

Brain and Spinal Cord

1. Introduction

The brain controls our thoughts, intelligence, memory and emotions. It coordinates body functions (like movement, blood circulation and production of hormones) and interprets information from our senses (sight, hearing, smell, touch and taste).

The average brain weighs about one and a half kilograms and is surrounded and protected by the skull. The spinal cord is encased in the spinal column (backbone): it 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.

The brain and spinal cord form the central nervous system. The parts of the central nervous system are made largely of nerve cells called neurons. Neurons transmit messages around the body, which enable us to act when we wish (for example, to stand up and walk). They also enable body functions we are barely aware of: for example, controlling digestion of food and causing the heart to beat rapidly when we exercise.

Brain tumours

Some types of brain tumour are benign and some are malignant. A benign tumour is made of slow growing cells and is unlikely to spread. Some benign brain tumours can cause problems by pressing on and damaging the surrounding brain tissue; however, they can often be successfully removed. Common types of benign brain tumours are meningiomas, neuromas, pituitary tumours, cranio-pharyngiomas and juvenile pilocytic astrocytomas.

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

Brain tumours are usually known for the cell type from which they arise. Types of malignant brain tumours include: gliomas (astrocytomas, oligodendrogliomas, ependymomas, glioblastomas and anaplastic astrocytomas) and mixed cell type gliomas, medulloblastomas, chordomas and central nervous system lymphomas.

Hydrocephalus

The brain contains four cavities filled with cerebrospinal fluid, which flows through narrow passages between the cavities and the surface of the brain. Occasionally, a brain tumour can block this flow. When this happens, the fluid can collect and build up, creating pressure on the brain. This is called hydrocephalus and it is common in children with brain tumours.

Spinal cord tumours

The spinal cord connects nerves from all parts of the body with the brain. It extends from the base of the brain to just below the waist. It is about as thick as a little finger and is protected by the spinal column. Tumours are less common in the spinal cord than in the brain.

A tumour on the spinal cord may stop the flow of messages along the nerves between the brain and body, in much the same way, as does injury to the spinal cord. Most commonly, a tumour in the spinal cord will affect the spinal cord by pressing on it. Tumours can occur in the spinal cord or membrane surrounding the spinal column. They can be benign or malignant. Like brain tumours they are named according to the type of cell they arise from.

Causes of brain and spinal cord tumours

The causes of these tumours are not fully understood. Researchers around the world are investigating possible causes.

How common are brain and spinal cord tumours

Malignant tumours of the central nervous system are diagnosed in around 350 Victorians every year.

2. Diagnosis

Symptoms of tumours of the central nervous system vary depending on what part of the brain or spinal cord a tumour presses on. Sometimes, when a tumour develops so gradually that they are scarcely noticed.

Symptoms of brain tumours

As a tumour grows inside the skull it presses on the surrounding brain tissue, creating pressure. Benign and malignant tumours can cause the brain around them to swell. Headaches are often the first symptom. Headaches caused by brain tumours can be severe, persistent, or can come and go.

Other symptoms include:

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

If you have not been diagnosed with a brain tumour and are just reading through this information, please be aware that most headaches are not due to brain tumours and some of the symptoms listed above can be caused by other illnesses. However, see your doctor if you have any concerns about your health.

A brain tumour may also cause seizures (also known as fits or convulsions) by irritating the nerve cells in the brain. Seizures may simply be a loss of consciousness for a few seconds, or they may involve muscle spasms or abnormal movements for 30 seconds or more.

Symptoms of spinal cord tumours

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 disease. Loss of feeling, muscle weakness and loss of movement in legs and arms may follow.

What doctors and other health professionals will I see?

Your general practitioner will refer you for initial tests to confirm whether or not you have a brain or spinal cord tumour. He or she may later refer you to a specialist who will advise you about treatment options.

You will see some of these health professionals:

neurosurgeons and neurologists: who diagnose and treat people with brain and spinal cord tumours (neurosurgeons with surgery)

- * medical oncologists: who are responsible for chemotherapy
- * radiation oncologists: who are responsible for radiotherapy
- * dieticians: who recommend the best diets to follow while you are in treatment and recovery
- * nurses: who assist you through all stages of your hospitalisation and cancer experience

How a brain or spinal cord tumour is diagnosed

Your doctor will take a detailed history of your symptoms and examine you thoroughly. If a tumour is suspected, you may be referred to a neurologist or neurosurgeon: doctors who

specialise in diseases of the brain, spinal cord and related nerves.

