



Understanding Brain Tumours

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

Cancer
information

Cancer Council Helpline

13 11 20

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

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Understanding Brain Tumours is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain appropriate independent professional advice relevant to your specific situation and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council 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, and primary and secondary tumours.

Many people feel understandably 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 give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

This information was developed with help from a range of health professionals and people who have been diagnosed with brain and spinal cord tumours. It does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your family and friends for their information.

If you're reading this book for someone who doesn't understand English, let them know that Cancer Council Helpline **13 11 20** can arrange telephone support in different languages. They can also call the Translating and Interpreting Service (TIS) direct on **13 14 50**.



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What is cancer?

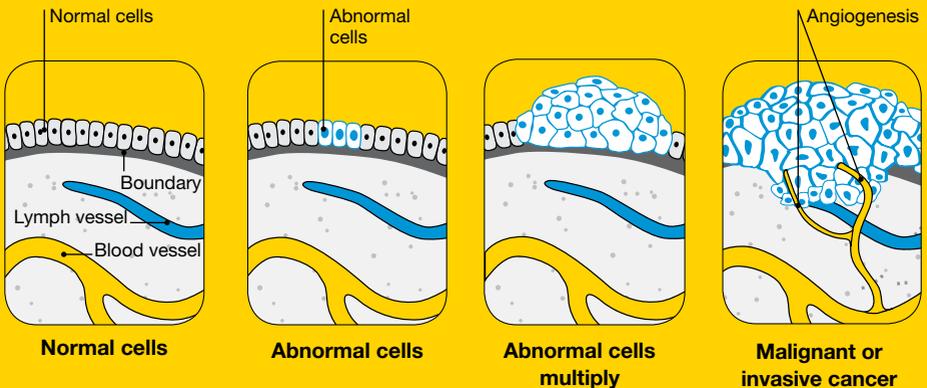
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through surrounding tissue and, for some cancers, through the blood or lymphatic system.

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis).

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

How cancer spreads

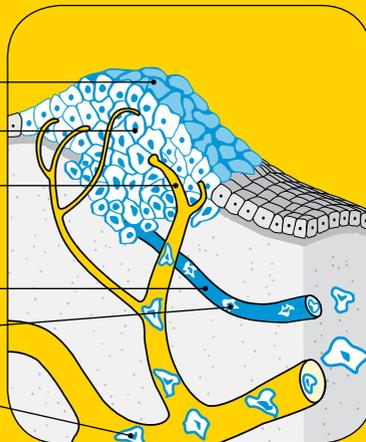
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

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





The brain and spinal cord

The brain and spinal cord make up the central nervous system (CNS). The CNS receives messages from cells called nerves, which are spread throughout the body (in the peripheral nervous system). The brain interprets information and relays messages through the nerves to muscles and organs.

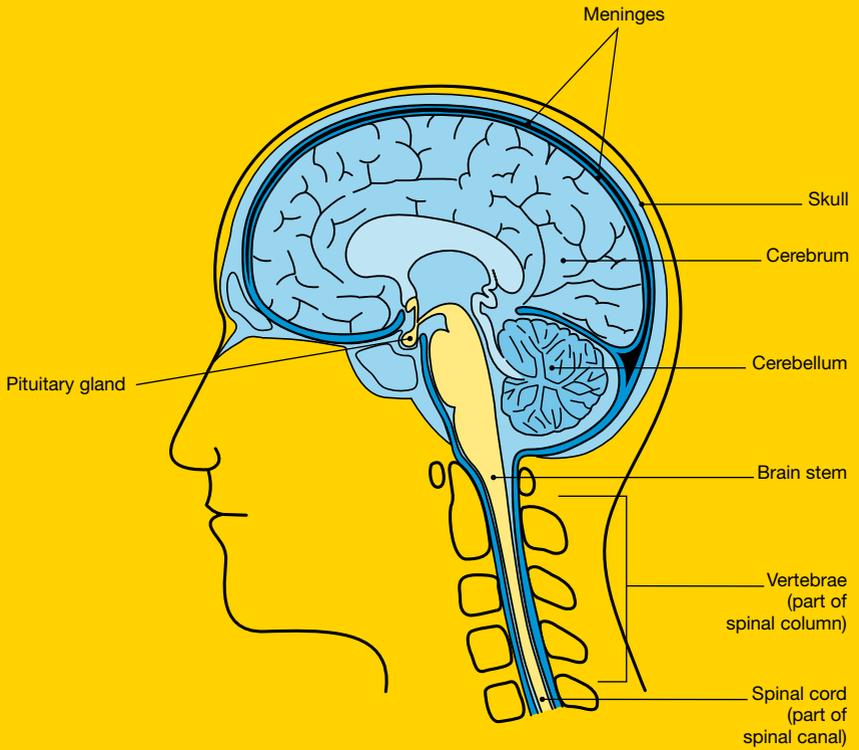
The brain is the one of the most important organs in the body because it controls all voluntary and involuntary processes, such as moving, learning, sensing, imagining, remembering, breathing, blood circulation and heart rate, body temperature, digestion, and bowel and bladder control (continence).

