Introduction

This booklet is designed to help you understand your child’s illness and treatment more fully. Although we have used ‘he’ throughout, it is of course applicable to girls too.

The brain and spinal cord make up the central nervous system (CNS). The CNS controls our behaviour, personality, senses, basic bodily functions, movement and coordination. Considering how important a role the CNS plays in our ability to function, it is easy to see why a brain or spinal cord tumour would cause serious problems. There are additional issues when a tumour occurs in a child as their body and brain are still developing.

A tumour is an abnormal growth or lump caused by uncontrolled cell division. At present, there is no known cause for brain and spinal cord tumours. They are not infectious, nor are they inherited.

At the back of this booklet is a glossary of terms you may hear during your child’s illness and treatment, you may find it useful to refer to this while you are reading it. Please bear in mind that all children are unique and no child will behave in an identical way to another. The tumour type, area of the brain or spinal cord affected, the extent of the tumour and a child’s age all contribute to important differences. Even two children of similar ages with apparently identical tumours will react and respond to treatment in very different ways.

The information in this booklet is a basic guideline. Your child’s team will give you exact information about your child’s treatment and care, and will be able to give you greater detail than is possible here.
The brain

There are four main parts of the brain: the cerebrum (forebrain) with right and left hemispheres, the cerebellum (hindbrain), diencephalon (above the midbrain) and the brainstem (see diagrams on the next page).

Cerebrum

This is the largest part of the brain and is divided into two sides, known as hemispheres. Hemispheres control movement, touch and sensation. The right hemisphere controls the left side of the body and the left hemisphere the right side of the body. This area is also responsible for functions such as thought, reasoning and remembering. Each cerebral hemisphere is divided into four lobes: frontal, parietal, temporal and occipital, each involved with a number of different activities (see diagram on next page).

Diencephalon

The diencephalon involves areas deep within the centre of the brain including the thalamus and the hypothalamus. The hypothalamus is a regulatory centre involved in hormone secretion, and controls functions such as eating, sleeping, temperature and emotion. Sitting above the hypothalamus, the thalamus acts as an information processor for much of what goes on in the brain.

Cerebellum

This is the area at the back of the brain and main functions include balance and coordination. The cerebellum continually and automatically makes allowances that let the body maintain its balance. This is carried out below the level of consciousness and is not under the person’s control. If a tumour grows in the cerebellum, a child may stagger when walking (ataxia) or have very jerky movements.

Brainstem

This area of the brain connects the cerebral hemispheres to the spinal cord. There are twelve pairs of cranial nerves, numbered I to XII (written in Roman numerals I to XII). Most originate in the brainstem and control important things such as swallowing, facial movement, eye movements and sensation on the opposite side of the body. Areas of the brainstem also control the basic functions of blood pressure, breathing and heartbeat.

Ventricles

The ventricles are cavities inside the brain where cerebrospinal fluid is made. Cerebrospinal fluid (CSF) flows through the ventricles and around the brain and spinal cord before the body absorbs it. The body makes and absorbs CSF in a continuous process. There are four ventricles in the brain: one on each side (lateral) and two others. A narrow tube called an aqueduct links the third and fourth ventricles. Openings in the fourth ventricle let the CSF flow around the brain and spinal cord.
Signs and symptoms of brain tumours

Signs and symptoms are dictated by the tumour position. Occasionally, some children develop other symptoms, but it is highly unlikely that a child experiences all of the symptoms listed. The most common signs and symptoms are listed here.

When one-sided weakness (hemiplegia) is a symptom, if it affects the face it will be on the same side of the head as the tumour. However, weakness below the neck is on the opposite side of the body to the tumour as nerves leaving the brain to other areas of the body, such as our limbs, cross over in the brainstem. So, for example, a right-sided brain tumour can cause right-sided facial weakness and/or left-sided body weakness.