If a spinal cord tumour is suspected, you will need to have x-rays of the affected spinal areas. The doctor may also order a magnetic resonance imaging (MRI) scan.

If a brain tumour is suspected, the specialist will check how different parts of your brain are functioning. 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 and to distinguish between hot and cold on your skin. You may be asked to do some mental exercises, such as some simple mental arithmetic.

The doctor will also probably look into your eyes, using an ophthalmoscope, to see the end of your optic nerve. This nerve connects the eye directly to the brain and it may bulge a little if a tumour is pressing on your brain, increasing the pressure inside your skull (the intracranial pressure).

Two main tests, CT scan and magnetic resonance imaging, are used to detect brain tumours and help the doctors to plan the most effective treatment for you.

Computerised tomography (CT) scan

You may have a computerised tomography (CT) scan.

The 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. It usually takes about 30-40 minutes to complete this painless test.

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 do not eat or drink for about four hours before the scan. The dye injection can cause a burning sensation.

You will be asked to lie flat on a table while the CT scanner, which is large and round like a doughnut, rotates around you. Most people are able to go home as soon as their scan is over.

Magnetic resonance imaging (MRI)

This test is similar to a CT scan, but it uses magnetism instead of x-rays to build up a series of very clear and detailed pictures of the affected area.

Like a CT scan, MRI is painless, and the magnetism is harmless. You will be asked to lie very still on a couch inside a metal cylinder, which is open at both ends. The machine is noisy. The whole test may take up to an hour to complete. The cylinder makes some people feel quite claustrophobic, but you may be able to take someone into the room with you to keep you company.

Angiogram (also called an arteriogram)

This test is used only rarely in people with tumours. Dye is injected into an artery and a series of x-rays is taken as the dye flows through the blood vessels of the brain. This will show up the position of the tumour and the blood vessels supplying it.

Further tests

Other tests which are sometimes used in the diagnosis of tumours of the brain and spinal cord are:

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

If your doctor recommends any other tests, ask him or her to explain the tests before you have them. Understanding what is in store can help to relieve some of the anxiety you may feel before having a test.

3. Treatment

Tumours of the central nervous system may be treated with surgery, radiotherapy, chemotherapy or steroid therapy. These treatments may be used alone or in combination. Prompt treatment may prevent or lessen the effects of spinal cord tumours. Radiotherapy,

chemotherapy and surgery may all play a role in the treatment of these tumours. Your specialist will advise you of the best treatment course for your situation.

The choice of treatment will depend on:

The actual tumour what type it is, its size, and exactly where it is in your central nervous system, and the individual patient: your age, medical history and general state of health. Having diagnosed the type of tumour the aim of treatment will be: to remove or destroy the tumour or, if this is not possible to slow the growth of the tumour and to relieve the symptoms by reducing the size of the tumour and any swelling around it, so that it puts less pressure on other parts of the brain or spinal cord.

Before your treatment starts, make sure you have discussed it with your doctor so that you know what to expect, including any risks involved. You may find it helpful to have your partner or a friend or relative with you when you talk to the doctor. You may also find it helpful to write down your questions before your visit. A list of questions you might like to ask your doctor is included at the end.

If your doctor suggests that you have more than one type of treatment, this does not necessarily 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.

Surgery

Some tumours can be completely removed by surgery. Where a tumour is more spread out, or where it cannot be removed completely without damaging other important parts of the central nervous system, 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 or spinal cord. Occasionally this is not possible.

Whether surgery removes all or only part of the tumour it often improves a person's condition and frequently enables someone who was seriously ill to lead an active life, at least for a time.

Surgery for a brain tumour

The operation to treat a brain tumour is called a craniotomy (a temporary opening of the skull). 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 itself is then removed, the piece of skull replaced, and the skin stitched back in place.

If the tumour is at the back of your brain, the surgeon may not need to replace the piece of skull, as the muscles at the back of the neck are often strong enough to support the brain. This sort of operation is called a craniectomy (the permanent removal of a piece of skull). If hydrocephalus (building up of the cerebrospinal fluid in the brain) is a problem, particularly if the tumour itself is in too dangerous a position to remove, the surgeon may put a small permanent drain, tube, called a shunt, just beneath the skin. The shunt will take the excess fluid from the brain and drain it into the abdomen. Sometimes, if the hydrocephalus has made a person very ill, a shunt may be put in first to relieve the symptoms, and surgery for the brain tumour may follow a week or two later.

