electrical impulses that carry information from one part of the body to the other. The three types of neurons are sensory neurons, motor neurons and interneurons.

neuropsychologist
A psychologist who specialises in helping people with brain impairments.

neurosurgeon
A surgeon who specialises in operations on the nervous system.

oligodendrocyte
A type of glial cell.

oligodendroglioma
A type of malignant brain tumour.

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

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

pituitary tumour
A type of benign brain tumour.

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

**prognosis**
The likely outcome of a person’s disease.

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

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

**resectable**
Able to be surgically removed.

**secondary cancer**
See metastasis.

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

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

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

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

**spinal tap**
See lumbar puncture.

**stereotactic surgery**
Surgery done using a computer to guide the surgeon.

**stereotactic radiosurgery**
Highly focused, precisely targeted radiotherapy done in a single day treatment.

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

**vertebrae**
The bones or segments of the spinal column that protect the spinal cord.
How you can help

At Cancer Council we’re dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

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

**Make a donation:** Any donation, whether large or small, will make a meaningful contribution to our fight to defeat cancer.

**Buy sun protection products from our website or retail stores:** Every purchase helps you prevent cancer and contributes financially to our work.

**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 cancer issues and help us defeat cancer by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council does research to investigate the causes, management, outcomes and impacts of different cancer types.

To find out more about how you or your family and friends can help, please call your local Cancer Council.
Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

### Regional offices

<table>
<thead>
<tr>
<th>Region</th>
<th>City</th>
<th>Ph:</th>
</tr>
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<tbody>
<tr>
<td>Central and Southern Sydney</td>
<td>Woolloomooloo</td>
<td>(02) 9334 1900</td>
</tr>
<tr>
<td>Central Coast</td>
<td>Erina</td>
<td>(02) 4336 4500</td>
</tr>
<tr>
<td>Far North Coast</td>
<td>Alstonville</td>
<td>(02) 6627 0300</td>
</tr>
<tr>
<td>Hunter</td>
<td>Broadmeadow</td>
<td>(02) 4923 0700</td>
</tr>
<tr>
<td>Mid North Coast</td>
<td>Coffs Harbour</td>
<td>(02) 6659 8400</td>
</tr>
<tr>
<td>Northern Sydney</td>
<td>Crows Nest</td>
<td>(02) 9334 1600</td>
</tr>
<tr>
<td>South West</td>
<td>Wagga Wagga</td>
<td>(02) 6937 2600</td>
</tr>
<tr>
<td>North West</td>
<td>Tamworth</td>
<td>(02) 6763 0900</td>
</tr>
<tr>
<td>Southern</td>
<td>North Wollongong</td>
<td>(02) 4223 0200</td>
</tr>
<tr>
<td>Western</td>
<td>Orange</td>
<td>(02) 6392 0800</td>
</tr>
<tr>
<td>Western Sydney</td>
<td>Parramatta</td>
<td>(02) 9354 2000</td>
</tr>
</tbody>
</table>
For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancercouncil.com.au