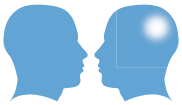
Brain and Spinal Tumours in Children and Young People

A PARENT'S GUIDE



SAMANTHA DICKSON BRAIN TUMOUR TRUST

Head to head with brain tumours

This booklet has been sponsored by Samantha Dickson Brain Tumour Trust

Children's Cancer and Leukaemia Group - www.cclg.org.uk

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Introduction

How To Use This Booklet

This booklet has been written to provide information for parents, or carers, who have a child diagnosed with a brain or spinal **tumour**. Older children may also find this booklet helpful. To make the text easier to read, all tumours of the central nervous system (brain and spinal cord) will be referred to as brain tumours. Any unusual terms have been highlighted in **bold** and are defined in a glossary at the end of the booklet. The diagrams on pages 37 and 38 will also help. The booklet is structured so that you can dip in to different parts as you need the information. The booklet covers all stages, from initial diagnosis to long term follow-up. Don't try and read it all at once.

Explanation of medical terms and treatment

It is devastating to be told that your child has a brain tumour. The information contained in this booklet has been organised to explain the many medical terms that may be used in explaining your child's tumour, its treatment and how they will impact upon your child's future life.

Helping you to cope

Experience has shown us that the more the family and the child know about the tumour and treatment, the better they are able to cope. The better the family can cope, the better we can treat the child. The processes of diagnosis and treatment are complex and every child and family must be treated to suit their own special circumstances.

This booklet should be read alongside other information booklets about children's cancers, including those that provide information about such things as **central venous lines**.

Brain and spinal tumours affect 1 in 2,500 children and young people (i.e. those in the age group 0 to 16 years). This means that about 350 young patients are diagnosed in the UK each year. This booklet does not contain detailed information about the different types of brain tumour; these are included as separate factsheets to accompany the booklet. You will be given the one that tells you all about your child's tumour.

We hope you find this booklet useful. However, it does not replace the valuable information and advice you will receive from your treatment team. You do not need to understand all the information in this booklet to help your child through their treatment but you may find some of it useful.

Diagnosis

What Are The Typical Signs And Symptoms Of Brain Tumours?

Each area of the brain has very specific functions. The signs and symptoms of a brain **tumour** depend on the particular area of the brain in which the tumour grows. Possible symptoms are listed below, divided into different areas of the brain. However, not all symptoms may occur in any one child. The symptoms may help a doctor to know where to look for a tumour in your child's brain and that is why you were asked so many questions at diagnosis.

See the section "The Brain - Structure and Function" on page 28 for more information about how the brain works.

The Cerebral Cortex (or Cerebral Hemispheres)

Frontal lobe

Possible symptoms of a tumour here include:

- Changes in behaviour or character
- Emotional instability
- Fits (seizures)
- Headaches
- Slurred speech
- One sided weakness of legs and arms (hemiplegia)
- Memory problems

Temporal and parietal lobes

Possible symptoms of a tumour here include:

- Speech problems (if the tumour is on the left side of a right handed child and vice versa)
- One sided weakness (also known as hemiplegia) (if the face is affected, the tumour will be on the same side of the brain as the weakness on the face. If areas of the body below the neck are affected, the tumour will be on the opposite side of the brain to the weakness).
- Fits (seizures)
- Headaches

Occipital lobe

Possible symptoms of a tumour here include:

- Visual problems

The cerebellum and fourth ventricle

Possible symptoms of a tumour here include:

- Raised intracranial pressure
- Headaches
- Vomiting
- Squint
- Double vision
- Uncoordinated walking
- Clumsiness

- Slurred speech
- One sided weakness

The brain stem

Possible symptoms of a tumour here include:

- Squint
- Problems with eye movements
- Uncoordinated clumsy walking
- One sided weakness
- Speech difficulties
- Swallowing difficulties
- Headaches and vomiting

The midline of the brain (pituitary, hypothalamus, optic nerve pathways, pineal body, thalamus)

Possible symptoms of a tumour here include:

- Visual disturbances
- Problems with eye movements
- Headaches
- Nausea and vomiting
- Tremors in the arms and legs
- Personality changes
- Behavioural problems
- Changes in the level of consciousness
- Problems with hormonal secretions (growth, water balance, age of puberty)
- Raised intracranial pressure

How Are Brain Tumours Diagnosed?

The first stage of diagnosis is usually when your GP refers you to a specialist because your child has had a specific symptom or their behaviour has changed. In a small number of cases a child may become suddenly unwell and they will be seen first in an accident and emergency department and be referred from there for an urgent appointment. Soon after this, the **neuro-oncology** team become involved. They will tell you what has been seen in your child to cause concern, what the possible causes are, and how a diagnosis will be made.

Diagnosing a brain tumour is a very rare event for any general doctor (i.e not an oncology specialist). In a small number of cases there can be a long delay in diagnosis due to mild non-specific symptoms that build up slowly, or perhaps a number of symptoms that did not originally seem related.

Scans as part of the diagnosis

Tumours of the brain are usually first discovered on a scan. However, your child will be thoroughly examined by a doctor before this and a careful history taken to assess all their signs and symptoms of a tumour. Details of when any signs or symptoms first started will be recorded. This will help the doctor to see if any have got worse. All the signs and symptoms discussed on pages 2-3

will be considered. Your child will then have a scan in the radiology department. There are a number of different scans that can be performed:

- CT Scan (Computerised Tomography)
- MR Scan (Magnetic Resonance Scan Or MRI)
- Other Types Of Scan:

  Positron-Emission Tomography (PET) Scan

  Magnetic Resonance Spectroscopy (MRS)

These are all described in the following sections.

CT Scan (Computerised Tomography)

This scan uses radiation (a series of x-rays) to see structures and fluids within the brain. It is best used for looking at swellings and fluid problems, or for looking for bleeding. The scan can be arranged relatively quickly and the scanning time may only be a few minutes. This may be an initial scan carried out in a local hospital to identify that a tumour is present, but will show little detail about what it is made of. CT scans are painless but your child may be given a sedative or general anaesthetic to make sure that they lie still. In many cases your child will need to receive an injection into a vein of a chemical which can help to highlight the tumour on the scan. This is called contrast.

MR Scan (Magnetic Resonance Scan or MRI)

This scan uses radio waves and a strong magnet to create very detailed pictures of the brain and spinal cord and the exact position of any tumour within these. This is the most common scan for making a diagnosis of a brain tumour. The process is harmless and painless, but the machine is very noisy so your child will be given earplugs or headphones to wear. A sedative or general anaesthetic may be given to make sure the child lies still. Intravenous contrast may also be necessary in this type of scan (see above).

Other types of scan

In recent years some more specialised scans are becoming available. They are used to increase our knowledge of how tumours behave in addition to their position.

Positron-Emission Tomography (PET) Scan

This scan mainly looks at metabolism (or the chemical processes of living cells) through the brain and spinal cord, as well as through the tumour. It uses low-dose radioactive glucose and shows up tumour cells because they use glucose in a different way from normal cells.

Magnetic Resonance Spectroscopy (MRS)

This is like an MR scan as it shows detailed pictures of the brain. However, an MRS scan can also pick up pictures of the amount of less common chemicals in the brain, telling us a great deal about how the tumour cells work. This is still an experimental technique, but it is hoped in time that it may provide more information about cancer cells that will aid treatment. The data from this machine can be combined with a conventional MR scan to give even more detailed information about the tumour.

What Further Investigations May Be Needed?

Once it is known where the tumour is and how it is behaving, some further tests need to be performed to confirm exactly what type of tumour it is and whether it has spread to the fluid surrounding the brain. The following tests may be used:

- Biopsy
- Blood tests – in some tumours a blood test can confirm a diagnosis
- Lumbar puncture – in some tumours this test can tell us if the tumour has begun to spread

Blood tests

There are certain tumours (**germ cell** tumours) that release chemicals that can be detected in the blood, e.g. alphafetoprotein (**AFP**) and **beta human chorionic gonadotrophin (HCG)**. If these tumours are suspected, it is possible to take a blood sample to look for these chemicals and diagnose the tumour without the need for a biopsy.

Lumbar puncture

A fine needle is inserted into the spine to remove some of the fluid surrounding the spinal cord. This is usually done under a general anaesthetic. The fluid is analysed. If tumour cells are found this tells us that the tumour cells are spreading via the fluid, and if not treated will cause metastases (secondaries) in other areas of the brain.

Tumour diagnosis and the use of biopsy

In most situations we base our diagnosis on a piece of tissue obtained from surgical resection of the tumour. However, there are a few situations when resection is not possible or advisable and then a biopsy is performed to confirm a diagnosis. A biopsy is when a small sample of the tumour is removed in an operation by either directly opening up the skull or using a stereotactic method. The stereotactic approach uses a metal frame to hold the child's head in a particular position whilst a needle is inserted through the skull and guided accurately to the tumour. The samples of tumour are sent to a **histopathologist**

who will make the definite diagnosis that all members of the medical team will work from. The **histopathologist** can tell whether the tumour is **low grade** or **high grade** and therefore how well it will respond to treatment. This definite diagnosis ensures that the best form of treatment is offered to your child.

What is the difference between a Low and High Grade tumour?

Tumours are groups of cells that keep multiplying in an uncontrolled way, and usually develop into a lump.

