

Understanding Brain Tumours

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



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The Cancer Council New South Wales

The Cancer Council is the leading cancer charity in New South Wales. 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.

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Before commencing any health treatment, always consult your doctor. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor's or health professional's advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

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Introduction

This booklet has been written to help you understand more about brain and spinal cord tumours. Both are tumours of the central nervous system.

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

You may be reading this booklet because your child has been diagnosed with a brain tumour. We cannot advise you about the best treatment for your child or for you. You need to discuss this with your doctors. However, we hope this booklet will answer some of your questions and help you think about the questions you want to ask your doctors.

You do not need to read it from cover to cover – just read the parts that are useful to you.

If you find this booklet helpful, you may like to pass it on to your family and friends, who may also find it useful.

Some medical terms that may be unfamiliar are explained in the glossary.

If you're reading this booklet for someone who doesn't understand English, tell them about the Cancer Council Helpline available in different languages (see page 33).



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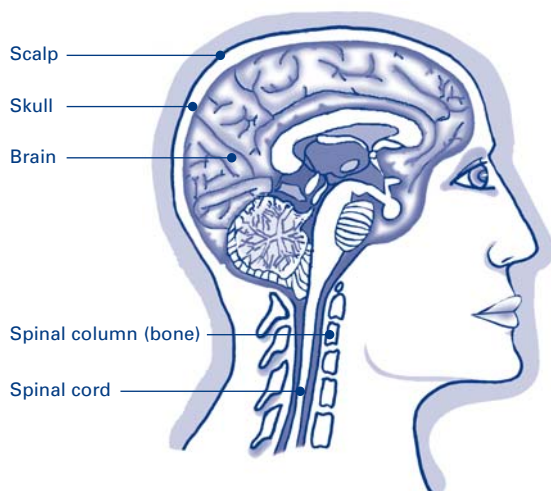
The brain and spinal cord

The brain and spinal cord, which are made mostly of nerve cells called neurons, form the central nervous system. Neurones transmit messages around the body, which allow us to move when we want to. Other cells support the nerve cells, including astrocytes and oligodendrocytes. The brain also controls body functions we are barely aware of, such as breathing, blood circulation, maintaining body temperature, production of hormones, digestion of food, urinary and bowel motions and making the heart beat faster when we exercise.

The brain also interprets information from our senses and controls our thoughts, memory and emotions.

The largest part of the brain is called the cerebrum, which is made up of two hemispheres.

The spinal cord, which is encased in the spinal column or backbone, consists of nerve cells and bundles of nerves that connect the brain with all parts of the body. The spinal cord extends from the base of the brain to the base of the spinal column.





What is a brain or spinal cord tumour?

Our bodies are constantly making new cells to enable us to grow and to replace worn-out cells. Normally, cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. These cells may grow into a mass called a tumour.

Sometimes cells break away from the original (primary) tumour and spread to other organs. When these cells reach a new site, they may continue to grow and form another tumour there. This is called a secondary cancer or metastasis.

Primary brain tumours almost never spread to other parts of the body, but they can recur in the part of the brain where they first grew. Primary cancers in other parts of the body can spread to cause tumours in the brain.

There are more than 40 major types of brain tumours, which are grouped into two main types: benign and malignant.

The difference between benign and malignant is not as clear cut with brain tumours as it is with other types of tumours.

Benign tumours

Most benign tumours are made up of slow-growing cells and are unlikely to spread. Common types of benign brain tumours are meningiomas, neuromas, pituitary tumours and cranio-pharyngiomas.

Malignant tumours

Malignant tumours are cancerous and able to spread into other parts of the brain or spinal cord. These tumours are still life threatening because they grow large and cause problems by pressing on the surrounding brain tissue.

Malignant tumours vary widely in how they grow and respond to treatment. In some malignant tumours, the cells are confined to a specific area. In other tumours, malignant cells are also found in tissue around the tumour.

Malignant brain tumours are usually named after the cell type from which they arise. They include astrocytomas, oligodendrogliomas, ependymomas, glioblastomas and mixed gliomas.

Hydrocephalus

The brain has four cavities filled with fluid, which flows through narrow passages between the cavities and the surface of the brain. Sometimes a brain tumour can block this flow. When this happens, fluid can build-up, putting pressure on the brain. This is called hydrocephalus and it may occur in children with brain tumours. It can be dealt with a shunt, see page 14.

Grades of tumour

Brain tumours are usually graded on a scale of I to IV based on how quickly they are growing, as well as their ability to invade nearby tissue.

- Grades I and II are the slowest growing tumours and are also called low-grade tumours.
- Grade III tumours grow at a moderate rate.
- Grade IV are the fastest growing tumours.