During surgery, the surgeon will 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 examined under the microscope, to discover exactly what type of tumour you have. This helps the doctors to offer advice about further treatment.

After the operation

For the first 12 hours or so after the operation, you will be closely observed by your care team. Your head may be completely bandaged and for the first day, a small tube may be placed to drain any excess blood from the operation site into a bottle.

Your face and eyes may feel swollen after the operation, but this should go down within about a week. The length of your stay in hospital 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 spinal cord tumours is a laminectomy. This is a temporary opening of the spinal column. The surgeon cuts into the spinal column and removes the tumour/s affecting the spinal cord. Care is taken to avoid weakening the spinal column.

After the operation

After the operation, the nurses will regularly check your pulse, blood pressure, temperature and dressing, and check the movement and sensation in your legs. You will be turned in bed in a way that avoids twisting your spine and hips. The staff, including a physiotherapist, will teach you how to move to reduce the strain on your spine. 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 activity again.

Radiotherapy

Radiotherapy (x-ray treatment) treats cancer by using high-energy x-rays to kill the cancer cells, while doing as little harm as possible to the surrounding healthy tissues. In children, radiotherapy to the head is given in lower doses than is used for adults, because it can slow a child's intellectual development. It 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. Radiotherapy can also slow a child's growth by affecting the pituitary gland in the brain, which secretes hormones that control growth. These children may need hormone therapy to help them to grow and develop normally. In adults, radiotherapy is often used after surgery for malignant brain tumours and malignant spinal cord tumours. The course of radiotherapy you receive will depend on the type and the size of cancer that you have. Some people find that their symptoms fluctuate after surgery and during radiotherapy. The extent of this fluctuation varies from person to person. In order to make absolutely certain that exactly the same area is being treated each time, the radiation therapist will make a number of marks on your skin. These marks will consist of lines, crosses and dots applied with special inks. Sometimes these non-permanent marks will need to be redone during the course of the treatment. Occasionally, permanent marks, each consisting of a fine dot, may be suggested to you. These small black 'tattoo' dots are about the size of a pinhead. If these are necessary, the procedure will be explained to you so that you may give your informed consent.

Side effects of radiotherapy

Radiotherapy to your head 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. Scalp and skin in the treatment area may also become red, dry and tender. Do not use any creams, lotions or soaps without talking to your doctor or radiation therapist first. You also need to check before shaving any affected skin. It is important to keep the affected skin out of the sun, as **the sun's rays very easily damage it**. A rare side effect of radiotherapy to the spine is damage to the spinal cord, called radiation myelopathy. This sometimes occurs in the months following radiotherapy. It causes an unusual sensation from the neck to the hands or feet. If you notice this feeling, speak to your doctor. Common side effects of radiotherapy are tiredness, which may last a month or so after radiotherapy has finished, and nausea, which can be helped by medication. Mild headaches are also quite common.

Chemotherapy

Chemotherapy is the use of anti cancer (cytotoxic) drugs to damage or destroy cancer cells. The drugs work by stopping the cancer cells from growing and reproducing themselves. Chemotherapy is not a common treatment for brain and spinal cord tumours in adults. (In children with these tumours it is more effective and is therefore used quite often.) 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 of the treatment. The number of courses given will depend on the type of cancer, and how well it is responding to the drugs. You may have chemotherapy in hospital over a few days through an intravenous drip. Alternatively, you may have chemotherapy in tablet form, as an outpatient.

Side effects of chemotherapy

Some drugs used in chemotherapy can cause side effects. People undergoing chemotherapy often experience fatigue. Ask your doctor what side effects to expect from the treatment, as these will vary, depending on the type of chemotherapy you have.

Steroid therapy for brain tumours

Steroid drugs (usually dexamethasone) are used to reduce the swelling that often surrounds brain tumours either before or after surgery or radiotherapy. They do not treat the tumour itself but they do help to relieve the swelling and pressure caused by the tumour. Steroids can be used at many stages of treatment, for varying lengths of time. Some people may need to take them for days, others for months.

Side effects of steroid therapy

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.