The 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 essential functions. 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 lies in the spinal canal. Bony vertebrae (spinal column) protect the spinal canal.

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

The brain and spinal cord



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 cells 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 to neurons and clear away dead neurons and germs.



Key questions

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. It 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.

Benign tumours usually have slow-growing cells and clear borders (margins) to separate them from normal tissue, and they rarely spread. However, they may be found in areas of the brain that control vital life functions, and require urgent treatment (see pages 24–39).

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

Q: What types are there?

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

- **Benign tumours** – The most common types are pituitary tumours, meningiomas, neuromas, schwannomas, craniopharyngiomas, and pilocytic astrocytomas. Benign tumours can cause problems by pressing on the brain and spinal cord.



Some benign brain tumours can develop into a rapidly growing malignant tumour. This process is called malignant transformation.

- **Malignant tumours** – This includes low- and high-grade astrocytomas, oligodendrogliomas and ependymomas, and mixed gliomas, medulloblastomas and glioblastomas (also known as glioblastoma multiforme or GBM). Primary malignant tumours are usually confined to one area of the brain and CNS.
- **Metastatic brain tumours** – These begin as a primary cancer in another part of the body before spreading to the brain. The most common types of cancer that can spread to the brain include melanoma, bowel, breast, kidney and lung cancer.

Q: What are the risk factors?

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

- **Family history** – It is possible to have a genetic predisposition to developing a tumour. This means that you may have a fault in your genes, usually passed down from one of your parents, that increases your risk. For example, some people have a genetic condition called neurofibromatosis, which causes nerve tissue tumours.

- **Radiotherapy** – People who have had radiation to the head, usually to treat another type of cancer, may be at an increased risk of developing a tumour. This may affect people who had radiotherapy for childhood leukaemia.

Electromagnetic radiation and brain cancer

Concerns about a link between mobile phones, microwave ovens and brain cancer have attracted community interest over recent years.

Evidence to date does not show that mobile phone use causes cancer. However, an association cannot be ruled out because the effect of long-term mobile phone use is yet to be studied.

People who are concerned about the risk should limit call time and/or use hands-free devices. Many authorities recommend limiting mobile phone use by children.

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

“ I’ve wondered about a link between mobile phones and brain tumours. The jury’s still out, but I choose to err on the side of caution. I try not to use my phone in low-reception areas, and I send text messages or use the hands-free function when possible. ” Gary

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, so you may not take much notice of them. Symptoms 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 36).

Other symptoms of brain tumours

- 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

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

Most people who have common symptoms, such as a headache, do not have a tumour. However, new or worsening symptoms should be reported to your doctor.

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 28).

Q: How common are these tumours?

A: Every year about 1400 malignant brain tumours are diagnosed in Australia. The most common type of tumour is glioblastoma multiforme or GBM. About 80 people are diagnosed with other malignant central nervous system tumours, including malignant spinal tumours.

Data about benign brain and spinal cord tumours are not collected, but they are more common than malignant tumours. An estimated 2000 people – including children – are diagnosed with a benign tumour each year.

About 100 children are diagnosed with malignant brain tumours each year – this is the second most common cancer in children. About 20 children are diagnosed with a spinal cord tumour. The section about caring for a child with a tumour may be helpful – see page 51.





Diagnosis

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

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

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

Physical examination

Your doctor will assess your nervous system to check how different parts of your brain and body are working, including your speech, hearing, vision and movement.