How common are they?

In NSW every year malignant brain tumours are diagnosed in about 450 people, and malignant spinal tumours in about 30 people.

Causes of brain tumours

The causes of brain tumours are not known. Doctors can rarely explain why one person gets a brain tumour and another does not.

However, it is known that brain tumours are not contagious, so no-one can catch the disease from someone else. Researchers around the world are investigating the possible causes.

“It was not a priority of mine to know exactly what had caused my tumour. I accept that some things happen with no current explanation.”

What are the symptoms?

As a tumour grows inside the skull it presses on the surrounding brain tissue, creating pressure. Benign and malignant tumours can cause the brain to swell. Symptoms vary, depending on what part of the brain a tumour presses on. Sometimes, when a tumour grows slowly, the symptoms develop so gradually that they are hardly noticed.

Symptoms can include:

- headaches
- nausea and vomiting
- difficulty speaking or remembering words
- disturbed vision, hearing, smell or taste
- weakness or paralysis in parts of the body
- loss of balance
- general irritability, drowsiness or a change in personality.

Seizures

A brain tumour may cause seizures (also called fits or convulsions) by irritating the nerve cells in the brain.

There are two main types of seizures:

- Partial – affects one part of the body e.g. an arm or a leg. These often cause twitching, jerking, tingling or numbness, or other sensations like a strange smell or taste, or *deja-vu*. Sometimes they cause a brief loss of consciousness.
- Generalised or grand mal – involves both arms and legs. These cause muscle twitching or spasm of the muscles and loss of consciousness.

For more information contact Epilepsy Action on 1300 374 537.

If you are with someone who has a seizure

- Remain calm. Stay with the person and protect them from injury. Put something soft under their head or rest their head in your hands.
- Don't try to restrain them or put anything in their mouth, just try to clear anything from around them that they might hurt themselves on.
- Lie them on their side, particularly if they are unconscious or if they vomit or have food or fluid in their mouth.
- Most seizures last two or three minutes. Call an ambulance if the seizure lasts more than five minutes, or if they have another fit straight after the first, or if they injure themselves or are having trouble breathing.
- People are often confused after a seizure; just explain to them what has happened. Find a place where they can rest for a few minutes or they may want to have a sleep.

Further seizures can often be prevented by medication called anti-epileptics or anti-convulsants (see page 20).

Symptoms of spinal cord tumours

A tumour pressing on the spinal cord may stop the flow of messages along the nerves between the brain and body. Pain in the back is a common symptom, as the tumour presses on the spinal cord in its narrow space within the spinal column. Most back pain, however, is due to other spinal problems. Loss of feeling, poor balance and muscle weakness in legs and arms may occur if a tumour is present.



Diagnosis

Your doctor will take a detailed history of your symptoms and examine you thoroughly. You may be referred for a computerised tomography (CT) scan or magnetic resonance imaging (MRI) and then to a neurologist or neurosurgeon.

The specialist will check how different parts of your brain are working. This may include checking your reflexes (for example, your knee jerks), the strength in the muscles of your arms and legs, and your ability to feel pin pricks. You may be asked to do some mental exercises, such as some simple arithmetic.

The doctor may look into your eyes, using an instrument called an ophthalmoscope, to see the end of your optic nerve.

Which health professionals will I see?

Your GP will order initial tests and refer you to a specialist if needed. The health professionals who may care for you include:

- neurosurgeon and neurologist: diagnose and treat people with illnesses of the brain and nervous system
- radiation oncologist: prescribes and co-ordinates the course of radiotherapy
- medical oncologist: prescribes and co-ordinates the course of chemotherapy
- dietitian: recommends an eating plan to follow while you are in treatment and recovery
- nurses: assist and support you through all stages of your treatment
- research co-ordinator or clinical care co-ordinator: advises you on support services and clinical trials
- social worker, physiotherapist and occupational therapist: link you to support services and help you get back to normal activities.

CT scan

A CT scan is a special type of x-ray which gives a three-dimensional picture of the organs and other structures (including any tumours) in your body. You will be asked to lie flat on a table while the CT scanner, which is large and round like a doughnut, takes pictures. Most people are able to go home as soon as their scan is over. It usually takes about 30 to 40 minutes to complete this painless test. CT scans are usually done at a hospital or a radiology service.

To make the pictures that the scanner takes clearer, you may drink, or have injected, a dye or contrast fluid. This will mean that you can't eat or drink for about four hours before the scan. The dye injection can cause a burning sensation.

The results of a CT scan or MRI are not usually available straight away. They need to be checked by a specialist called a radiologist. Your doctor will explain the radiologist's report to you.