Low grade (benign) tumours

Benign tumours (often called low grade) are made up of cells that are growing abnormally but are less aggressive than **malignant** tumours. The cells of a benign tumour divide relatively slowly. They usually grow within a defined space and are less likely to spread into other brain tissue. It may, therefore, be possible to surgically remove all of this type of tumour, resulting in a cure. Some benign tumours may, however, grow in very sensitive areas of the brain, making surgery difficult. In these cases other forms of treatment may be needed. Benign tumours only rarely metastasise (spread).

High grade (malignant) tumours

Malignant (high grade tumours) are very aggressive tumours whose cells divide rapidly. These tumours often invade the surrounding normal brain, which can make it difficult and sometimes impossible to remove all of the tumour cells by surgery. As a result, surgery only rarely cures high grade tumours and other treatments such as radiotherapy or chemotherapy are needed. Malignant tumours can metastasise to other parts of the brain and spine by cells breaking off the main tumour.

Treatment

What Treatment Can Be Given?

After a definite diagnosis has been made, the doctor will discuss with you which treatment is best for your child. The treatment is likely to involve one or more of the following: **Neurosurgery**, **Radiotherapy** and **Chemotherapy**. These are all described in the following sections.

Your doctor may also talk to you about treatment that is available as part of a **clinical trial**. See page 12 for more details.

Neurosurgery

Neurosurgery is an essential part of the care of brain **tumours** in children. The neurosurgeon will often be the first specialist to see the family and child with a brain tumour. The explanations and support they give will form part of a family's first impressions as they come to terms with the reality of their child's illness. There are three mains aims of neurosurgery for brain tumours. They are to:

1. Obtain a diagnosis of the tumour
2. Relieve raised intracranial pressure
3. Surgically remove the tumour

These are all described in the following sections.

Obtaining a diagnosis of the tumour

The main aim of **neurosurgery** is to obtain a diagnosis, either as part of the open surgery to remove the tumour, or as a **biopsy**. Biopsies are performed when the tumour is either too close to vital structures to be removed safely or if a diagnosis needs to be made first before a complex plan of treatment, which may or may not include surgery, can be drawn up.

Relieving raised intracranial pressure

As the skull is a rigid container, the presence of the brain tissue and cerebrospinal fluid exerts a pressure within the skull. This pressure is called intracranial pressure and is closely monitored by the body. This pressure increases if there is an increase in brain tissue (caused by the presence of tumour tissue) or an increase in the volume of cerbro-spinal fluid (too much being made or too little being drained away). Some tumours cause a serious build up of pressure, requiring urgent relief. This may happen before or after a tumour is removed (see page 8). Surgery can be used to relieve pressure, by removing tumour tissue or through placing either a **shunt** or drain, or by performing an **endoscopy** (keyhole surgery).

Removing the tumour

Surgery is used to remove the tumour and so improve the chance of a cure. Recent advances in equipment such a **neuro-navigation** (using a computer to show where the surgeon is in the brain and to navigate around it) have made surgery more accurate and safe. In most tumours, complete removal greatly improves the chances of survival and, in some cases, immediately saves a life. This applies when a large tumour is causing acute pressure or unconsciousness. In some tumours, such as low-grade **astrocytomas**, surgery may be the only treatment necessary.

Sometimes surgical removal is not possible because the tumour is too close to vital areas in the brain. Other types of therapy, such as chemotherapy and radiotherapy, then have to be considered. Even if the tumour cannot be removed, neurosurgery plays a large role in relieving symptoms such as reducing raised intracranial pressure.

Hydrocephalus

The brain and spinal cord are surrounded by **cerebrospinal fluid** (CSF). It circulates around the outside of the brain and spinal cord to bathe it with nutrients and remove waste products. It is then drained through special veins back into the blood system. This is a constantly flowing system and significant problems can occur if this is blocked or interrupted in any way. **Hydrocephalus** occurs when the circulation of CSF builds up around the brain and its drainage back into the blood is blocked in some way.

A tumour within the central nervous system may lie along the circulation or drainage pathway and cause this type of blockage. If more CSF builds up in the brain than is required, then the body will experience the symptoms of raised intracranial pressure, ranging from mild to severe, as too much fluid is now held within the rigid container that is the skull.

First this problem needs to be diagnosed. Scans can help to confirm hydrocephalus, but a complete diagnosis can be made only when combined with information gained from a detailed history of the child's symptoms and a full neurological examination. If the hydrocephalus is severe or it is not possible to remove the obstruction straight away, then the hydrocephalus itself may need to be treated quickly. Occasionally, the hydrocephalus may be so severe that urgent treatment is needed first, and the tumour removed at a planned later date.

How is surgery performed?

Surgical treatment can be performed in two ways; by inserting a **shunt**, or by creating another drainage route. The

neurosurgical team will be able to discuss the advantages and disadvantages of each of these procedures, should there be an obstruction of CSF at any time during treatment.

Inserting a shunt

A **shunt** can be put into the ventricles where the fluid is made. This redirects the excess fluid into another part of the body (usually the abdomen) where it can be reabsorbed. The shunt has a one-way valve so that fluid cannot return to the brain. The shunt is plastic and can sometimes cause problems such as blockage or infection. These problems can cause the child to appear to have the same symptoms as the original hydrocephalus or perhaps even of meningitis. If the shunt becomes blocked it will usually be replaced or adjusted by an operation. If it becomes infected it may need to be removed, **intravenous** antibiotics will be given and an external drain will be used until the infection is gone. Then a new shunt can be placed.

Creating another drainage route

The second and increasingly popular option is to enter the ventricles and create another drainage route for the fluid around the obstruction. This is called a **ventriculostomy**, (effectively a bypass) and can be done using endoscopy (**keyhole surgery**).

What happens after the hydrocephalus has been treated?

Once the hydrocephalus has been treated, all the symptoms of raised intracranial pressure should stop and the rest of the child's treatment for their tumour can begin. However, on some occasions, even after the tumour (and therefore the blockage) has been removed, hydrocephalus can develop again due to scarring after the surgery. This can cause a temporary deterioration of your child's condition: they may need further surgery and possibly a shunt.

More information on hydrocephalus

If you would like more detailed information on hydrocephalus please speak to your neuro-oncology team or contact any of the organisations listed at the end of this booklet.

Can surgical treatment of the tumour cause injury to the brain?

The aim of **neurosurgery** for a brain tumour is to try to remove the tumour without cutting or removing parts of the brain, which would have a big impact on the ability of a child or adolescent to function as they were before their illness. Damage to any of the parts of the brain may be permanent if nerves are cut or pieces of brain are removed.

Some damage may be temporary, especially if there is bruising after

the operation, or swelling of the surrounding brain. Neurological symptoms due to this sort of damage frequently lessen as the brain heals.

Radiotherapy

Radiotherapy uses high-energy radiation to destroy cells. It is often used alongside surgery and **chemotherapy**. The radiation energy is focused into a beam, rather like a strong x-ray, which is directed at a very specific part of the body where it penetrates the tumour and kills cancer cells directly. Extreme care is taken when planning the route of the beams (more than one will be used at once), and their intensity. This enables the exact position of the tumour to be targeted in order to cause as little harm as possible to normal healthy tissue. The energy beam is created using highly specialised equipment (often linear accelerators) in specialised units, which may not be in a paediatric hospital.

How often is radiotherapy given?

The energy dose is divided into small daily amounts called fractions. These fractions are usually given every day, Monday to Friday, with a rest at weekends. Occasionally the fractions can be given twice a day for particular clinical trials. This is known as hyperfractionated radiotherapy.

How is radiotherapy given?

It is essential that the dose is given each day to exactly the same place (the tumour field). This means that your child's head or spine must keep completely still during each treatment and that they lie in exactly the same position each day. For these reasons, your child may have a clear plastic mould made of their head to wear at each session. Marks are put on the mould to guide the beam to exactly the same spot each time.

What are the side effects of radiotherapy?

No matter how carefully the radiotherapy is planned, side effects to normal healthy tissue cannot be avoided. These can be short term, such as inflammation of any affected tissue (skin, lining of the mouth, ears, healthy brain tissue). Long-term side effects start more gradually, months or sometimes years after the treatment and can affect learning, memory, hormonal balances and growth. These effects will depend on where the beam was aimed and how big a dose that portion of the brain was given (see page 19 - the section on Ongoing Needs After Therapy).

Benefits of radiotherapy

Despite the possible side effects, radiotherapy is a very effective way to destroy brain tumours. Specialist

doctors are constantly working to improve its success by reducing these side effects and combining radiotherapy into chemotherapy **trials**. Each child's situation is unique and the need for radiotherapy will be discussed with you along with detailed information on the likely side effects in your child's case.

Chemotherapy

This is treatment using drugs (called **cytotoxic** drugs) that interfere with the ability of a cell to divide and reproduce itself. The chemotherapy drugs affect dividing cells, including some normal cells. Normal cells can repair the damage caused by chemotherapy but cancer cells cannot. Therefore, cancer cells become damaged and eventually die.

How is chemotherapy given?

Chemotherapy can be given in different ways: orally (by mouth), **intravenously** (by injection into a vein), or **intrathecally** (into the spinal fluid). There are many technical terms used to describe how the drugs are given and you will see these on drug charts and on treatment plans (protocols). Whichever way the drugs are given (except intrathecally), they are absorbed into the blood and carried around the body so they can reach all the cancer cells. This makes chemotherapy particularly useful when cancers have spread to different areas of the body.