This is called a neurological examination and may cover:

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

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

CT scan

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

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

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

“ I had a CT scan because I was having persistent, strong headaches, felt disorientated and couldn't think clearly. The scan showed that I had a brain tumour. ”

Richard



The dye that is injected into your veins before a CT or MRI scan may contain iodine, and may affect your kidneys. If you are allergic to iodine, fish or dyes, or if you have kidney problems, let the person performing the scan know in advance. You may need to have blood tests to check your kidney function.

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 contrast dye may be injected into your veins before the scan.

You will lie on a table in a metal cylinder, which is a large and powerful magnet. Some people feel anxious or claustrophobic lying in the narrow cylinder during the MRI. Let your health care team know if you feel uncomfortable or afraid in confined spaces. It may help to take a mild sedative, or you can talk through an intercom to the person operating the machine. The scan can be paused if necessary.

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 and some 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 below, which show how quickly or aggressively a tumour is growing (the grade) – 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.

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

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 gamma camera. This takes 3D pictures of your body to assess blood flow in the brain. A brain tumour may have higher blood flow than the rest of 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 and highlights the active cells.

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, some or all of the tissue may be removed for examination (biopsy). In some cases, the neurosurgeon makes a small opening in the skull and inserts a needle to take a sample. In other cases, the neurosurgeon removes a larger part of the skull to get to the tumour.

Blood tests – Blood may be taken to check the levels of certain hormones in the body. Changes could be due to a brain tumour.

Grading tumours

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

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

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

Prognosis

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

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

Some brain or spinal cord tumours can come back (recur). In this case, treatments such as surgery, radiotherapy or chemotherapy can often relieve symptoms for some time.

For information about the prognosis of children with brain or spinal cord tumours, see page 51.

If you want to know your prognosis, it's important to talk to your specialist about your situation. 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.



Which health professionals will I see?

Your general practitioner (GP) will often arrange the first tests to assess your symptoms. If these tests do not rule out cancer, 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 treatment. This multidisciplinary team will probably include some of the people listed on the next page.

| Health professional | Role |
|--|---|
| neurologist | diagnoses and treats diseases of the brain and nervous system, particularly those not requiring surgery |
| neurosurgeon | diagnoses and treats diseases and injuries of the brain and nervous system, and uses surgery to treat them |
| nurses | administer drugs, including chemotherapy, and provide care, information and support throughout your treatment |
| care coordinator | supports patients throughout treatment, coordinates referrals and liaises with staff |
| medical oncologist | specialises in diagnosing cancers and treating them using chemotherapy and biological therapies |
| radiation oncologist | prescribes and coordinates the course of radiotherapy |
| dietitian | recommends an eating plan for you to follow while you are in treatment and recovery |
| social worker, psychologist, neuropsychologist, psychiatrist and pastoral care worker | link you to support services and help with emotional, spiritual, physical, social or practical issues |
| physiotherapist, speech therapist and occupational therapist | provide rehabilitation services and help with physical issues |



Key points

- Many people diagnosed with a brain or spinal cord tumour have symptoms caused by the tumour, such as dizziness, headaches or difficulty walking.
- You will probably have many tests to diagnose the disease.
- A physical examination checks how different parts of your brain are working.
- Scans, such as CT and MRI, allow the doctor to see inside the brain.
- Other scans assess the chemical make-up of the brain, blood flow in the brain, and whether there are active cancer cells in the central nervous system.
- You may also need a blood test to check hormone levels, and a biopsy, which removes some tissue for examination under a microscope.
- The tests help doctors diagnose the type of brain or spinal cord tumour you have, as well as its grade and if it has spread. The grade shows how abnormal the cells are and how quickly the tumour is growing.
- Many people want to know the likely outcome of their disease (prognosis). You will need to discuss this with your doctor, as it depends on many factors.
- You will see a range of health professionals who specialise in different areas of your treatment. You will usually be referred to a neurologist or a neurosurgeon.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 56 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

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

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call the Helpline for a free copy of *Understanding Clinical Trials and Research* or visit www.australiancancertrials.gov.au.



Treatment

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

There also may be new and experimental treatments, or improvements in existing treatments. These are given in clinical trials – for more information, see page 23.

The aim of treatment, where possible, is to remove the tumour, slow its growth, or relieve symptoms by shrinking the tumour and swelling. Treatment cannot begin until the diagnosis is confirmed.

Your 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.

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. However, you may also have other treatments.

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

called a partial resection or debulking. Partial removal may be because the tumour is widespread, near major blood vessels, or cannot be removed without damaging other important parts of the brain or spinal cord. A partial resection may improve your symptoms by reducing the pressure on your brain.