Frontal lobe of cerebrum
- Headaches
- Seizures (fits)
- One-sided weakness
- Changes in behaviour and/or character
- Slurred speech
- Memory difficulties

Temporal and parietal lobes of cerebrum
- Headaches
- Seizures (fits)
- Speech impairment
- One-sided weakness
- Loss of sensation to one side

Occipital lobes of cerebrum
- Visual disturbances

Cerebellum
- Headaches
- Vomiting, particularly early in the morning
- Squint (crossed eyes)
- Double vision
- Clumsiness or uncoordinated movements
- Slurred speech
- Weakness on one side or sometimes both

Brainstem
- Squint
- Abnormal eye movements
- Uncoordinated, clumsy walk
- One-sided weakness or sometimes affecting both sides
- Speech impairment
- Swallowing difficulties
- Headaches and vomiting (rare)
**Diencephalon**

- Visual disturbances
- Abnormal eye movements
- Headaches
- Nausea and vomiting
- Personality changes
- Behavioural disturbances
- Alterations in the level of consciousness
- Impairment in hormone functions, leading to delayed or accelerated growth, water imbalance within the body or early or delayed puberty

**Hydrocephalus**

Hydrocephalus is a common symptom associated with a brain tumour. It occurs when the ventricles in the brain become enlarged. A tumour can cause hydrocephalus by blocking the CSF pathways either because it develops in one of the ventricles or because it presses on a part of it. Signs and symptoms of hydrocephalus are different in babies and children:

**Babies**

- Enlarging head circumference
- Lethargy and irritability
- Reluctance to feed or vomiting

**Older children**

- Headaches growing in intensity and persistence
- Vomiting
- Tiredness leading to a decreased level of consciousness

If hydrocephalus is present surgery may be required prior to removal of the tumour to allow temporary drainage of CSF into an external ventricular drain. For more information, please see our External Ventricular drainage leaflet. Once the tumour is removed this may resolve the hydrocephalus. If it remains it may be necessary for your child to have a further operation to insert a ‘shunt’, which is a narrow, flexible tube containing a valve, that allows the CSF to bypass the blockage. Alternatively a small hole can be made in the base of the third ventricle to allow CSF to drain out. Hydrocephalus can develop at any stage of treatment and does not always mean that the tumour is still present.

Further information about hydrocephalus and ways of treating it is available from the ward or the hospital website.

**Metastases**

Metastases are seeds of a tumour that have spread from the original site and have settled in a new location. For the majority of tumours, an assessment of the child’s spine must be made to look for metastases along the spinal cord. This is because it is known that certain tumours spread via the cerebrospinal fluid into the spinal cord.

Spinal metastases (seedings) are found more often when the tumour is in the posterior fossa region (back of the brain) than in other areas of the brain. The seedings are often minute and may not cause any symptoms. If investigations highlight the presence of seedings, treatment can be altered accordingly. To assess the spinal cord either a spinal MRI scan or lumbar puncture will be performed.

Occasionally, tumours are found to metastasise into other areas of the brain. Very rarely they can metastasise into bones elsewhere in the body, but generally, tumours that originate in the brain do not spread into other organs of the body.
The spinal cord

The spinal cord acts as the pathway for nerve impulses and is responsible for relaying sensory information such as touch, temperature, pressure and pain to the brain, and relaying commands such as movement and reflexes from the brain to the other parts of the body. There 31 spinal nerves attached by roots that branch out to different parts of the body through spaces in the vertebrae. The spine is a bony structure that protects the spinal cord and nerve roots, and extends from the base of the skull down to the base of the back, known as the sacrum and coccyx. The spinal column consists of bones, discs and joints and encloses the spinal cord and nerve routes in the spinal canal. The spinal cord ends just below the lumbar segment of the spine, which is just above the small of the back, below this only nerve roots are found in the spinal canal.

Signs and symptoms of spinal cord tumours

Tumours are described according to the area affected. Spinal cord tumours are described depending on whether they are inside the spinal cord (intrinsic) or outside the spinal cord (extrinsic). Most symptoms of spinal cord tumours develop because the tumour is compressing or squashing the spinal cord. The symptoms can be described as ‘focal’, affecting the area immediately around the tumour or ‘distal’, which interfere with transmission of nerve impulses.