Chemotherapy has to be carefully planned. It may, for example, be given intensively in high doses over a short period, or it may be given in lower doses over a longer period. Each dose destroys some of the cancer cells and will cause damage to normal cells and tissues. After each dose there is usually a rest period to allow the normal cells to recover before the next dose.

Giving chemotherapy by intravenous injection

When treatment is given by **intravenous** injection, the drugs are usually diluted into a bag of liquid such as saline (salt water), or a sugar solution. They are then given through a drip attached to a **central venous line** (see your own hospital's booklet on this subject) or a thin tube (called a **cannula**) that is inserted into a vein and taped securely to your child's arm.

What are the side effects of giving chemotherapy?

Most chemotherapy drugs cause unpleasant short-term side effects, such as hair loss, nausea and vomiting. Most of the side effects are temporary and there are effective ways of controlling some of these problems and reducing the distress they may cause. However, some treatments may have longer term effects. These may not always be obvious at the time so careful follow up is needed to detect any of these after treatment has finished.

Chemotherapy is most likely to affect areas of the body where normal cells rapidly divide and grow: the mouth, digestive system, skin, hair, and bone marrow.

Chemotherapy and the brain

The brain is protected from chemicals in the bloodstream by a **blood brain barrier**. This barrier makes it difficult for chemotherapy drugs to enter the brain from the bloodstream. Fat-soluble chemotherapy drugs are frequently used as they cross the blood brain barrier more easily than those that are water soluble. However, there is not an absolute block on other types of chemotherapy drugs as there is considerable proof that the blood brain barrier within a tumour is not normal and has holes in it. These holes allow drugs, which would not otherwise enter the brain, to enter the tumour.

Chemotherapy and the spinal fluid

Drugs can also be injected into the **cerebrospinal fluid** by **lumbar puncture** or through plastic tubes inserted into the ventricular chambers within the brain. Putting drugs into the spinal fluid puts the cancer cells, which are either on the surface of the brain or floating in the spinal fluid itself, in direct contact with the cancer drug. This method of treatment is used to treat leukaemia, which develops on the surface of the brain. This method of giving chemotherapy to brain tumours is currently being explored.

Releasing chemotherapy into the place where the tumour started

Drug delivery devices are jelly-like wafers, which contain the chemotherapy drug and release it slowly over a prolonged period of time, measured in days or weeks. Once the tumour has been removed, these devices can be inserted into the place where the tumour originally started. This method of drug delivery has been shown to work well in adult brain tumours and is likely to be used in the future in children, in selected circumstances.

What are Clinical Trials?

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials.

Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, in order to make them more effective, or to reduce side effects
- compare the effectiveness of drugs used for symptom control
- find out how cancer treatments work.

Clinical trials are the only reliable way to find out if a different operation, or type of

chemotherapy or radiotherapy, is better than what is already available.

Discussing your child's treatment with your oncologist

Your **oncologist** will talk to you in detail about whatever treatment may be needed for the care of your child. If the protocol (treatment plan) is a **clinical trial** this will also be discussed with you in detail. At all times you can ask to discuss any information in more detail to increase your understanding of your child's treatment. You can also have a copy of your child's therapy plan to follow through the weeks.

The use of new anti-cancer drugs in clinical trials

New anti-cancer drugs are constantly being tested and developed. Experiments in test tubes or in animals screen the drugs that work the best and cause the least side effects. Drugs that pass these screening tests are then tested in humans in clinical trials, first in adults and then in children. Drugs are tested in adults first because children handle drugs differently in their kidney, liver and circulation to the way that adults handle them, and because they are smaller and less mature.

What happens in a clinical trial?

Depending on your child's diagnosis, you may be asked for your permission to let your child take part in a clinical trial. There can be benefits in doing this. The trials help to improve knowledge about cancer and the development of new treatments. Your child will be carefully monitored during and after the study, as specified in the treatment protocol. Usually, most hospitals around the country treating children with cancer take part in these trials, which are coordinated by UK **oncologists** and **haematologists**. If you agree to your child taking part in a trial, you will be given a detailed information sheet and be asked to sign a consent form.

What is randomisation?

A process called **randomisation** may be used in trials trying to find out whether a new treatment is better than the best available standard treatment. This means that a computer will randomly allocate suitable patients to have the different treatments in the trial (i.e. the standard or the new treatment). This is done so that each treatment group has a similar mix of patients of different ages, sex and state of health. If it were left to the researchers to decide who should get which treatment, they might be influenced by what they know about their patients. Consciously or unconsciously, they might put patients who were more likely to respond to a new treatment into the new treatment group. This would introduce bias, making the results unreliable. You can ask your child's doctor to explain this to you in more detail if you would like more information.

Supportive Care During Treatment

Who Can I Ask For Help?

Diagnosis can be a very anxious time for parents, the child and other family members. It can start unexpectedly with a child becoming suddenly unwell and needing surgery, or perhaps they have undergone investigations for what were relatively mild symptoms (e.g. restricted eye movements). Suddenly the whole family is thrown into the world of cancer care, full of unfamiliar words and actions. After the initial rush at the beginning, the process to full diagnosis can become slow at times. Waiting for test results and second opinions causes anxiety for all involved.

How the children's cancer team can support you

The children's cancer team will know from experience the difficulties that you may have to face and how these may affect you and your family. They can guide and support you through this and become a significant help throughout your child's illness.

Oncology outreach nurse

You and your child will be cared for by a paediatric oncology outreach nurse, who will work at the hospital and visit your home to ensure good communication between the whole cancer care team, and good clinical care away from the hospital.

Oncology social worker

Most treatment centres also have an oncology social worker to help you with both financial and social concerns, as well as being a skilled counsellor with whom you can discuss difficult issues. They can help you and your family to talk openly and freely about any worries that you and your child may have.

Care outside the hospital

Outside of the hospital, your family and friends, places of worship and schools can all provide support. You should tell them clearly about the help you need and how you would like it to be given, so that you and your child can stay in control and not feel your lives are being taken over. There are many local and national support networks and groups for you, your child and any brothers and sisters, including specific groups for teenagers. As the shock of diagnosis wears off and treatment begins, these can be excellent sources of help. Contact details will be available from your own treatment centre and there are some listed at the end of this booklet.

Your employer may be able to provide additional support for you whilst your child is going through treatment.

Finding out more about treatment

Knowing what is going on with your child, their treatment and what the future holds, will help you to cope with this diagnosis. Information will be available from the professionals caring for your child. There is also a wealth of other information (good and bad) available from many sources, e.g. internet, libraries, health education centres, newspapers, friends and the TV. This may become overwhelming and, at times, confusing. Please do not hesitate to bring any or all of the information you receive back to the cancer care team (hospital or community) and discuss it with them to ensure that it is accurate and relevant to you and your child.

The whole cancer care team are there to help you in practical and supportive terms. Please use them and work with them to help you, your child and your family get through this difficult time.

Dietary Needs Of A Child With A Brain Tumour

Due to the physical and psychological effects of the disease and its treatment, children with brain **tumours** may have severe weight loss and dietary problems. Tumours use up a lot of the body's energy. A well balanced diet is needed to help your child respond to treatment, tolerate chemotherapy, fight infection and repair damaged cells from either **radiotherapy** or surgery.

Common side effects

Common side effects of radiotherapy and chemotherapy include:

- Weight loss
- Nausea and vomiting
- Sore mouth and throat
- Tiredness
- Not wanting to be bothered with activities and friends

Radiotherapy to the head and neck often also affects the ability to eat or swallow due to the lining of the gut, salivary glands and taste buds being damaged.

Weight loss due to treatment

All of this treatment may cause your child to lose weight. Therefore, when it is confirmed your child has a tumour, you will be introduced to a specialist dietician. He/she will be able to assess your child's needs straight away and plan for their future needs during the upcoming treatment.

If your child is not able to eat or drink enough to maintain weight, nutritional support is used to:

- reverse the weight loss often seen at diagnosis
- prevent weight loss and tiredness that comes with a tumour and its treatment
- promote weight gain and growth.

Nutritional support can be given as special high calorie drinks and milkshakes. However, in more severe cases a tube may be placed directly into the stomach via the nose (a **nasogastric tube**), or by a small incision made in the abdomen (a **gastrostomy tube**), so that highly nutritious food can be pumped in slowly overnight. Your dietician will be able to give you support and advice on feeding and diet throughout treatment and during follow up.

Continuing Supportive Care

What Happens During Rehabilitation And Recovery?

The length of time it takes a child to recover from the effects of a brain tumour and treatment varies from child to child. Children have an amazing ability for recovery and are able to do much of their own rehabilitation (recovery) through play. The speed of your child's recovery will depend on their age, the position and type of their tumour, and the extent of the damage caused by the disease and the side effects of treatment.

Who will help my child and me?

There is often a team of people to help you and your child in the hospital. They will continue to arrange care for you and your child when it is time to go home. They will contact their colleagues in the healthcare community if you are not close enough to the hospital for your child to receive rehabilitation there. After you have left the hospital, it is unlikely that you will see each therapist as often as you did when you were in hospital. If your child has been discharged, it usually means that such intensive therapy is no longer required. The team of people to help you include the following:

- Physiotherapist (physio)
- Occupational Therapist (OT)
- Speech and Language Therapist (SLT)
- Psychologist

These are all described in the following sections.