MRI

An MRI uses magnetism to build-up a series of clear and detailed pictures. An MRI is painless and the magnetism is harmless. You will have to lie very still on a couch inside a metal cylinder, which is open at both ends.

The machine is noisy and has been described by some people as like putting your head inside a washing machine, but you will be given ear plugs. The test may take up to an hour.

The cylinder makes some people feel claustrophobic, but you may be able to take someone into the room with you to keep you company. You will be given a buzzer so the technician can stop the machine, and talk to you if you feel unwell or worried.

Further tests

Other tests that are sometimes used later are:

- magnetic resonance spectroscopy (MRS)
- positron emission tomography (PET)
- single photon emission computerised tomography (SPECT)
- lumbar puncture (also known as a spinal tap).

If your doctor recommends any other tests, ask him or her to explain the tests. Understanding what will happen can help you feel less worried before the test.

Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis with your doctor, but it is not possible for any doctor to be precise about the prognosis.

The prognosis for tumours of the brain and spinal cord varies. It depends on your age, the type of tumour you have, how much of the tumour can be removed, and how well it responds to treatment.

If you have a benign tumour that is completely removed, cure is likely.

The rate of growth and spread of malignant tumours also varies. Some types of malignant tumour develop slowly over a number of years, while others grow and spread rapidly, such as glioblastoma. Response to treatment also varies a lot.

After treatment for a brain tumour, some people appear to be cured and may live for many years. However, brain tumours can recur. If a cure is not possible, treatment can often relieve symptoms for several years.



Treatment

Tumours of the brain or spinal cord may be treated with surgery, radiotherapy (x-rays), chemotherapy (drugs) and steroid therapy. These treatments may be used alone or in combination. Prompt treatment may prevent or lessen the effects of the tumour.

Your specialist will discuss the best treatment for your situation with you.

The choice of treatment will depend on:

- the tumour: its type, size and location
- your age, medical history and general state of health.

The aim of treatment is to remove the tumour or, if it cannot be removed, to slow the tumour's growth and relieve symptoms by shrinking the tumour and any swelling around it.

If your doctor suggests you have more than one type of treatment, this does not mean that your disease is worse or better than the disease of somebody who has only one type of treatment. Each person is different and treatment needs to be planned individually.

“A year after being first diagnosed, I had an MRI that showed no signs of tumour growth. This knowledge encourages me to continue with treatment although I am aware my tumour may recur.”

Surgery

Some tumours can be removed completely by surgery. If a tumour is more spread out, or if it cannot be removed without damaging other important parts of the brain, the surgeon may be able to remove part of the tumour. This will improve your symptoms by reducing the pressure on the rest of the brain. Sometimes tumours cannot be operated on because it would be too dangerous.

Removing all or part of the tumour often improves your condition and lets you lead an active life for sometime.

Surgery for a brain tumour

The operation to treat a brain tumour is called a craniotomy. Some of your hair will be shaved off, and you will be given a general anaesthetic. The surgeon cuts and moves aside the skin, then removes a piece of skull above the tumour. The tumour is removed, the piece of skull replaced, and the skin stitched back in place.

The tumour is examined by a pathologist to see what type of tumour you have. This helps the doctor plan your treatment.

Shunts

If a fluid build-up in the brain (hydrocephalus) is a problem, the surgeon may put in a small permanent tube, called a shunt, just beneath the skin. The shunt will take the extra fluid from the brain and drain it into the abdomen.

Sometimes, if hydrocephalus has made you very ill, a shunt may be put in first to relieve symptoms, and surgery for the brain tumour may be done a week or two later.

Biopsy

In some cases, the surgeon will only do a biopsy. Sometimes this is done with computer guidance, through a small hole made in the skull. A tiny piece of tumour is removed and looked at under the microscope, to see what type of tumour you have. This helps the doctors to decide on further treatment.

Results from a biopsy can take between two days and a month to come through because a pathologist needs to check it carefully.

After the operation

A nurse will watch you closely for the first 12 hours or so after the operation. Your head may be bandaged for the first day, and a small tube may be placed near the wound to drain any excess blood from the operation site into a bottle.

Your face and eyes may be swollen after the operation, but the swelling should go down within about a week. You might also have a black eye, but this is not usually painful. You may need to wear pressure stockings while you are resting in hospital, to prevent blood clots in your legs. The length of your hospital stay will depend on the extent of the operation and on any treatment you may need afterwards.

Surgery for a spinal cord tumour

The main surgery for a spinal cord tumour is a laminectomy. The surgeon makes an opening in the spinal column and removes the tumour affecting the spinal cord.