- Local symptoms include: pain that is often worse at night, numbness or tingling and/or arm or leg weakness
- Distal symptoms (situated away from the tumour) include: weakness, loss of feeling or muscle control leading to paralysis at or below the level of the tumour and/or problems with bladder and/or bowel control
- Longer-term symptoms may include: stiffness on walking, neck pain or head tilt and/or curvature of the spine.
How is a tumour diagnosed?

The aim of diagnosis is to build up as big a picture as possible of the tumour. Usually you would have seen your family doctor or paediatrician who would have examined your child. If a brain tumour were suspected, you would have been referred to a specialist doctor. This involves various tests, some of which may have already been done before you get to Great Ormond Street Hospital.

A CT or MRI brain scan shows the location of the tumour, but cannot determine the exact nature of the tumour. This can only be achieved by analysing a piece of the tumour tissue itself in the laboratories and occasionally by a blood sample.

Neurological examination

A neurological examination is a series of assessments that test the nervous system, and can include checking reflexes, their vision and power in their limbs. It may involve:

- Eye examination - using an ophthalmoscope (an instrument that shines a bright light at the back of the eye)
- General eye movements and vision test
- Facial muscle test – chewing, smiling, grimacing
- Tongue appearance and movement
- Swallow (gag) reflex – a lollipop stick may be put to the back of the throat to test the retch response
- Hearing test
- Strength in arms and legs
- Knee jerks and other reflexes
- Coordination – picking object up and transferring it from hand to hand
- Walking – checking for any balance problems walking unaided, heel to toe, on tiptoe or on heels
- Examination of the back to look for curving of the spine

Physiotherapy assessment

If your child is having an operation, the physiotherapist will try to see them before to get an idea of what their movement, walking and development is like. This helps the physiotherapist to work out if there is anything they can do to help with your child’s movement following surgery, for instance, stretching muscles. It can also be useful for you and your child to meet the physiotherapist before they have an operation to assess their mobility as they may need further physiotherapy after the operation.

This assessment may involve just looking at your child lying in bed or it may involve active things, like walking, balance and hand co-ordination. It is useful for the physiotherapist to know if your child has had any problems with their movement in the past or if they have had any previous physiotherapy.

Once the physiotherapist has met your child they will give you advice on activities to do if required. They may also arrange rehabilitation sessions where appropriate. If your child is unwell in bed for a period of time, they may make splints to keep joints loose. Some children having neurosurgery get a stiff neck from holding it in one place all the time. The physiotherapist will also encourage your child to move their head and neck to stop it from becoming tight.

When you are transferred to another hospital or discharged home, we will assess whether your child needs ongoing physiotherapy. They will discuss this with you and contact the local physiotherapist to arrange this if required.
**Occupational Therapy assessment**

The occupational therapist is most likely to meet you following your child’s operation and will carry out a series of tests, as well as observing your child and talking to you. Areas assessed include: home and school environment, seating, skills in self-care, visual perceptual skills, handwriting and other fine motor skills, and pain and sensory issues.

The occupational therapist will be able to advise you on seating, the provision of wheelchairs while your child is an inpatient, splints to stop limbs becoming stiff and may refer to local services for ongoing treatment.

The occupational therapist and physiotherapist will provide a written report, giving recommendations and advice, and give you a copy. The occupational therapist is also available for consultation and advice after your child has been discharged home, both by telephone and in the outpatient clinic.

**Ophthalmology assessment**

If your child has visual difficulties, various eye tests may be required before and after surgery.

**Spinal Investigations**

The brain and spinal cord are linked together by the flow of CSF. Some tumours have a tendency to spread from the brain down into the spine. In these situations an MRI of the spine will be performed to highlight the presence of any seedings (‘metastases’).

**How is surgery used?**

If accessible surgery will be recommended to attempt removal of as much tumour as is feasible. The duration of surgery is dependent on the size and position of the tumour and your child's surgeon will discuss this with you prior to the operation. The ward staff will prepare you and your child for surgery explaining the most likely course of events related to your child.