Physiotherapist (physio)

The physiotherapist, often known as the 'physio', is the person who will assess and help your child improve physical skills, such as standing, sitting, and walking, after treatment. This is achieved through exercises and activities that are carried out by the bedside, in the gymnasium, in the hydrotherapy pool (if one is available), at home or in school. As it can quickly become a chore for young children, therapy needs to be fun. The physiotherapist must gain the child's confidence and this can take a long time. The physio will work with your child whilst they play, ensuring they are sitting or standing in a good position, or helping them with their balance. The physio will also teach you and your family how to help your child, as you spend the most time with them and you know them best.

Occupational Therapist (OT)

The **occupational therapist**, often known as the 'OT' will assess and help your child with **fine motor skills**, such as feeding, dressing and written work. They work alongside the physio and together they help your child

cope with all the activities they need to perform in daily life. This includes identifying equipment your child may need at home, such as special seating or cutlery.

Speech and Language Therapist (SLT)

The role of a speech and language therapist (SLT) is to assess, advise and help your child with speech, language and communication. They will be able to help with forming words and sounds, and also work with your child if they have a language disorder, for example difficulty choosing or saying the correct word. They can also assess or advise on eating and swallowing problems.

Psychologist

The role of the psychologist is to help your child cope emotionally with what has happened to them. They help the child express their feelings in a way that is not frightening. This can be done through play as well as counselling. Children may feel frustrated due to difficulties in function and daily living and this can lead to relationship difficulties with both family and friends. Psychologists are invaluable in helping the child and family to cope with such changes, whether temporary or permanent.

How long will it take my child to recover?

Some children do not need help from the rehabilitation team. For others it can become a major part of their lives. At first, progress may appear slow but steady but, with time, the rate of improvement slows and this can be very frustrating for both you and your child. Nerve recovery can continue for many years. It can be useful to keep a diary to help you look back and see even the smallest improvements.

The rehabilitation team often works with schools to ensure that your child's school environment is safe and accessible. Sometimes practical alterations need to be made at your child's school. This can take some time to organise, so the sooner the process is started the better.

Ongoing Needs After Therapy

Why will my child's growth and hormone levels need to be monitored?

A brain **tumour** and its treatment can sometimes interfere with the normal hormonal changes that happen as children grow. Your child may need treatment to help restore these normal processes.

How is growth and development controlled?

Throughout childhood and adolescence there is growth (an increase in size) and development (the gaining of new skills and learning). When puberty starts, rapid physical, mental and social change takes place. These natural processes are carefully controlled by hormones (messages), which go back and forth from the brain to glands in the body (much like a telephone conversation), so that just the right amount of each hormone is produced. Too much or too little of a hormone is quickly recognised and the body tries to bring it back to normal. If it is unable to do this after treatment, then help must be given in the form of drugs.

What happens if there is too little of a hormone?

Any illness can result in a temporary "shut down" of the hormone system whilst the body uses up energy for healing elsewhere. However, after a brain tumour and its treatment, a permanent lack of certain hormones may occur. Some hormones are important to well-being and future quality of life (e.g. growth or puberty hormones). Others are essential for life: too little of them may be dangerous (e.g. a lack of the hormones that help us respond to stress, or those that control thirst and water balance).

How can hormone control be affected?

The hormonal control centre is called the **hypothalamo-pituitary axis (HPA)**, situated near the centre of the brain. The position of a brain tumour (and the treatment it receives) is very important in working out which hormones will be affected and by how much. The further the tumour is from the centre of the brain, the less likely it is that there will be problems. Tumours that are nearer to the HPA (e.g. optic, pineal, thalamic, hypothalamic, sellar or suprasellar) are more likely to cause problems across many different hormones, sometimes even before any cancer treatment has been given.

What does the hypothalamus do?

The **hypothalamus**, in the centre of the brain, controls the amount of hormones that are released by the anterior (front)

part of the **pituitary** gland. These hormones control:

- growth
- metabolism
- puberty
- fertility
- response to stress and/or illness.

If hormone problems occur, it is usually in the above order. Therefore **growth hormone (GH)** deficiency is the most common problem and affects many children treated for a brain tumour, especially those who have had radiotherapy. It is the result of both the tumour and radiation therapy and occurs more quickly after higher radiation doses. Younger children may need hormone replacement therapy. Older children, whose growth and development is virtually complete when they start treatment, may not need it. This hormone's importance in adulthood (for general health, muscle and bone strength) may mean it stays under review for many years into follow up.

Is puberty affected by radiotherapy?

Early puberty is often seen after radiotherapy for brain tumours. This causes a child to grow very quickly over a short time and can result in the child reaching smaller than average height, even if growth hormone is given.

Puberty and fertility may be affected by different treatments. This may vary depending on the treatment given, the age of the child when they received it, and whether they are male or female.

Children need to receive enough hormone replacement to ensure the stages of puberty are gone through gradually at an appropriate age, and to help improve the success of any help with fertility that might be needed in the future.

It is important to remember that problems with puberty and fertility hormones may not be seen until adolescence. However, many problems with the puberty hormones are correctable and treatment can result in some level of fertility.

Tumours within the pituitary

The posterior (back) pituitary controls two further hormones which are rarely disturbed unless the tumour has been within the pituitary area itself.

These are:

- Oxytocin (which stimulates the womb to contract during labour and the breast to release milk during breast feeding)
- Antidiuretic hormone (ADH) or vasopressin (which controls fluid balance and is linked to thirst).

How will hormone levels be tested?

Tests may be taken to examine hormone levels as a baseline level or in response to stress. The whole HPA can be

assessed in one morning of tests. Extra time and preparation may be required if your child is very young, suffers from fits, or is on regular medication (hormonal or other).

How safe is hormone replacement?

All hormones are now available in a man-made form and are very similar to the naturally produced hormone. Most are taken daily in tablet form or by injection and have been in use for many years. Puberty hormones are also available as a skin patch. Since they are replacing what the body cannot produce, and in natural (not excessive) quantities, they are considered safe. This is particularly true of the steroid hormone, cortisol, which should not be confused with the (larger) doses of steroids used in other medical therapies.

How is growth hormone given?

Growth hormone is now also available as a synthetic agent. It is given as a daily subcutaneous (under the skin) injection using a simple "pen" device, which children as young as eight or nine can be taught to use. Growth hormone replacement should ideally begin early to get the best growth potential, particularly in cases of early puberty or when a child has had spinal irradiation.

Why is lifelong hormone surveillance needed?

Hormones are so important to general well-being, as well as sexual and reproductive health, that, once their replacement has begun, it is likely the child will need hormone surveillance for their whole life (except in the case of growth hormone). Hormones will be closely monitored (every 4-6 months) during childhood and adolescence. The frequency of follow-up may be reduced once adulthood is reached.

Will Any Loss Of Senses Occur?

The senses that are most at risk from damage are sight and hearing (see following sections). Touch, smell and taste can also be affected.

The treatment goal is always to preserve hearing and sight. It is important to discuss possible threats to these senses and any concerns you have about treatments with your child's doctor.

Hearing problems

Hearing is rarely damaged by a tumour or surgery to remove it, although tumours can grow on the hearing nerve. It is usually the treatments for tumours, even those away from the hearing centre that can harm your child's ability to hear. When the tumour target area is close to the hearing nerves or hearing apparatus, radiotherapy to the brain can cause some hearing loss, which is likely to be permanent. There are also some chemotherapy drugs, used to treat certain brain tumours, that can cause

considerable hearing loss. Your child's hearing may be checked by **audiometry** (a hearing test) before, during, and long after these types of therapy.

Eyesight problems

Sight is most commonly harmed by the tumour rather than any treatment employed to cure it. Sight may be harmed in one of three ways: tumour damage to the eye, tumour damage to the nerves that run from the eye to the brain carrying images, and tumour damage to the part of the brain that interprets those images. Therapy rarely causes damage and doctors try to reduce the risk by avoiding radiation or surgery in that area. Damage due to a tumour can be harder to control. The aim is to treat these tumours before too much harm has been caused, and so prevent your child's vision getting worse.

What Neuropsychological Changes Might Occur?

Neurological problems

Neurological problems are problems that affect the brain and spinal cord or the nerves. Neurological problems are sometimes due to the tumour but they can also be caused by surgery. Examples of this are **hemiparesis** (weakness down one side of the body), cerebellar syndrome (difficulty balancing), or facial palsy (drooping face). Neurological problems often lessen over time, and a child's ability to overcome these disabilities is sometimes remarkable.

Damage caused by either the tumour or its treatment can also cause difficulties when it comes to learning. These difficulties can limit the social integration and academic achievement of a child who also may not be able to manage manual work, or be able to drive. Complications following surgery, such as meningitis, coma, or prolonged time on a ventilator post-operatively, may, in some cases, increase the risk of neuropsychological problems.

Neuropsychological problems are problems that affect behaviour and mental functions such as language, memory and attention span. Some problems may not appear to occur until later in life. The time delay may be as a result of an accumulation of problems (physical and psychological) that the child experiences during therapy and even in later life when he/she is supposed to be cured. Learning difficulties and psychological troubles may make it more difficult for the child to return to their old social and school life. There is no clear proof that these problems can be made better, but they are issues that may need to be discussed and planned for to help adjustment.

What learning difficulties may occur?