Sometimes a tumour cannot be removed because it is too close to certain parts of the brain and would cause serious problems. This is called an inoperable or unresectable tumour. Your doctor will talk to you about other ways to try to ease the symptoms.

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

Preparing for surgery

The types of scans used for diagnosing the tumour (e.g. CT, MRI 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 which areas of your brain control speech and movement. Brain mapping is another way to find these parts of the brain. A tiny electrode is placed on the outside layer of the brain and stimulated with a low dose of electrical current.

Identifying the brain’s sensitive areas can help the surgeon avoid causing damage during the operation.



One week before surgery, ask your doctor about what medication to take. Some medications interfere with the anaesthetic used during the operation, so you should temporarily stop taking them. You may also be advised to stop smoking before surgery.

Surgery for a brain tumour

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

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

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

Awake craniotomy – This operation is done if the tumour is near parts of the brain that control speech or movement. All or part of the operation is done with the patient awake (conscious) but relaxed, so they can speak, move and respond. This is not painful because the brain itself does not feel pain, and local anaesthetic is used to numb surrounding tissues. During the 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. An electrode is also used to stimulate the brain with a small electrical current to identify the important areas.

Endoscopic transnasal brain surgery – This rarer type of surgery is used for tumours near the base of the brain (e.g. a pituitary gland tumour). The surgeon puts a long tube (endoscope) into the nose, then removes all or part of the tumour through the nostrils. This type of surgery may have a faster recovery time than a craniotomy.

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

Stereotactic surgery

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

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

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

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

Surgery for a spinal cord tumour

The 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 removed part of the vertebra may be replaced. You will be given a general anaesthetic for this operation.

After your brain or spinal cord operation

- For the first 12–24 hours after the operation, you will be closely monitored. Nurses will regularly check your breathing, pulse, blood pressure, temperature, pupil size, arm and leg strength and function, and how aware (conscious) you are. These are called neurological observations. They show how your brain and body are recovering from surgery.
- Some people have a build-up of fluid in their brain. This is called hydrocephalus. The surgeon may place a long, thin, permanent or temporary tube called a shunt from your brain into your abdomen to drain the extra fluid. The fluid can then be safely absorbed into the bloodstream. A small valve is inserted just under the scalp to make sure the fluid flows away from the brain.
- You may need to wear pressure stockings on your legs to prevent blood clots from forming while you are bedridden. Tell your doctor if you have pain or swelling in your legs or suddenly develop difficulty breathing.

“ 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*

- If you are recovering from a craniotomy, your head will be bandaged. Your face and eyes may be swollen or bruised, but this is not usually painful and should ease within about a week.
 - You may have a headache or nausea after the operation. Both can be treated with medications.
 - If you have had an operation on your spinal cord, the nurses will regularly check the movement and sensation in your arms and legs. You may need to lie flat in bed for 2–5 days to allow the wound to heal. A physiotherapist will help you learn how to roll over and how to get out of bed safely so the wound is not damaged.
 - 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 40.

Radiotherapy

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

Before your radiotherapy 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.

A radiation therapist 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. For spinal cord tumours, some small tattoos may be marked on your skin to indicate the treatment area. For brain tumours, a face mask – also called a cast – is made to keep the head in position. It is a tight-fitting mesh, but you will only wear it for about 10 minutes at a time. However, let the radiation therapist know if wearing the mask makes you uncomfortable.

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



In some cases, the entire brain receives treatment – for example, this may be done for secondary tumours. Your medical team will tell you if this is recommended for you.

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. Treatment is so accurate that surrounding areas of healthy brain tissue are unlikely to be 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 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, as they require a larger treatment area.

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

Radiotherapy for children

Radiotherapy is not often used for children under age 5 because high-dose therapy can affect intellectual development and slow hormone production and physical growth. 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. Young children may require a general anaesthetic for radiotherapy.

Side effects of radiotherapy

Radiotherapy causes many possible side effects. Most occur in the treatment area and are temporary, but some may be permanent or last for a few months or years.

The side effects vary depending on if you have a brain or spinal cord tumour. They may include:

- nausea – often occurs during the course of treatment
- headaches – often occur during the course of treatment
- tiredness or fatigue – worse at the end of treatment for a brain or spinal cord tumour, and fades over time (see page 45)
- red, sore, inflamed or flaky skin in the treatment area – usually happens at the end of treatment for brain tumours, but can worsen before improving
- hair loss in the treatment area – for brain tumours
- swallowing problems (dysphagia) – for spinal cord tumours
- diarrhoea – for spinal cord tumours.