After the spinal operation, the nurses will regularly check your pulse, blood pressure, temperature and dressing, and the movement and sensation in your legs. You may need to rest flat in bed for three to five days, to allow the wound to heal. Your doctor will tell you when you can start normal activities again.

Radiotherapy

Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply, while doing as little harm as possible to the surrounding healthy tissues. In adults, radiotherapy is often used after surgery for malignant tumours or combined with chemotherapy. Treatment is usually given over several weeks, but the length of radiotherapy will depend on the type and size of the tumour that you have.

The radiation therapist will make several marks on your skin to make sure that exactly the same area is being treated each time. A personalised plastic face mask is often worn during treatment to assist the targeting of the radiotherapy.

Side effects

Common side effects include:

- Tiredness: may last a month or so after radiotherapy.
- Nausea: can be helped by medication.
- Headaches: common but usually mild.
- Hair loss: may cause any hair in the treatment area to fall out. This hair usually grows back slowly, though it may not be as thick as before and it may change colour.
- Skin changes: scalp and skin in the treatment area may become red, dry and tender.

Most side effects are short term, but ask your doctor if you are likely to have any long-term side effects.

Tips for radiotherapy

- ✓ Do not use any creams, lotions or soaps without talking to your doctor or radiation therapist first.
- ✓ Check with your doctor or radiation therapist before shaving any affected skin.
- ✓ Keep the affected skin out of the sun, as it is easily burnt.

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to damage or destroy cancer cells. The drugs stop the cancer cells from growing and reproducing themselves.

Chemotherapy may be used alone or with radiotherapy.

If you have chemotherapy for your tumour, the doctor will decide on the dose and frequency of the treatment. Each treatment will usually be followed by a rest period of a few weeks to allow your body to recover from any side effects. The number of courses given will depend on the type of tumour and how well it is responding to the drugs.

You may have chemotherapy in hospital over a few days through an intravenous drip, or you may have chemotherapy in tablet form, as an outpatient.

The Cancer Council's booklets on chemotherapy and radiotherapy discuss ways of managing side effects. Call 13 11 20 for a copy or visit www.cancercouncil.com.au/.

Side effects

Some chemotherapy drugs can cause side effects, including:

- feeling sick
- mouth sores
- tiredness
- thinning or loss of hair from your body and head.

Ask your doctor what side effects to expect, as these vary depending on the type of chemotherapy you have.

The side effects are temporary and there are ways to prevent or reduce them. Tell your doctor or nurse of any side effects you experience. They may prescribe a break in your treatment, or change the kind of treatment you are having. Any nausea can be controlled with medication.

Don't use aspirin or any other pain-killer or medicine, unless the doctor says you can. These can affect how chemotherapy works in your body.

Complementary and alternative therapies

Many people with brain tumours will consider complementary and alternative therapies. Some of the information about these therapies on the Internet is not reliable, but a good source of information is the Cancer Council Helpline and the US National Cancer Institute's website (see page 35).

Some herbs, supplements and vitamins can interfere with your conventional treatment, so let your doctor know about any other therapies you are using.

Steroid therapy

Steroid drugs (usually dexamethasone) are used to reduce the swelling that often surrounds brain tumours before or after surgery or radiotherapy. These are different steroids to those talked about in sports drug scandals. Steroids can be used at many stages of treatment, for varying lengths of time. For more information on steroid treatment, call the Sydney Neuro-Oncology Group on (02) 8425 3369 or see their website (see page 35). You can also ask staff at the oncology unit where you are receiving treatment.

Side effects

The dose of steroids given will be kept as low as possible as steroids may cause the following side effects if taken over a long period of time.

- **Increased appetite and weight gain:** You may put on weight within a few weeks, especially on your face (sometimes called a moon face), waist and shoulders. Steroids often produce a feeling of well-being, and may also make you feel like eating more, so have some healthy snacks handy. Some people also get acne and water retention.
- **Steroid-induced diabetes:** The level of sugar in your blood may increase, and needing to urinate more often can be a warning sign. You may need to do a simple daily test to check for sugar in your urine or blood. Your doctor or nurse will show you how to do this.
- **Muscular weakness:** This can be a problem, especially if your tumour is also causing weakness. This is a rare side effect and is more common with high-dose, long-term steroid treatments. Tell your nurse or doctor if you have any muscle weakness.

Most of these side effects are temporary and will gradually disappear as your steroid dose is reduced. Steroid drugs often make people feel emotionally uplifted and it is common to feel depressed for a while after you finish your dose.

It is a good idea to carry a list of the medications you use and the dose, in case you become ill and need medical treatment.