Learning difficulties vary according to the age of the child but are usually memory

problems, which make learning difficult. Multiplication tables, reading, grammar and foreign languages are examples of areas where the full extent of memory problems can be seen. For children who are a little older at time of diagnosis, long term memory remains, but there is sometimes a memory gap resulting from damage to the brain or severe emotional distress during the period of treatment or afterwards.

Learning difficulties can affect both the understanding and the carrying out of tasks and skills. This makes unassisted schooling difficult and leads to anxiety, possibly with a feeling of failure. These problems can be made worse by difficulties in the layout of mainstream school environments and timetables.

The main learning difficulties that are seen in these children affect the ability to reason and problem solve. The child may be unable to adapt knowledge gained from one situation to problem solve in another. Difficulties paying attention and lack of concentration can also inhibit the child in daily school life. The optimal attention span varies from child to child but doesn't usually exceed 30 minutes. This explains some half-understood lessons and the possible exhaustion of the child at the end of a school day, trying to concentrate much longer than could reasonably be expected. The maturity of the child may contrast strongly with his/her basic learning difficulties. This makes it hard for both teachers and psychologists to understand the problems. Surprisingly, creativity seems unaffected or indeed is often enhanced among these children. This must be taken advantage of in order to increase the social standing of the child in their class.

Finally, problems in speech or hearing can make relationships with friends and teachers more difficult, and this in turn can make the child feel more isolated.

Is there a test for assessing learning difficulties?

Some specific tests are used to assess learning difficulties. Intelligence Quotient (IQ) is the one most commonly used. This may be misleading, however, as it does not really reflect the situation of the child. It does not take into account either the natural speed of the child or if depression has affected the child's performances. Moreover, these tests give technical information without offering any specific solutions.

How Might My Child's Education Be Affected?

The impact of a brain tumour in children is different from other cancers. **Intracranial** surgery is a traumatic event, even without subsequent neurological problems. The consequences of cancer in these children are due to the brain damage caused by the disease, plus the

late effects of additional treatments, such as radiation therapy or chemotherapy. These treatments can further increase the risks of disability and/or developmental delay. These effects may be considered in terms of their timing. They may be short term, medium term or long term effects.

What happens when my child goes back to school?

For a child with cancer, going back to school is the best way to return to normal life. This is vital to their confidence. It enables them to feel that things are going to be OK and that things will improve after the difficult times they have already been through. For both children and parents, returning to school is a way of moving on from the world of hospital and disease.

Problems that may occur when your child returns to school

Unfortunately, for children with brain tumours, problems can occur usually due to long absences from school, or remaining physical or neurological weaknesses. Despite their best intentions, the child may not be able to keep up with their original class. They may often have to give up playtimes to catch up with their work. They may not be able to remember previous lessons or understand as quickly as they did before. This may lead to feelings of isolation or inadequacy, and some children feel quite depressed about themselves and their future.

Special support for children returning to school

Special support programmes have been developed to try to reduce any feelings of isolation that children may suffer from and to help them get settled back into their academic and social life.

Most teachers have no knowledge of the neurological, intellectual, psychological and emotional changes associated with brain tumours and are apprehensive at having to cope with them. The child's doctor, **oncologist**, paediatrician and oncology liaison nurse can work with teachers and schools to provide support to aid learning and work out how to deal with physical and psychological difficulties. There is also more and more literature available now for teachers and schools to increase their understanding of your child's situation (see section – Useful References - on page 47).

What Emotional Difficulties Might My Child Have?

The trauma of having a brain that is malfunctioning due to disease can make the child feel fearful and less confident. They then have to face the need to have a part of their brain removed by open surgery. The addition of a long stay in hospital, possibly being left out of some aspects of normal life, and neurological side effects can all add

up to unbearable stress that makes them seem a different child.

Parental anxiety, both for survival and what the future may hold, and over protectiveness may also affect the child. Follow up in an oncology clinic with lots of scans and investigations can cause the child to worry about the chance of the tumour returning. The child may also have to come to terms with the fact that curing the tumour may have resulted in long-term side effects that affect their self-image and quality of life. This may, in some cases, result in withdrawal, a negative attitude, or even aggression against parents, friends or teachers. On the other hand, some children can seem too passive at school. They may appear to be a child who is almost 'too good'.

It may sound as if these effects are very difficult to identify, manage and cope with. However, there are professionals who can help you and your child, e.g. a Clinical Psychologist. Not every child who has had treatment for a brain tumour will have any or all of these emotional difficulties. It can be a very complex set of circumstances that can lead to these feelings. Therefore, it is important that you and your child have an opportunity to talk about such things. You and your close family will also need information to identify these issues and the support to deal with them. The multi-professional team is there throughout follow up to help you to access such support.

How Will My Child Be Monitored In The Long Term?

Monitoring and follow up can begin once your child has recovered from treatment (whether that was surgery, radiotherapy, chemotherapy, or all three). Therapy may be finished but the care of your child is not. At the first clinic visit, your child will undergo a full reassessment of both the area of their head or spine where the tumour was found and also any parts of the body that may have been damaged by the tumour or treatment. This should confirm that your child is now free of the tumour, and also give a baseline level for any other areas of the body that need to be monitored, e.g. weight and appetite, blood counts, kidney function, mobility, hearing, vision, hormone levels, etc. The baseline level lets the doctors see if your child's condition improves or worsens in the future.

The follow-up clinic

The appointments at the follow-up clinic should give you and your child an opportunity to go back over your experience and clarify any confusing information, to evaluate how treatment went and discuss what the future holds. Returning to your family's normal routine can seem frightening and be quite a slow process. It is hard not to feel over protective of your child and not to constantly look for symptoms of the tumour returning. School, college or even employment for your child needs

to be considered. Whatever happens, you can ask for the support and advice you need at the follow-up clinic.

Issues regarding rehabilitation and school re-entry are often the main focus of family concerns after hearing the scans are clear. However, clinic staff take each family as an individual case. They will discuss an action plan to meet your child's needs until the next clinic appointment. Any scans and investigations that are needed for the next appointment will also be arranged.

All the neuro-oncology team is actively involved in follow up and, by the time you reach this stage, you will have got to know the team well. You and your family may wish to use their professional skills to help you to move forward with family life.

Appendices

The Brain – Structure and Function

Glossary of Terms

Useful Contacts

Useful References

Factsheets

The Brain – Structure and Function

When told that their child has a brain tumour, most parents want to know what this will mean, in practical terms, for them and their child. Some, however, want to know more about the brain. This section may help.

The anatomy of the brain is complex. There are many names you will not have come across before. It is also hard to remember what they mean, what the different parts of the brain do, and how they are all connected. We hope that the explanations given in this section will help you understand some of the terms, as well as something about the location of the brain and its coverings, and the way the brain is organized to control our minds and bodies. The diagrams at the end of this section will also help.

If, when you have read this section, you still have questions, or if there is anything else you do not understand, then don't hesitate to talk to your child's doctor or any other member of the team.

How Do The Parts Of The Central Nervous System Fit Together?

The central nervous system is complex. The explanations given in this section are intended to describe as simply as possible the location of the brain and its coverings, as well as the way it is organised to control our mind and body.

The Brain: An organ in a rigid container

The brain is a semi-solid structure within the skull, out of which the **spinal cord** grows and runs down the middle of the spinal column. The skull, when it is fully developed, is a rigid container. When it is immature (children under the age of 2 years), it is more flexible. The rigidity of the skull protects the soft brain from physical damage. However, this rigidity means that there is limited space for the brain to increase rapidly in size. When the brain does expand with fluid or tumour, it causes the pressure inside the skull to be raised (**raised intracranial pressure**). This is very often the cause of the symptoms when a child first presents with a brain tumour.

The Brain: Floating in fluid

The brain and spinal cord lie within the skull and spinal column and are contained in a sac made of a specialised membrane. The sac is filled with fluid in which the brain and spinal cord float. The fluid, called **cerebrospinal fluid (CSF)**, is constantly being made in the middle of the brain within an area called the ventricular system (four fluid filled chambers within the centre of the brain) (see diagram on page 38). The spinal fluid, after bathing the brain and spinal cord, circulates along pathways around the surface of the brain and spinal

cord, and is finally absorbed through structures called **arachnoid villi**, which drain the spinal fluid back into the veins in the skull.

This constant production of spinal fluid is normally in balance with the constant absorption of spinal fluid by the arachnoid villi. If the flow of spinal fluid is interrupted by narrowing of one of the chambers (ventricles), or by problems with its re-absorption, the resulting blockage to the flow of fluid raises pressure inside the head. This is the commonest reason for symptoms of raised intracranial pressure associated with a brain tumour.

Cerebrospinal Fluid: Cancer spread and drug delivery

The **cerebrospinal fluid** can spread cancer. This happens if cells break away from the tumour and travel in the cerebrospinal fluid, causing new tumours to grow in other sites on the surface of the brain and spinal cord. This flow of spinal fluid can, however, also be used to deliver anti-cancer drugs directly to the cells that are circulating or growing on the surface of the brain.

Nerves and their organisation

The brain is a complicated structure that contains many different areas. These areas are linked together by many millions of nerves that conduct electrical messages between them all. These processes control our mind, movement, memory, hormonal system and senses. The nerves are like wires carrying electric currents. They have junctions called **synapses**, which allow them to branch and interconnect. In the developing brain, brain growth involves cell division to make more brain cells, nerve growth and nerve branching. These last two processes are vital to the development of the human brain.