Some people experience similar side effects for several years after treatment. However, it is not always clear if these changes are caused by radiotherapy, the tumour or other treatment. You may benefit from rehabilitative therapy (see page 41) or medication, and your pituitary gland may be monitored.

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 or read more information in Cancer Council's *Understanding Radiotherapy* booklet – call 13 11 20 for a free copy.

Chemotherapy

Chemotherapy is the use of drugs to treat cancer. Generally, chemotherapy drugs travel through the bloodstream and damage or destroy rapidly dividing cells such as cancer cells, while causing the least possible damage to healthy cells. Healthy fast-growing cells, such as your bone marrow, may also be affected, causing side effects (see the next page).

However, it can be difficult to treat brain tumours with chemotherapy drugs because the body has a protection system called the blood-brain barrier. This guards the brain from 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 by taking an oral capsule or through a drip inserted into your vein (intravenously). Each treatment session is usually followed by a rest period of a few weeks.

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 glioblastomas (grade 4 tumours). This combination improves outcomes, compared with radiotherapy alone.



Side effects of chemotherapy

The way your body reacts to chemotherapy will be monitored through regular blood tests. Your treatment schedule may change when your doctor sees how you are responding to the drugs.

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

- increased risk of infection
- nausea, vomiting or loss of appetite
- tiredness, fatigue and lack of energy
- mouth sores and ulcers
- diarrhoea or constipation
- breathlessness due to low red blood cell levels (anaemia)
- the feeling of pins and needles (nerve damage known as peripheral neuropathy).

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

Ask your doctor what side effects to expect and how to control them. You may be prescribed medication to make you feel better. You can also read Cancer Council's free booklet about chemotherapy, available by calling 13 11 20.



The Sydney Neuro-Oncology Group produces useful fact sheets for patients with brain tumours and their carers. See the Patient & Carer Kit information at www.snog.org.au.

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

Steroids

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

You must eat some food before taking steroids. This decreases the likelihood of the steroids irritating your stomach.

The side effects you experience depend on the dose and the length of treatment. Steroids given for a short time may cause increased appetite, weight gain, insomnia, restlessness and mood swings. 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 will also be more likely to get infections.

Most side effects are temporary and will fade if your medical team reduces your dose. Short-term side effects can be managed with medication and counselling (if you have mood swings or behavioural changes). If you or your family members are worried about side effects, talk to your doctor or a counsellor.

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).

Generalised seizures – These types of seizures typically affect the whole body. The most common type is called a tonic-clonic seizure (previously known as a grand mal seizure).

A seizure often starts with a sudden cry, followed by the person falling down and losing consciousness. The person's muscles may twitch violently and their breathing may be shallow for up to two minutes. They may lose control of their bladder or bowel and bite their tongue.

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

Anti-convulsant medications

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

Ways 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 how long the seizure lasts.
- 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.
- Talk to the person and explain what has occurred. In many cases, people are confused after a seizure.
- Observe 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 the person from their seat, if possible. Roll them onto their side if there is food, water or vomit in their mouth.
- If help is needed, call an ambulance **(000)** immediately.
- Allow the person to rest after having a seizure.
- For detailed information about seizures, contact Epilepsy Action Australia on **1300 374 537** or visit **www.epilepsy.org.au**.



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

Side effects of anti-convulsant drugs vary and may include tiredness, weight changes, gum problems, tremors, nausea, vomiting and depression. If you are allergic to the medication, you may get a rash. Tell your medical team if you have any skin changes or other side effects.

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

Palliative treatment

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

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

Call Cancer Council Helpline 13 11 20 for more information about palliative care and advanced cancer.



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, into a vein via a drip, or as wafers that are placed directly in the brain during surgery.
- Other treatments include steroids to reduce brain inflammation, and anti-convulsants to prevent seizures occurring.
- Treatments may cause short- and long-term side effects. Talk to your doctors and nurses about managing symptoms and side effects, including if you will need rehabilitation.



Rehabilitation

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

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

School-aged children with brain tumours may benefit from tutoring as part of their rehabilitation. This may be available through some cancer charities, or you can 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.