Do not stop taking steroids suddenly, as this can be dangerous. When it is time to stop taking steroids, your doctor will advise you how to gradually reduce your dose.

Anti-convulsant medication

Anti-convulsants are used to prevent seizures. With some anti-convulsants you need regular blood tests to make sure the dose is right but this isn't necessary with newer medications. You may need blood tests regularly at first and then every six to 12 months. You may also have a liver function test to make sure there are no abnormal changes.

Side effects

Everyone reacts differently to anti-convulsants, so talk to your doctor about how they are going for you. Possible side effects and ways to cope include:

- Swelling of gums: use a soft toothbrush.
- Tiredness: have regular rest periods.
- Insomnia or feeling on edge: try relaxation or meditation.
- Poor co-ordination, feeling off balance and concentration problems: take time doing tasks, ask for help.
- Weight changes: may lose or gain weight.
- Rash, or nausea and vomiting, constipation or tremors: seek medical advice.

Tips for taking anti-convulsants

- ✓ Keep a diary and note when to take the medication and when blood tests will be done.
- ✓ Have regular blood tests to monitor your blood level.
- ✓ Discuss your care plan with your doctor.
- ✓ Do not reduce your medication, take it in different doses or change brands without medical advice. These changes may increase the number of seizures.
- ✓ Check with your doctor or pharmacist if you can eat grapefruit or Seville oranges – they may interfere with the way the body absorbs and breaks down some anti-convulsants particularly Carbamazepine.
- ✓ Limit your alcohol intake – anti-convulsants interact with alcohol. One glass of wine or beer is fine.

After treatment

After treatment, you will need regular checkups, often involving an MRI. To begin with, these checkups occur several times a year, and then usually only yearly. Checkups are important to make sure the tumour has not come back and that a new one has not developed.

It is natural to feel anxious about the tumour coming back. Talking over your concerns with your family and your own doctor can be helpful. The regular checkups will reassure you that all is well. If there are any problems, they can be found early, when treatment is most likely to work.

You may find that you need reassurance from your specialist. Ask lots of questions if you want to. Remember that you are not alone and that your feelings are normal.

Rehabilitation

Depending on their location, brain tumours can affect some of the normal functions of the brain, such as speech, personality, movement, balance or memory. If you have problems in these areas, you may need the help and advice of a speech pathologist, physiotherapist and occupational therapist. This can start in hospital and people who need help for some time can continue their therapy as outpatients.

Palliative care

Palliative care helps you relieve symptoms caused by your cancer, such as pain, nausea or constipation, at any stage of advanced disease, and helps you with the practical problems of daily life.

Palliative care can be provided by a community nurse or a team of people including doctors, nurses, physiotherapists, occupational therapists and social workers.

Your hospital doctor or nurse can put you in touch with a palliative care team for treatment in hospital, and your GP can refer you to a community palliative care team for treatment at home. Palliative care nurses in the community monitor you at home to check for any distress, whether it is physical, emotional or psychological. They are also able to organise access to equipment for home. An occupational therapist and physiotherapist can organise access to other aids for around the home.

When your symptoms are controlled and your support systems are in place, the palliative care team will usually step back and help you later if needed. For further information, contact the Cancer Council Helpline on 13 11 20.

Making treatment decisions



Sometimes it is difficult to decide on the right treatment for you. You may feel everything is happening so fast you don't have time to think things through.

You need to make sure you understand enough about your illness, the treatment and side effects to make your own decisions.

You always have the right to find out what a suggested treatment means for you, and the right to accept or refuse it, and to seek a second opinion.

If you are offered a choice of treatments, you will need to weigh the advantages and disadvantages of each treatment. If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.

Some people 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. Some may choose not to have treatment but to have symptoms managed to maintain the best possible quality of life.



Talking with doctors

When your doctor first tells you that you have a brain or spinal cord tumour, it is obviously very stressful and you may not remember very much. It is often difficult to take everything in, and you may need to ask the same questions more than once. Before you see the doctor, it may help to write down your questions – see the list of questions to ask your doctor on page 36.

Taking notes during the session or tape-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.

“I took a friend with me for support to the second appointment. It was like a dream where I just said ‘yes, yes, yes’ and luckily my friend wrote down all the information.”

Talking with others

Once you have discussed treatment options with your doctor, you may want to talk them over with family or friends, with nursing staff, the hospital social worker or chaplain, a pastoral care worker, your own religious or spiritual adviser, a cancer support group (see page 32) or the Cancer Council Helpline. Talking it over can help sort out the right course of action for you.