What Are The Structures In The Brain And What Do They Do?

The brain has many separate parts, each with a specific function for the control of body functions, communication, emotion, memory, senses, personality and ability. There are six main groups of structures: the ventricular system, the **cerebral cortex**, midline structures, **cerebellum**, nerve connections and **brain stem**.

This section describes all these different areas of the brain, where they are, and what they do. We hope this will help you to discuss the position of your child's tumour, and the problems it is causing with your **oncologist**.

Ventricular system

This is a system of four different chambers that are interconnected and filled with cerebrospinal fluid (see Fig 3).

Ventricles one and two are referred to as the **lateral ventricles** (see Fig 3). They lie one in each cerebral hemisphere

and both have a direct channel to the third ventricle (interventricular foramina). The third ventricle lies in the midline and at its base is a narrow passageway (called the cerebral aqueduct or Aqueduct of Sylvius) down towards the fourth ventricle, which lies between the cerebellum and the brainstem. All four ventricles are lined with a layer of cells called **ependymal cells**. These cells, as well as those of the **choroid plexus** (a network of small blood vessels in the roof of each of these chambers), make much of the cerebrospinal fluid that passes through the ventricles and then goes on to wash over the brain. Blockages or obstructions within this system lead to a problem called hydrocephalus (see page 38) and symptoms of raised intracranial pressure. These blockages occur most easily at narrow points in the system, such as the interventricular foramina, the third ventricle or the aqueduct of the fourth ventricle.

Cerebral cortex

In the upper part of the brain there are four sections called lobes in each of the two hemispheres (making 8 lobes in total). When grouped together these are called the **cerebral cortex** or cerebral hemispheres. They straddle the midline of the brain (and the special organs within that compartment) and are separated from the other parts of the brain by a membrane called the tentorium, on which the hemispheres rest. The function of the lobes is to help us understand information presented to our brain and to respond with actions that help us control and maintain our bodily functions. The left side of the cerebral cortex controls the right side of the body below the base of the brain, and vice versa. The names of the four lobes are: **temporal**, **frontal**, **parietal**, and **occipital**. The function of each is explained below.

Temporal lobe

This is the main auditory receptive area, i.e. the area responsible for the interpretation of sounds that are transmitted through the ear. If this area is damaged, sounds and words may be heard but the brain cannot work out what they mean. So even though you could speak, it would be full of errors. This area is also very important for memory and the understanding and interpretation of many types of information: visual, hearing and somatic (information about muscle movement). Therefore, it influences vision, hearing, smell, learning, memory and emotions. Very detailed parts of our memories are kept here and it has a big effect on our intellectual ability.

Frontal lobe

This is the area of the brain needed to perform the most complex of brain functions such as reasoning, concentration, problem solving,

organisation and ultimately the control of our emotions and thoughts. This lobe provides storage areas for a great deal of information - a memory bank. It also has a role in the muscular control of breathing, blood pressure and the movements of the gastrointestinal tract (gut). The frontal lobe is vital for many of the voluntary aspects of our senses such as eye movements to allow us large field of sight and the muscle actions involved in controlling speech. Much of our personality is expressed through the workings of this lobe and it is, therefore, an essential part of our identity.

Parietal lobe

Interpretation of sensation from our feet to our face is carried out here. In addition, some complex muscle movements, including those of the facial muscles so necessary for expression and communication, are also controlled here. Skin and deep tissue sensation is also fed back to the parietal lobe. Touch, position, pressure and vibration in skin or deep tissue are felt here. This lobe allows us to determine size, shape, weight, texture and consistency of the many objects that are in our environment.

Occipital lobe

The occipital lobe houses the visual cortex, the area where images picked up by our eyes are put together and understood. Visual understanding and perception are all carried out here. Finally, the involuntary movements of the eye muscles are controlled from here.

Midline structures

Hypothalamus

This is a small structure located in the centre of the brain, surrounded by the cerebral hemispheres. It lies next to the fluid filled ventricles (the laterals and third ventricle) and above the brain stem. This is a vital organ for the safe and stable maintenance of the internal body environment. It monitors many factors about the environment such as temperature, water concentrations in bodily fluids, hormone levels etc. It then regulates: appetite (by monitoring glucose), thirst (by monitoring water content of fluids including the blood), temperature, water levels in the body (through its action on the kidney and sweat glands). It also secretes the hormones that control its close neighbour, the pituitary. In addition, the hypothalamus has a role in the regulation of heart rate, gut movements, pupil reactions and sexual arousal. The physical expressions of emotions such as pleasure, anger or anxiety, and the sleep wake cycle, all come under hypothalamic influence.

Pituitary

This is a bean shaped organ that lies right underneath the brain connected by a small passage to the hypothalamus. This organ is divided into two distinct lobes,

the anterior and the posterior. The anterior lobe manufactures many important hormones, although their release is under the control of the **hypothalamus** which collects the information from the body on hormonal need and then activates the pituitary as necessary.

Any damage to the pituitary would slow down or even halt the production/ secretion of these vital hormones. This leads to severe problems with growth, metabolic rate, body water and salt regulation, puberty, fertility and childbirth.

Cerebellum

The cerebellum is a very distinctive looking structure cushioning the base of the brain in the **posterior fossa**. It has horizontal ridges all across its surface and is separated into two lobes, one on either side of the brain stem.

The main role of the cerebellum is balance and the coordination of bodily movements. This allows us to regulate timing and balance so that we can make precise fine motor movements. It does not control movements but ensures their quality (including speech).

If the cerebellum is damaged by tumour or therapy, then this quality is lost and coordination deteriorates. The child could possibly be seen to shake or have very jerky erratic movements like being drunk (**ataxia**). The damage is noticeable on the side of the body that corresponds to the hemisphere that has been damaged. That is the left side of the body reacts to the left hemisphere of the cerebellum.

Brain stem

The brain stem is one of the most complex parts of the entire brain. It controls the most basic functions for human life, which are breathing, heart beat and blood pressure.

It lies at the very bottom of the skull below the level of many other parts of the brain and connects the brain with the spinal cord. This part of the brain acts as a relay station for nerve impulses from the brain to the spinal cord, and from the large complex cranial nerves to the cerebral hemispheres. As well as the essential life functions, it also plays a role in hearing, taste and other senses.

There are 12 pairs of cranial nerves: two leave the brain from the cerebral cortex, ten leave from the brain stem. They have sensory or motor (movement) function or both, and problems with them can indicate severe brain dysfunction. They control many essential functions including the five senses, tongue and face movements, swallowing and breathing.

There are four main areas to the brain stem: midbrain, pons, medulla oblongata and reticular formation.

Midbrain – A small area at the top of the brain stem connecting cerebral

hemispheres (cerebrum) to the pons. It helps control eyeball movements and those of the head. It allows the eye to focus and help pupils to adjust their size for effective sight. It is also a communication centre for sight and hearing information.

Reticular formation – This area lies buried deep within the brain stem and controls eating, sleep wake cycle, sleeping patterns in general, alertness and awareness.

Pons – Mainly a connecting station for fibres that run between all the other important structures of the brain. It assists in the regulation of breathing. Finally, it coordinates the activities of the cerebral hemispheres and the cerebellum by relaying messages between them and the spinal cord.

Medulla oblongata – This area controls breathing by monitoring the amount of carbon dioxide in the blood. It stimulates breathing to keep this gas at the correct level in the blood. It also has a role in the regulation of heart beat, swallowing, sneezing, coughing and vomiting. Many important cranial nerves have their origins here or nearby.

Spinal cord

This is an extension of the brain, but in a different structural form, that extends out of the skull through an opening called the Foramen Magnum. It goes down through the middle of the bony spine

The table below describes the hormones produced by the anterior lobe:

Hormone	**Abbreviation**	**Action**
Growth Hormone	GH	stimulates growth
Adrenal Stimulating Hormone	ACTH	helps the body deal with any form of stress
Thyroid Stimulating Hormone	TSH	helps to regulate our metabolic rate
Follicle Stimulating Hormone	FSH	stimulates egg/sperm production
Luteinising Hormone	LH	stimulates the release of ovarian hormones and testosterone by the testes
Prolactin		stimulates breast development and the production of breast milk

The table below describes the hormones produced by the posterior lobe:

Hormone	Action
Vasopressin (ADH)	maintains the right water content in the blood
Oxytocin	stimulates contraction of the womb in childbirth and helps the breasts express milk during breast feeding

sending out nerves to the body through openings in the many vertebrae that make up the bony column. It is protected by the same membranes that line the brain and is bathed in the same fluid (CSF). It carries both sensory and motor nerves to and from the body. The spinal cord is not as long as the spinal column and actually finishes about the level of the upper part of the waist. After this point the spinal column is filled with a bundle of nerves on their way out of the spine through various lower vertebrae.

What Happens To The Individual Parts Of The Brain Or Spinal Cord If A Tumour Grows There?

The following pages describe what happens if a tumour grows in the:

- Brain stem
- Cerebellum
- Fourth ventricle
- Surface of the brain (Cortical)
- Middle of the brain
- Visual paths
- Frontal lobes
- Nerve injury

Brain stem

This is the part of the brain responsible for conducting the nerves to and from the higher part of the brain where movement and sensation are organised. It is like a complex telephone cable. Mixed in between the nerves are nuclei, which stimulate the cranial nerves that move the face, the eyes, and the muscles, which allow us to chew our food, speak, hear, breathe and swallow. Tumours within the brain stem can, therefore, interfere with some or all of these functions.