Other helpful resources

Cancer Institute NSW has fact sheets to help people and families affected by a brain tumour. They cover a range of topics such as anxiety, anger, social behaviour, memory and concentration. Go to

www.cancerinstitute.org.au and search for 'brain cancer fact sheet'.

The organisation BrainLink may also have rehab services. See www.brainlink.org.au.

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 eating.

Occupational therapy – This helps you increase or maintain your independence.

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 pain-killers) can cause changes in vision, mobility, coordination, perception and judgment. These changes can affect a person's driving skills.

You must inform your local 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 decide if you are medically fit to drive.

You may have an occupational therapy driving assessment. This can determine the type of difficulties you are experiencing while driving (for example, a slow reaction time).

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

Some people feel upset or frustrated if they are no longer able to drive or they have restrictions placed on their licence. These reactions are natural and understandable.

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

However, it may help to remember that the decision is made for your safety and wellbeing. It is also made for the safety of passengers, pedestrians and other road users who could be injured if your driving is unsafe. If you have to stop driving, you may want to talk to a counsellor or someone who has been through a similar experience (see page 48). Depending on your situation and your ongoing health, you may be able to return to driving at a later stage.

Cancer Institute NSW produces a free brochure, *Brain Tumours and Driving*, which has more information on these issues. Although it is a NSW resource, the information may be relevant to people in other areas of Australia. Call (02) 8374 5600 for a copy.

The impact of 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 licence has restrictions but you ignore them or drive unsafely, your licence may then be suspended or cancelled.

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



Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council Helpline 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

Staying active – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

Complementary therapies – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

Tiredness and fatigue

Having a brain or spinal cord tumour can make you feel tired. Fatigue is not only a result of the tumour and treatment – it can also be caused by travelling to and from hospitals and clinics. Plan activities so you can rest regularly, and talk to your loved ones about how you are feeling so they can support you. If you feel up to it, doing light exercise for about 30 minutes a day may make you feel more energetic. Your medical team can give you more suggestions.

Call **13 11 20** for free copies of other booklets, including *Sexuality, Intimacy and Cancer* and *Emotions and Cancer*, or download the booklets from the website.



Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as

treatment and side effects, your self confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.



Cancer Council Helpline **13 11 20** can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

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

people are able to get a Medicare rebate for sessions with a psychologist or psychiatrist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://www.beyondblue.org.au) has information about anxiety and depression. To order a fact sheet, call **1300 224 636** or visit www.beyondblue.org.au.

After treatment: follow-up and recurrence

After your treatment, you will need regular check-ups – this may include blood tests, scans and physical examinations. Check-ups will usually become less frequent if you have no further problems and more time passes since you were diagnosed.

For some people, a brain or spinal cord tumour does come back or continues growing after treatment. If the tumour returns, this is known as a recurrence. Your doctor will talk to you about your treatment options. Some people choose to have further treatment; others decide not to have any. Your subsequent treatment will depend on your situation and the treatments you've already had. For example, some people who have had radiotherapy may not be able to have any more.



Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

You may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. Talk to your nurse, social worker or Cancer Council Helpline about what is available in your area. This may include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as www.cancerconnections.com.au.

Other resources

Cancer Council Australia and the Clinical Oncological Society of Australia have a guide for patients and families about adult gliomas (astrocytomas and oligodendrogliomas). See www.cancer.org.au and search for 'glioma'.

Brain Tumour Alliance Australia provides a free copy of the American Brain Tumor Association's *About Brain Tumors: A Primer for Patients and Caregivers*. To order this detailed resource, phone **1800 857 221**.



Caring for someone with a tumour

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

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia.

Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for information and resources.

You can also call Cancer Council Helpline 13 11 20 to find out more about carers' services and get a copy of the *Caring for Someone with Cancer* booklet.



BrainLink may also have helpful services for carers of people with brain diseases – visit the website www.brainlink.org.au.

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 about hospital trips and explain tests that may hurt.
- Give your toddler choices where possible. E.g. “Would you like to wear the red or blue shirt to hospital?”
- If they are in hospital for a period of time, put up some family photographs.



Preschool children, 3–5 years

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

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

School-age children, 6–12 years



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

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

Teenagers, 13–18 years



Many teenagers have an adult understanding of cancer and often want detailed information. They are starting to separate from the family. This is a vulnerable time, as they don't want to appear different 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 consistent. It is important to continue to show your love and support. It may help to keep rules and discipline as normal as possible. Although you may be tempted to relax the rules, this can lead to confusion over time.