A second opinion

You may want to ask for a second opinion from another specialist. This is understandable and can be a valuable part of your decision-making process. Your specialist or local doctor can refer you to another specialist and you can ask for your results to be sent to the second-opinion doctor.

You can ask for a second opinion even if you have already started treatment or still want to be treated by your first doctor.

Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Clinical trials are a vital part of the search to find better treatments for cancer. Doctors conduct clinical trials to test new or modified treatments and see if they are better than current treatments.

Many people all over the world have taken part in clinical trials that have resulted in improvements to cancer treatment. However, the decision to take part in a clinical trial is always yours.

If your doctor asks you to take part in a clinical trial, make sure you understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What treatments are being tested and why?
- What tests are involved?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if problems occur while I am in the trial?
- What happens if I decide not to join the trial?

If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

If you decide to join a randomised clinical 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.

Being in a trial gives you important rights. You have the right to withdraw at any time. Doing so will not jeopardise your treatment for cancer.

For more information about clinical trials, call the Cancer Council Helpline on 13 11 20 for a free copy of *Understanding Clinical Trials* or download it from www.cancer council.com.au/.

Research into causes and treatment

Research is being done in Australia and elsewhere to identify the causes of brain and spinal cord tumours, to find better treatments and evaluate current treatments.

Experimental treatments include refinements of existing treatments, like computer-guided radiotherapy. Others are new treatments, like gene therapy: using normal genes to treat disease caused by abnormal genes.

Ask your doctor if these new treatments or others are relevant to your tumour.



If your child has a brain tumour

All types of brain tumour can occur in children. While the symptoms, diagnosis and treatment of brain tumours in children are much the same as in adults, children's brain tumours pose several different problems.

Effects of treatment

In children, radiotherapy to the head is given in lower doses than is used for adults because high-dose therapy can slow a child's intellectual development. Radiotherapy is used rarely for children under the age of two or three years for this reason.

For some types of childhood tumours, it may be necessary to give radiotherapy to the spine as well as the head. This can slow down bone growth in the spine, and the child may not grow as tall as they would have otherwise. Radiotherapy can also slow a child's growth by affecting the pituitary gland in the brain, which produces hormones that control growth. These children may need hormone therapy to help them to grow and develop normally.

Prognosis

Some tumours are simple to deal with and easily cured, while others are much more difficult to treat and there is less chance of a cure. While a significant number of children will recover completely, a proportion of children whose tumours are cured or controlled for many years will be left with disabilities. These range from mild learning or behaviour problems to severe physical or intellectual disability. They may also develop secondary tumours.

What do I tell my child?

It is quite natural to want to protect your child from the news of something as threatening as a brain tumour, and some parents will find it difficult to talk openly to their child about the tumour. Children, however, quickly pick up that something is seriously wrong, whether or not they are told. If you can talk openly and honestly about the brain tumour, it will help your child to be less anxious and to feel a little more in control of the situation. Your openness and calm confidence can help to reassure your child.

Try to keep things normal

One of your child's main 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 because although you may be tempted to spoil your child or relax your usual discipline, this can lead to confusion in the long run.

Who is available to help?

The hospital staff who work with your child will often be people who specialise in working with children. Some hospitals and cancer treatment centres employ play therapists who can help children work through their fears and feelings and cope with treatment.

A number of organisations and parents' support groups offer practical and emotional support for families and children, camps for children and other services. Ask at your hospital, or ring the Cancer Council Helpline for further information.



Seeking support

When you are first diagnosed with a brain or spinal cord tumour, it is normal to experience a range of extreme emotions, such as fear, sadness, depression, anger or frustration. It will help to talk about your feelings with your partner, family members or friends or, if you prefer, talk to the hospital social worker, psychologist, your religious or spiritual adviser, a support group, or the Cancer Council Helpline on 13 11 20.

You may find that your friends and family don't know what to say to you: they may have difficulty with their feelings as well.

Some people may feel so uncomfortable that they avoid you. They may expect you to 'lead the way' and tell them what you need. This can be hard to handle and can make you feel very lonely.

You may feel able to approach your friends directly and tell them what you need. You may prefer to ask a close family member or a friend to talk with other people for you.

The Cancer Council's booklet *Emotions and Cancer* may help at this critical time. Call 13 11 20 for a copy or download it at www.cancercouncil.com.au/.



Practical and financial help

A serious illness often causes practical and financial difficulties. You don't need to face these alone.

Many services are available to help:

- Financial assistance, through benefits and pensions, can help pay for the cost of prescription medicines and for travel to medical appointments.
- Home nursing care is available through community nursing services, or through the local palliative care service.
- Meals on Wheels, home care services and aids and appliances can make life easier.