Cerebellum

Tumours of the cerebellum are amongst the most common tumours of childhood and frequently start with problems with balance, coordination and abnormal eye movements.

Fourth ventricle

Between the brain stem and the cerebellum is an area called the **fourth ventricle**, which is one of the fluid filled chambers of the brain. At the bottom of the fourth ventricle are three small holes through which the spinal fluid escapes from the brain, to the spinal fluid sac. These small holes, and the passages immediately above them, are very commonly obstructed by tumours. This causes **hydrocephalus** and symptoms of raised intracranial pressure.

Surface of the brain (Cortical)

These tumours may upset the electrical impulses leading to uncontrolled electrical activity resulting in epileptic fits. If the tumours get very large, then they may cause raised intracranial pressure or interfere with parts of the brain that control movement or interpret sensations from the skin.

Middle of the brain

If the tumour is deep in the middle of the brain, it may interfere with nerve connections. This leads to abnormalities of movement causing paralysis, or interference with hormone control causing abnormalities in areas such as growth and pubertal development. It may affect parts of the brain responsible for our emotions, appetite and temperature control, and may lead to problems with behaviour.

Visual paths

On the underside of the brain, there is the apparatus that carries the nerve impulses from our eyes to the back of the brain, where they are interpreted. Tumours involving these visual paths can lead to defects in vision.

Frontal lobe

The frontal lobes are poorly understood. They are not fully mature until adolescence. The frontal lobes are responsible for organisational ability. They also allow us to control our behaviour. Tumours of the frontal lobe can get very large before the effects are noticed. When effects are seen in early childhood they can be mistaken for childlike behaviour. In adolescents, the effect may not be noticed as, if only one lobe (either left or right) is affected, the other lobe can cope on its own. The loss of both lobes, however, leads to significant change in behaviour, which can be disabling and extremely distressing for the family and the child/adolescent. The frontal lobe also has some control of the movements of the eyes and the muscles that assist in speech. Therefore, damage in this area can lead to erratic eye movements and some speech dysfunction, such as hesistancy.

Nerve injury

The brain communicates with the rest of the body through the nerves to the spinal

column and out along the spinal nerves which run to all parts of the body.

The nerves that send messages from the brain to muscles are called motor nerves. If a motor nerve is damaged on its way down the spinal column, before it has formed a junction (**synapse**), the nerve from the spine to the muscle remains active. This activity makes the muscle become tense or spastic. This makes the limb or area of the body it supplies, rigid. This is called an upper motor neurone brain injury.

If the nerve that is damaged is one running from the spine to the muscle below the junction (synapse), the nerve dies and the muscle remains loose (flaccid). The area of the body that has lost its nerve supply will not have any tone or tension. This is called lower motor neurone nerve damage.

Sensory nerves

The nerves that run from skin and deep tissues back to the brain are called sensory nerves. If nerves that carry sensation to the brain are damaged, there can be loss of sensation in the skin, meaning that we no longer feel pain, light touch, pressure or temperature, etc. This will mean that our body is vulnerable to damage because we cannot feel these danger warnings and act accordingly, such as moving away from heat. There are other types of sensory nerves, which tell us the position of our joints and muscles, thereby helping us to balance and control our fine movements. If these nerves are damaged, then we are clumsy or uncoordinated in the area of the body from which the nerves start.

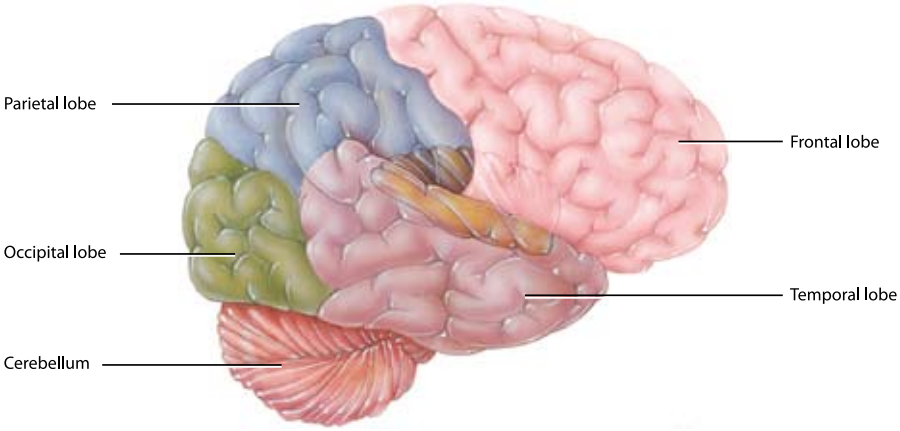

Figure 1: Side view of the brain showing the different lobal areas

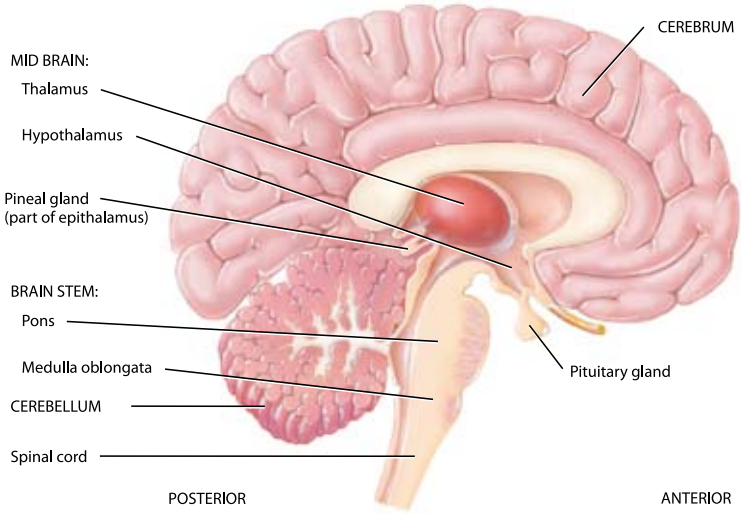

Figure 2: View of brain divided down midline showing main structures of the brain

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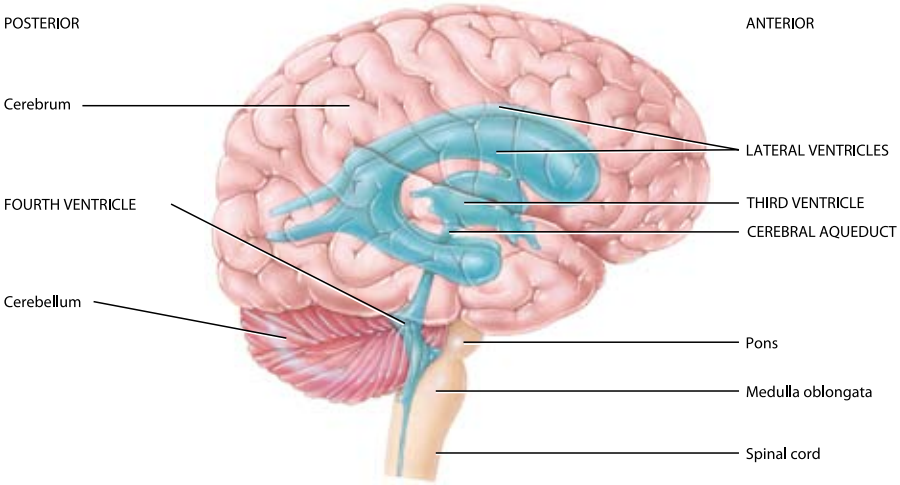

Figure 3: The pathway of cerebrospinal fluid within the brain

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Glossary of Terms

Term	Description
AFP	Alphafetoprotein is a chemical released by certain tumours into the blood. High levels of AFP may be used as a marker to suggest the presence of the tumour.
Arachnoid villi	Tiny channels in the skull that absorb CSF.
Astrocytoma	Tumour of the astrocytes (star shaped glial cells), which are one of the supportive cells (glial cells) in the brain. The most common type of glioma.
Ataxia	Jerky, erratic movements probably caused by damage to the cerebellum.
Audiometry	A measurement of hearing ability.
Benign	Low grade or less aggressive tumours, which rarely spread.
beta HCG	Beta human chorionic gonadotrophin is a chemical released by certain tumours into the blood. High levels of this may be used as a marker to suggest the presence of the tumour.
Biopsy	Taking a small sample of the tumour, which can be analysed by a histopathologist to give a diagnosis.
Blood brain barrier	A system whereby the composition of the membranes around the CNS protects the brain by not allowing some chemicals to cross it.
Brain stem	The brain stem controls the basic functions essential to maintaining life, including blood pressure, breathing, heartbeat and also eye movements and swallowing. It is the bottom part of the brain and connects the cerebral hemispheres to the spinal cord.