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

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

Who is available to help?

Many hospital staff members specialise in working with children and young adults (paediatrics). Some hospitals employ staff, such as play therapists, music therapists or art therapists, who can help children cope with the challenges of treatment.

Rehabilitation will also be important for your child's recovery (see page 40). CanTeen, Redkite and ONTrac (Peter MacCallum, Victoria only – see www.petermac.org) offer practical and emotional support for families and children. Some of support is also available to young people who have a parent or sibling with cancer.



Useful websites

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

Australian

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

International

| | |
|--|--|
| American Brain Tumor Association..... | www.abta.org |
| American Cancer Society..... | www.cancer.org |
| Macmillan Cancer Support..... | www.macmillan.org.uk |
| Cancer Research UK..... | www.cancerresearch.org.uk |
| National Brain Tumor Society..... | http://braintumor.org |
| Pediatric Brain Tumor Foundation | www.curethekids.org |
| Spinal Cord Tumour Forum..... | www.spinalcortumour.org.uk |
| US National Cancer Institute..... | www.cancer.gov |



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of brain or spinal cord tumour do I have? Is it benign or malignant?
- How extensive is the tumour? What grade is it?
- What treatment do you recommend and why? Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment? Is there anything I should watch out for?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment? Who should I go to for these appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?



Glossary

anaesthetic

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

astrocyte

A type of glial cell.

astrocytoma

A type of brain tumour.

benign

Not cancerous or malignant.

biopsy

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

central nervous system

The brain and spinal cord.

cerebellum

Part of the brain responsible for the coordination of voluntary movements.

cerebrospinal fluid

Clear, watery fluid surrounding the brain and spinal cord.

cerebrum

The largest, upper part of the 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.

craniectomy

An operation to open the skull by removing some bone in order to access the brain. The bone is

not replaced due to swelling.

cranio-pharyngioma

A type of benign brain tumour.

craniotomy

An operation to open the skull and access the brain.

CT scan

A computerised tomography scan.

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

ependymoma

A type of malignant brain tumour.

glial cell

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

glioblastoma

A type of malignant brain tumour.

Also known as glioblastoma multiforme or GBM.

grade

The degree of abnormality of cancer cells.

hydrocephalus

The build-up of cerebrospinal fluid in the brain.

inoperable

Not able to be surgically removed.

Also called unresectable.

interneuron

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

laminectomy

Surgery that involves cutting into the

spinal column and removing a spinal cord tumour.

lumbar puncture

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

malignant

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

malignant transformation

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

medulloblastoma

A type of malignant brain tumour.

meninges

The membranes surrounding the brain and spinal cord.

meningioma

A type of benign brain tumour.

metastasis

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

mixed glioma

A type of 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 brain tumour.

oncologist

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

palliative care

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

palliative treatment

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

peripheral nervous system

The system of nerves extending

outside the central nervous system to the limbs and organs.

pilocytic astrocytoma

A type of brain tumour.

pituitary tumour

A type of benign brain tumour.

primary cancer

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

prognosis

The likely outcome of a person's disease.

psycho-oncologist

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

radiotherapy

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

rehabilitation

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

resectable

Able to be surgically removed.

schwannoma

A type of benign brain tumour.

secondary cancer

See metastasis.

seizure

A disruption of the normal electrical impulses in the brain, causing a person

to convulse or have other symptoms.

sensory neuron

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

shunt

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

spinal cord

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

spinal tap

See lumbar puncture.

stereotactic radiosurgery

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

stereotactic surgery

Surgery done using a computer to guide the surgeon.

steroids

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

vertebrae

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

Can't find what you're looking for?

For more cancer-related words, visit www.cancercouncil.com.au/words or www.cancervic.org.au/glossary.



How you can help

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

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

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

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

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

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

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



Cancer Council Helpline 13 11 20

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

Central and Southern Sydney

Woolloomooloo
02 9334 1900

Hunter and Central Coast

Charlestown
02 4923 0700

North Sydney

Crows Nest
02 9334 1600

Northern

Byron Bay
02 6639 1300

Southern

North Wollongong
02 4223 0200

Western

Wagga Wagga
02 6937 2600

Western Sydney

Parramatta
02 9354 2000



Cancer Council
Helpline

13 11 20

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