Your appetite may increase, and you may find that you put on weight quite quickly (within a few weeks), especially on your face, waist and shoulders. Steroids often produce a feeling of wellbeing, and may also make you feel more like eating.

The level of sugar in your blood may increase, and you may need to do a simple daily test to check for sugar in your urine or blood. The doctor or nurse will show you how to do this.

Steroids cause muscular weakness in some people, and this can be troublesome, especially if your turnout is also causing weakness. This is a rare side effect, and more common with high dose, long term steroid treatments. Tell your nurse or doctor if you have any muscle weakness.

Steroids can cause acne and water retention.

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 a bit depressed for a while after you finish your dose. This depression lasts longer for some people than for others.

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

If you are having steroid treatment, you should always carry a steroid card (which your doctor or nurse will give you) to show the type of steroid you use, and the dose. This is in case you become ill and need medical treatment the doctor treating you will need to know which medications you are on.

Palliative treatment

If it is not possible to cure your illness, then your doctor will discuss various treatments for specific problems caused by the cancer. Palliative treatment is treatment that relieves or soothes pain and other symptoms of illness. Palliative care is available for all people who experience pain and distress associated with cancer, whatever their stage of cancer treatment. It is a particularly important type of treatment for people with advanced cancer, who cannot be cured but can expect to live without undue pain and distress.

Palliative care includes pain relief using pain-killing drugs and other measures. Pain is usually well controlled with oral medication. If pain is particularly severe or difficult to control, then you may have injections of pain-relieving medication. Steroids can be valuable palliative treatments for people with brain tumours. Discuss with your doctor their benefits versus their side effects.

General practitioners, cancer specialists and specialist palliative care teams in hospital all play important roles in palliative treatment for people with early and advanced cancer.

Prognosis

The prognosis (or 'outlook') 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 radiotherapy or chemotherapy. If you have a benign tumour that is completely removed, total cure is likely.

The rate of growth and spread of malignant tumours also varies. Some types of malignant tumour grow and spread rapidly while others develop slowly over a number of years.

Response to treatments also varies a lot.

After treatment for a brain tumour some people appear to be completely cured and may live for many years. In many people, however, brain tumours recur.

Where a cure is not possible, treatment can often relieve symptoms and make it possible to lead a good and relatively symptom-free life, sometimes for several years. Recurrence of symptoms after treatment varies from person to person. All types of brain tumours can occur in children. 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.

Making Decisions about treatment

Sometimes making decision about what the right treatment for you is very difficult. You may feel that everything is happening so fast that you don't have time to think things through.

Others may find that waiting for test results and for treatment to begin is very difficult.

While some people feel they are overwhelmed with information, others may feel that they don't have enough. You need to make sure that you understand enough about your illness, the possible treatment and side effects to make your own decisions. Don't be hurried into making decisions. Waiting a few days will not make a difference to the success of your treatment.

If you are offered a choice of treatments, you will need to weigh up 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 advised.

Some people with more advanced cancer will always choose active treatment, even if it only offers a small chance of cure. Others want to make sure that the benefits of treatment outweigh any side effects. Still others will choose the treatment they consider offers them the best quality of life.

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, or your own religious or spiritual adviser.

Talking it over can help to sort out what course of action is right 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 records to be sent to the second-opinion doctor. You can still 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 that 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 existing treatments. Your doctor will only discuss a clinical trial with you if the treatments are considered to be as good as or better than the standard treatments available. 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 that you fully 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 any problems occur while I am in the trial?

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, but it will always be at least the best treatment available. If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not jeopardise your treatment for cancer. It is always your decision to take part in a clinical trial. If you do not want to take part, your doctor will discuss the best current treatment choices with you.

Follow-Up

After treatment, you will need regular check-ups. To begin with, these checkups will occur several times per year, after which you will usually need to have a check-up at least once a year. These checkups are most important to make sure there is no reappearance of the original cancer and that a new one does not develop.

It is natural to feel anxious about the possibility of further changes developing. 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 be successful.

It can take time before you feel reassured by check up visits. You will need to rebuild your confidence in your body and in the future. You may find that you need reassurance from your specialist. This is quite normal. Ask lots of questions if you want to and try to be sure that all your concerns are answered. Remember that you are not alone and that your feelings are normal. Be patient with yourself as you find your way to live with having and having had a tumour. Brain tumours can affect some of the normal functions of the brain, such as speech, movement, balance or memory. If you have problems in these areas, you may need the help and advice of other members of the health care team, including the speech therapist, physiotherapist and occupational therapist. This can start in hospital and people who need help for some time can continue their therapy as outpatients.