Cannula	A fine tube inserted into a vein to give drugs through or take blood.
Central venous line	A long, hollow tube used for long-term insertion into a major vein, which can be used for taking blood tests and giving chemotherapy or blood transfusions.
Cerebellum	The back part of the brain concerned with balance and coordination.
Cerebral cortex	4 lobes on each side of the upper brain, which process information and maintain our bodily functions.
Cerebrospinal fluid, CSF	The fluid that circulates around the brain and spinal cord.
Chemotherapy	Treatment using drugs to interfere with the ability of a cancer cell to divide and reproduce itself.
Choroid plexus	Network of connective tissue encasing small blood vessels in the chambers of the ventricular system which produce CSF.
Clinical trials	Research trials on patients to discover new and better treatments.
Craniopharyngioma	A benign tumour that develops from remnants of primitive tissue behind the pituitary gland.
CT scan	A computerised tomography scan that uses radiation to see structures and fluids within the body.
Cytotoxic	A drug used to kill cancer cells; it may also damage healthy cells.
Endoscopy	An investigation by a surgeon using a special flexible telescope passed into an area of the body while the patient is under sedation or general anaesthesia.

Ependymal cells	Cells that line the ventricular system.
Ependymoma	Tumour of the ependymal cells, which are one of the supportive cells (glial cells) in the brain. A rare type of glioma.
Fine motor skills	The small precise movements such as those involved in feeding, dressing, writing etc.
Frontal lobe	One lobe of the cerebral cortex that controls our emotions, thoughts and our personality.
Gastrostomy tube (PEG tube)	A tube inserted directly into the stomach from an opening made on the outside of the abdomen through which you can be fed.
Germ cells	Sperm and egg cells of the reproductive system, which, as a baby develops, move to the ovaries or testes but can settle in other parts of the body and can develop into germ cell tumours.
Glioma	Tumour of the glial (supportive cells) of the brain.
Growth hormone (GH)	A chemical released to promote growth.
Haematologists	Doctors who specialise in treating blood disorders, including leukaemias and lymphomas.
Hemiparesis	Weakness down one side of the body.
High grade tumours	Malignant or aggressive tumours that can spread easily.
Histopathologist	The doctor who analyses the tumour under a microscope to give a diagnosis.
Hormones	Chemical messengers released from glands.
Hydrocephalus	Blockage within the brain leading to a build up of CSF and thus raised intracranial pressure.

Hypothalamo-pituitary-axis (HPA)	The hormonal control centre in the centre of the brain
Hypothalamus	A small structure located in the centre of the brain that controls the internal body environment, i.e. temperature, hormone levels. It also controls the expressions of emotions such as pleasure, anger etc. and the sleep wake cycle.
Intracranial	Inside the main part of the brain.
Intrathecal	Giving drugs by injection into the spinal fluid.
Intravenous	Giving drugs by injection into a vein.
Keyhole surgery	A method of carrying out an operation without having to make a large incision.
Lateral ventricles	Ventricles 1 and 2, lying one in each cerebral hemisphere.
Low grade tumours	Benign or less aggressive tumours, which rarely spread.
Lumbar puncture	A needle inserted into the spine to remove some of the CSF fluid for analysis.
Malignant	A growth with a tendency to invade and destroy nearby tissue and spread to other parts of the body.
Medulloblastoma	Tumour arising in the nerve cells in the cerebellum.
MR scan	A magnetic resonance scan that uses radio waves and a strong magnet to create a detailed image of the body.
MRS	A magnetic resonance spectroscopy image is like an MR scan but can give more information about the chemicals in the brain and the workings of the tumour cells.

Nasogastric tube (NGT tube)	A thin tube that is put down the nose and throat into the stomach and can be used to feed you, usually used for a short time.
Neuro-navigation	Surgery using a computer to assist the surgeon in moving around in the brain.
Neuro-oncology	Specialty concerning the diagnosis and treatment of brain and spinal cord tumours.
Neuroscience	Neuroscience is a field that is devoted to the scientific study of the nervous system.
Neurosurgery	Surgical treatment of diseases of the brain and spinal cord.
Occipital lobe	One lobe of the cerebral cortex where visual understanding and perception are carried out.
Occupational therapist, OT	The therapist who helps redevelop the fine motor skills needed to manage the daily activities of living.
Oncologists	Doctors who specialise in treating people with cancer.
Parietal lobe	One lobe of the cerebral cortex which interprets sensations of touch.
PET scan	A positron-emission tomography scan that mainly looks at the blood flow through the body and can identify active cancer cells, it involves the injection of a small amount of a radioactive material.
Physiotherapist (physio)	The therapist who helps with exercise and other physical treatments to regain normal movement.
Pituitary	A small bean shaped organ that lies underneath the brain. It consists of the anterior and posterior lobes both of which produce hormones.

PNET	Primitive neuroectodermal tumours are tumours arising in the nerve cells in any area of the brain other than the cerebellum.
Posterior fossa	A region near the base of the skull that houses the brain stem and cerebellum.
Psychologist	The therapist who helps to maintain the mental health of the patient usually through counselling.
Radiotherapy	Treatment using high-energy rays to destroy cancer cells.
Raised intracranial pressure	Increased pressure inside the skull due to expansion of the brain caused by excess fluid in the brain or the presence of a tumour.
Randomisation	A process in which a computer will randomly allocate patients to have the different treatments in a trial to ensure that no treatment is favoured.
Shunt	A device which allows CSF to be diverted from the brain to the abdomen.
Spinal cord	The extension of the brain down the spinal column sending out sensory and motor nerves to and from the body.
Synapses	Junctions in the nerves.
Temporal lobe	One lobe of the cerebral cortex that influences vision, hearing, smell, learning, memory and emotions.
Tumour	Group of cells that multiply in an uncontrolled way.
Ventriculostomy	Creation of another drainage route from the ventricles for the CSF fluid.

SAMANTHA DICKSON BRAIN TUMOUR TRUST
Head to head with brain tumours

Samantha Dickson Brain Tumour Trust

This leaflet was sponsored by a donation from the Samantha Dickson Brain Tumour Trust, which raises funds for research and offers a vital support link for patients diagnosed with a brain tumour and their families.

Tel: 0845 130 9733 www.braintumourtrust.co.uk

Other Useful Contacts for Further Information, Support and Advice

Brain and Spine Foundation

Services include information booklets and a telephone helpline run by neuroscience health professionals

Tel: 0808 808 1000
www.brainandspine.org.uk

Brain Tumour UK

Aims to help relieve the suffering of those affected by brain tumours through research, education and support.
Tel: 0845 450 0386
www.braintumouruk.org.uk

Cancerbackup

A national cancer charity providing information and resources for anyone affected by cancer. Provides information through publications, website, freephone line and local drop-in centres.
Tel: 0800 800 1234
www.cancerbackup.org.uk

Cancer Research UK

National charity devoted to the causes, treatment and prevention of cancer. Provides a range of information for anyone affected by cancer.
Tel: 0207 242 0200
www.cancerresearchuk.org

Children's Cancer and Leukaemia Group (CCLG)

An organisation for professionals treating children with cancer, including coordination of clinical trials. Provides a range of information for patients and families affected by childhood cancer.
Tel: 0116 249 4460
www.cclg.org.uk and
www.childcancer.org.uk

CLIC Sargent

An organisation providing information and support for all family members affected by childhood cancer.
Tel: 0208 752 2800
Helpline: 0800 197 0068
www.clicsargent.org.uk

Headstrong: All about brain tumours

Website providing information for children with brain tumours.
www.headstrongkids.org.uk

The International Brain Tumour Alliance

An alliance for the support, advocacy and information groups for brain tumour patients and carers in different countries.
www.theibta.org/

The Katie Trust

Offers practical and emotional support to children with cancer, and their families in the North-East of England and Cumbria.
Tel: 01642 470856 www.katietrust.org

Macmillan Cancer Support

UK charity offering support to people with cancer by providing expert care and practical support.
Tel: 0808 808 2020
www.macmillan.org.uk

National Alliance of Childhood Cancer Parent Organisations (NACCPO)

A national voice for parents of children with cancer, working with medical, government and charity organisations to address issues affecting children with cancer and their families.
Tel: 01785 603763
www.naccpo.org.uk

National Brain Tumor Foundation

American based charity offering information on a wide range of topics.
www.braintumor.org/

OSCAR

Offers support to children and relatives. For children with brain or spinal tumours and their families. Local to the Oxford Radcliffe Hospitals Trust.
Tel: 01865 224330
www.support-oscar.org

Useful References

A Parent's Guide to Children's Cancers.
Produced by CCLG and Cancerbackup

Aftercure: what does this mean for you?
Produced by CCLG
www.aftercure.org

Children with a brain tumour in the classroom.
Produced by Cancer Research UK

***Con*tact** – A helping hand for families of children and young people with cancer.
Quarterly magazine produced by CCLG.

Looking Forward – Survivors of childhood cancer share their remarkable stories.
Produced by CLIC Sargent

Relationships, Sex and Fertility.
Produced by Cancerbackup

Returning to School – A Teacher's Guide for Pupils with Brain Tumours.
Produced by Cerebra

Welcome Back! A guide for teachers.
Produced by Cancer Research UK

What's the point of coming to clinic?
Produced by CCLG

Factsheets

A range of individual factsheets is available to accompany this booklet:

Brainstem Gliomas in Children

Craniopharyngioma

Ependymoma

Germ Cell Tumours

Low Grade Glioma

Medulloblastoma/PNET

Spinal Cord Tumours

You will be given the appropriate factsheet for your child's diagnosis.

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Head to head with brain tumours

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Fax: 0116 254 9504
Email: info@cclg.org.uk
Website: www.cclg.org.uk
Registered Charity No: 286669

CCLG leaflets are available to download from www.childcancer.org.uk.