Contact the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline for information on these services.

Healthy eating

Eating nutritious food will help you to keep as well as possible and cope with the brain tumour and any treatment side effects. Depending on the kind of treatment you have had, you may have special dietary needs. A dietitian can help to plan the best foods for your situation – ones that you find tempting, easy to eat and nutritious.

The Cancer Council can send you information on nutrition during and after cancer treatment. Call 13 11 20.

Exercise and relaxation techniques

You will probably find it helpful to stay active and to exercise regularly if you can. The amount and type of exercise you do will depend on what you are used to and how well you feel.

Discuss with your doctor what is best for you.

Some people find relaxation or meditation helps them to feel better by releasing tension and anxiety. The hospital social worker or nurse will know whether the hospital runs any programs, or may know about local community programs. Your community health centre may also be able to help.

Living with Cancer Education Program

If you want to find out more about cancer and how to cope with it, you may find The Cancer Council's Living with Cancer Education Program helpful.

The program runs for about two hours a week over eight weeks. Groups are small, with plenty of time for discussion. Courses are held frequently at hospitals and community organisations throughout NSW.

Contact your hospital social worker or the Cancer Council Helpline for more information.

Cancer support groups

Cancer support groups offer mutual support and information to people with cancer and to their families. It can help to talk with others who have gone through the same experience. Support groups can also offer many practical suggestions and ways of coping.

Because of the small number of people with brain tumours, it has been difficult to maintain support groups specifically for brain tumours, although there are several in NSW. Your hospital may run a support group: check with your doctor, nurse or social worker, or contact the Cancer Council Helpline.

Electronic discussion groups on the Internet are useful for isolated people. Visit the Australian e-mail discussion group for people with brain tumours and their carers at <http://health.groups.yahoo.com/group/OzBrainTumour/>.

“Being able to talk with someone who has experienced cancer is the most marvellous feeling. With that person I can be completely honest with my feelings and fears.”

The Cancer Council Helpline

The Cancer Council Helpline is a service of The Cancer Council NSW. It is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with specialist cancer nurses. The nurses can send you written information and put you in touch with appropriate services in your own area.

You can call the Cancer Council Helpline on 13 11 20, Monday to Friday, 9am to 5pm, for the cost of a local call. The tele-typewriter (TTY) number for deaf or hearing-impaired people is (02) 9334 1865.

As well as English, the Helpline is offered in the following languages:

Cantonese and Mandarin	1300 300 935
Greek	1300 301 449
Italian	1300 301 431
Arabic	1300 301 625

To access the Cancer Council Helpline in languages not on this list, call the Translating and Interpreting Service on 13 14 50.

Caring for someone with a brain tumour

Caring for someone with a brain tumour can be very stressful. Try to look after yourself during this time. Give yourself some time out, and share your worries and concerns with someone.

You may have to make many decisions. You will probably have to attend many appointments with doctors, support services and hospitals. Many people have found it helpful to take another member of the family or a close friend with them.

Cancer support group membership is generally open to patients and carers. A support group can offer the chance to share experiences and ways of coping for all the family. No-one has to cope alone.

Carers NSW also offers support and information for carers. Call 1800 242 636.



Information on the Internet

The Internet can be a useful source of information, although not all websites are reliable. The websites listed below are good sources of reliable information.

The Cancer Council NSW www.cancercouncil.com.au

The Cancer Council Australia www.cancer.org.au

The Sydney Neuro-Oncology Group www.snog.org.au

Brain Tumour Australia www.bta.org.au

Australian e-mail discussion group for people with brain tumours and their carers

Epilepsy Action (Australia) www.epilepsy.org.au

CancerBACUP (UK) www.cancerbacup.org.uk

National Cancer Institute (US)
..... www.cancer.gov/cancer_information

American Cancer Society www.cancer.org

American Brain Tumour Association www.abta.org

Virtual Trials (US) www.virtualtrials.com



Information checklist

You may find the following checklist helpful when thinking about the questions you want to ask your doctor. If there are answers you don't understand, it is OK to ask your doctor to explain again.

- 1 What type of tumour do I have?
- 2 What is my prognosis?
- 3 What treatment do you advise and why?
- 4 Will my treatment be performed by a doctor who specialises in brain tumours?
- 5 Are there other treatment choices for me? If not, why not?
- 6 Are there any clinical trials of new treatments that I should know about?
- 7 What are the risks and possible side effects of each treatment?
- 8 Will I have to stay in hospital, or will I be treated as an outpatient?
- 9 How long will the treatment take? How much will it affect what I can do? How much will it cost?
- 10 Will I have a lot of pain with the treatment? What will be done about this?
- 11 If I need further treatment, what will it be like and when will it begin?
- 12 When will I have my checkups and what will they involve?
- 13 I would like to have a second opinion. Can you refer me to someone else?