Problems with speech can include difficulties in finding the right words using sentences properly, or difficulties in keeping your speech under control. Your speech therapist can help you to understand the problem and give you and your family some ideas and help on how best to communicate. A few brain tumours cause problems with swallowing; your speech therapist and dietician can also help with these. Your physiotherapist can help you to overcome or manage problems with movement, balance or coordination, and the occupational therapist can help you to cope with the ordinary practical tasks involved in everyday living.

Is there any research being done?

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

Experiment 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.

4. Seeking Support

When you are first diagnosed with cancer, you may feel a variety of emotions, such as fear, sadness, depression, anger or frustration.

Sometimes you may find that your friends and family do not 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 very difficult to bear 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.

Diet

A balanced, nutritious diet will help you to keep as well as possible and cope with the cancer and any side effects of treatment. Depending on the kind of treatment you have had, you may have special dietary needs. A dietician can help to plan the best foods for your particular situation - ones that you find tempting, easy to eat and nutritious. The Resource and Wellness Centre have a resident dietician. To make an appointment please call 03 2698 7300 or email contact@cancer.org.my

Exercise

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 upon what you are used to and how well you feel. Discuss with your doctor what is likely to be best for you.

Relaxation techniques

Some people find relaxation or meditation helps them to feel better. The Resource and Wellness Centre offer relaxation and meditation classes.

Caring for someone with cancer

Caring for someone with cancer can be very stressful, particularly when it is someone you care about very much. Look after yourself during this time. Give yourself some time out, and share your worries and concerns with someone outside.

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 with them another member of the family or a close friend. It also helps to write down questions beforehand, and to take notes during the appointment. 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.

If your child has a brain tumour

Although brain tumours occur considerably less often in children than in adults, they are still the second most common cancer in children (after leukaemia). While the symptoms, diagnosis and treatment of brain tumours in children are much the same as in adults, children's brain tumours pose a number of different problems.

Effects of treatment

Normal growth and development is obstructed in some children as a result of damage to the part of the brain that produces growth hormones. This damage may be caused by the tumour itself or by the treatment. Hormone therapy may be required.

What do I tell my child?

It is quite natural to want to protect your child from something as threatening as a brain tumour and some parents will find it very 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 with your child about the brain tumour, do so as this will help your child to be less anxious and to feel a little more in control of the

situation. How much your child actually wants to know will depend on his or her age and needs. Children are often satisfied with just a bit of information, or with simple answers to their questions. Your openness and calm confidence can help to reassure your child.

How do I treat my child?

Any serious illness is hugely disruptive to a child's and family's normal routine. It is also frightening for all concerned, and often uncomfortable or painful for the child. Hospitals, blood tests, large equipment, surgery, radiotherapy and chemotherapy may be threatening. Your child, just like you, is likely to feel angry, depressed, confused, afraid or overwhelmed. These feelings will change rapidly.

Your child needs as much security as possible to help him or her to cope. Throughout the course of the illness and its treatment, one of his or her main needs will be for as many things as possible to remain 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. Whether your child is in hospital or at home, try to treat him or her as normally as possible, within the limits of the illness.

What about the rest of the family?

How do you balance the needs and demands of your sick child and those of your partner and other children? There is no easy answer to this problem, but possibly the most important thing is to acknowledge the changes, discuss the problems and ask for help when you need it from relatives or friends, from hospital staff or anyone else who can help.

Everyone reacts differently: mothers and fathers, as well as other relatives, often react differently to cancer in a child. One, for instance, may focus on the good news, the other on the bad. Some parents protect themselves by distancing themselves, or getting lost in work, while others cope by being very involved in caring for the child. This sometimes puts a great deal of strain on family relationships, particularly your relationship with your partner, at a time when you most need those relationships to be strong.

It is important to recognise that there is no right or wrong way to react or to cope: everyone is different. The best way of understanding these differences is to talk about them with your partner, if you can, and to share your feelings of anger, sadness, and hope with each other, without blame or criticism.