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 a period of time.

benign

Not cancerous. Benign cells are not able to spread like cancer cells.

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 the spinal cord.

cerebrospinal fluid

The clear, watery fluid that surrounds and protects the brain and the spinal cord.

chemotherapy

The use of cytotoxic drugs, which kill or slow growth, to treat cancer.

craniotomy

The surgical removal of a portion of the skull.

CT (computerised tomography) scan

The technique that uses x-rays to build a picture of the body.

hydrocephalus

Build-up of cerebrospinal fluid in the brain.

laminectomy

The main type of surgery to remove a spinal cord tumour. This involves the surgeon cutting into the spinal column and removing the tumour affecting the spinal cord.

magnetic resonance imaging (MRI)

Similar to a CT scan, but this test uses magnetism instead of x-rays to build up cross-sectional pictures of the body.

malignant

Cancerous. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

metastasis

A secondary tumour that develops in a part of the body separate from the original (primary) tumour.

neurologist

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

neurone

A cell specialised to transmit electrical nerve impulses, thereby carrying information from one part of the body to the other.

neurosurgeon

A surgeon who specialises in operations on the nervous system.

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.

radiation oncologist

A doctor who specialises in treating cancer with radiotherapy.

radiation therapist

A health professional (not a medical doctor) who administers radiotherapy.

radiotherapy

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

secondary cancer

Also called metastasis. A tumour that has spread from the original site to another part of the body.

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 connecting all parts of the body with the brain.

steroids

Hormones used in the treatment of disease.



How you can help

The Cancer Council NSW is dedicated to defeating cancer and we need your help. Please:

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, Pink Ribbon Day or hold your own fundraiser.

Make a donation: Any donation whether large or small will make a meaningful contribution to our fight to defeat cancer or join our Breakthrough Appeal by making a regular donation.

Leave a gift in your will: Bequests are our most important source of funding. Leaving money in your will is an easy, effective and personal way of contributing to the cancer cause.

Buy your sun protection goods online or from one of our retail stores: Every purchase contributes to our work.

Become a volunteer: The work of volunteers is absolutely vital to The Cancer Council and there are many ways you can help.

Help us speak out: The Cancer Council is a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues.

Help us create cancer smart communities: You can help us defeat cancer by living and promoting a cancer smart lifestyle.

To find out more about how you can help please call 1300 780 113. We thank you for your support. Together, we can defeat cancer.

Regional offices



Central Coast Region

127 Erina Street
Gosford NSW 2250
Ph: (02) 4325 5444
Fax: (02) 4325 5688

Far North Coast Region

120 Tamar Street
Ballina NSW 2478
Ph: (02) 6681 1933
Fax: (02) 6681 1936

Hunter Region

22 Lambton Road
Broadmeadow NSW 2292
Ph: (02) 4961 0988
Fax: (02) 4961 0955

Mid North Coast Region

121 High Street
Coffs Harbour NSW 2450
Ph: (02) 6651 5732
Fax: (02) 6652 1530

North West Region

Shop 2
218 Peel Street
Tamworth NSW 2340
Ph: (02) 6766 1164
Fax: (02) 6766 7053

South West Region

40 Morrow Street
Wagga Wagga NSW 2650
Ph: (02) 6921 7760
Fax: (02) 6921 3680

Southern Region

1 Lowden Square
Wollongong NSW 2500
Ph: (02) 4225 3660
Fax: (02) 4225 1700

Sydney Metropolitan Region and Head Office

153 Dowling Street
Woolloomooloo NSW 2011
(PO Box 572
Kings Cross NSW 1340)
Ph: (02) 9334 1900
Fax: (02) 9334 1739

Western Sydney Region

43 Hunter Street
Parramatta NSW 2150
Ph: (02) 9687 1399
Fax: (02) 9687 1118

Western Region

84 Byng Street
Orange NSW 2800
Ph: (02) 6361 1333
Fax: (02) 6361 1863

Cancer Council Helpline 13 11 20

For support and information on cancer and cancer-related issues, call the Cancer Council Helpline. This is a free and confidential service.

Cancer Council Helpline	13 11 20 (cost of a local call)
TTY	(02) 9334 1865 for deaf and hearing-impaired
Cantonese and Mandarin	1300 300 935
Greek	1300 301 449
Italian	1300 301 431
Arabic	1300 301 625

For further information and details please visit our website:

www.cancercouncil.com.au



*Building a
Cancer Smart
Community*