If you are going to look after your child with cancer or other serious illness, and balance this with the needs of the rest of the family, you will need to eat and sleep well, and, most importantly, have a little time for yourself. Looking after yourself will help you to remain healthy and in control of the situation, and to support your child and family as effectively as possible.

Could I have prevented it?

Most parents wonder about this and feel guilty, but the answer is certainly 'NO'. There is no evidence to suggest that parents are in any way responsible for their child's brain tumour.

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 that can help children to work through their fears and feelings and can also prepare them to cope with treatments such as radiotherapy and chemotherapy. If your child has difficulties with speech or movement, the speech therapist, physiotherapist or occupational therapist may be called in. A number of organisations and parents' support groups offer practical and emotional support for families and children, camps for children and a number of other services.

If you are a teenager with a brain tumour

Your teenage years are the time you start to break free from your parents and take charge of your own life. A serious illness like a brain tumour turns this completely on its head: suddenly you seem to lose all control over your life and parents and doctors take over. While you need their support and love, you may also thoroughly resent them. One of the most difficult things

to handle is the change to the way you look, particularly if you lose your hair. It can help to talk over your difficulties with family, friends or someone right outside the situation.

Cancer Information and Support Service

The Resource and Wellness Centre is a service of the National Cancer Society of Malaysia. 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 specially trained staff. The staff can send you written information and can put you in touch with appropriate services in your own area. The Centre also provides complementary services such as relaxation & meditation, massage & aromatherapy, yoga and qi-gong. Telephone 03 26987300 or e-mail contact@cancer.org.my

5. Information Checklist

You may find the following checklist helpful when thinking about the questions you may want to ask your doctor about illness and treatment.

1. What type of cancer do I have?
2. How extensive is my cancer? (How much cancer is there?)
3. What treatment do you advise for my cancer and why?
4. Will my treatment be performed by a doctor who specialises in tumours of the central nervous system?
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. Will the treatment affect my sexual relationships?
13. How frequent will my check-ups be and what will they involve?
14. Are there any problems I should watch out for?
15. I would like to have a second opinion. Can you refer me to someone else?
16. Is my cancer hereditary?

If there are answers you do not understand, feel comfortable to say, 'Can you explain that again?' or 'I am not sure what you mean by...'

Other questions and notes

It can be useful to jot down any other points you may want to discuss with your doctors.

Glossary

anaesthetic

A drug given to stop a person feeling pain. A 'local' anaesthetic numbs part of the body; a 'general' anaesthetic causes temporary loss of consciousness.

angiogenesis

The formation of new blood vessels to support tissue. Angiogenesis enables tumours to develop their own blood supply, which helps them to survive and grow.

angiogram

An x-ray of blood vessels which have been injected with a dye.

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.

Brain

The mass of nervous tissue that forms the upper end of the central nervous system.

carcinoma in situ

Cancer that involves only the cells in which it began and has not spread to other tissue.

cells

The 'building blocks' of the body. A human is made of millions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

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 particular drugs to kill cancer cells or slow their growth.

computerised tomography (CT) scan

The technique for constructing pictures from cross sections of the body, by x-raying the part of the body to be examined from many different angles.

craniectomy

A type of surgery to the skull where pieces of bone are removed so the surgeon may gain access to the brain. The pieces of bone are not replaced.

craniotomy

The surgical removal of a portion of the skull

genes

The tiny factors that govern the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents. These genes are found in every cell of the body.

hydrocephalus

A building up of cerebrospinal fluid in the brain.

laminectomy

A temporary, surgical opening in the backbone.

lymph vessels

The lymphatic system is part of the immune system, which protects the body against 'invaders' like bacteria and **parasites**. It is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body.

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 which develops in a part of the body separate from the original (primary)

neurologist

A specialist 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. We are born with about 40 billion neurones. Unlike all the other cells in the body, nerve cells do not replace themselves.

neurosurgeon

A surgeon who specialises in operations on the nervous system.

ophthalmoscope

An instrument for viewing the inside of the eye.

primary cancer

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

radiation therapist

A health professional (not a medical doctor) who administers

radiotherapy

The use of particular forms of radiation, usually x-rays or gamma rays, to kill diseased cells.

secondary cancer

Cancer metastases.

spinal column

The bone surrounding the spinal cord.

spinal cord

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

steroids

Hormones used in the treatment of disease.

tissue

A collection of cells.

tumour

A new or abnormal growth of tissue on or in the body.