During surgery specimens of tumour are analysed to ascertain the likely nature of the cells involved. This initial analysis is performed quickly and is not always accurate. For this reason the doctors will not give you a firm diagnosis following the operation. The cells need several days-worth of tests performed on them before a definite conclusion can be made. Once a firm diagnosis is ascertained it will be discussed with you. This can take longer than a week and we know this can be an agonising time for you, however it is not advisable for you to be told the provisional diagnosis because an inaccurate premature result could cause unnecessary anguish or false relief.

In certain situations much of a tumour may not be able to be removed so a biopsy may be offered to aid in diagnosis and further treatment. This is where a small piece of tumour tissue is extracted with minimal amount of interference to the surrounding brain tissue. This will involve an anaesthetic and a small incision on the head or an operation known as a craniotomy. Children usually make a rapid recovery from this procedure as it is generally less invasive than removing a tumour.
After the operation

Most children are nursed in the high dependency bay on Parrot ward following neurosurgery. Your child will be monitored closely for at least 24 hours and the nurse caring for him or her will explain all the post operative care and monitoring to you. He or she is likely to have several monitors and infusions attached, which may appear daunting, and we encourage you to ask questions as you wish. Your child will be given regular medications to control pain, nausea and vomiting. Following certain neurosurgical operations some children are not allowed to eat or drink for at least 24 hours or until their swallowing ability has been checked by a doctor. Initially it will be necessary for the nurse to wake and check your child as frequently as every 15 minutes. This can seem to be a disturbance to your child’s rest and recuperation. However it is vital so that any changes in his or her level of consciousness, which may denote complications, can be detected and treated as early as possible.

Diagnosing the tumour type

This will be done in the pathology department using all available modern methods. You will be asked for your consent to save some of the tumour samples taken at the time of the operation. Some of this will be stored in case it is needed for future tests if your child’s clinical condition needs it. If you agree, we will store any tumour that is ‘left over’ for research purposes. This work will not directly benefit your child now but may help other children in the future. Your consent is entirely voluntary and you not have to give your permission. If you decline, it will not affect your child’s medical care in any way.

On receiving the official diagnosis, a decision will be made as to what further treatment will be recommended. Surgery may have resulted in a good removal of the tumour, but there is always a risk of a few (malignant) cut cells being left behind. Subsequent treatment may be essential to eliminate these stray cells and help prevent their re-growth, as it is in any situation where the definite presence of tumour is known. Further treatment involves the use of radiotherapy or chemotherapy or both. The doctors will explain to you which they recommend and why.

In some situations the doctors will decide to delay ongoing treatment for a period of several months. This may be because the tumour is ‘benign’ and has been fully removed, in which case a cure is assumed. Or, despite an incomplete removal, the best option maybe for the surgeons to wait to see if further growth occurs.

Investigations after surgery

It is likely that your child will have a CT scan or MRI scan within a few days of surgery to check that as much of the tumour as possible has been removed. Your child may also need a lumbar puncture (LP), where a needle is inserted into the space between the bones of the lower spine and a small sample of spinal fluid is drawn off. Cerebrospinal fluid (CSF) naturally flows around the brain and down the outside of the spinal cord. Investigations of this fluid may be necessary. This procedure can be quite uncomfortable so sedation may be given.
Possible complications after treatment

Sleep difficulties
Many children who have been in hospital have difficulty adjusting to being back at home again and this may show up as problems sleeping. This is especially true of children who have been treated for a brain tumour as they will tire easily and be less willing to put up with unusual or stressful situations. Also, if your child has previously been ill and sleepy but now feels better, it can be difficult to be firm and keep to a regular bedtime routine. Sleep difficulties can take many forms, but can include problems getting off to sleep, waking up during the night, moving to a parent’s bed during the night and waking up early in the morning.

Establishing a good bedtime routine will help with all of these. It is often best to start by adjusting your child’s evening routine, rather than deal with problems in the middle of the night. In time, once your child is used to his or her bedtime routine, sleeping problems will improve. Other helpful hints include:

- Establishing a set bedtime routine, with a regular time to go to bed
- Avoiding making the bedtime routine longer each night
- Avoiding activities before bedtime that could lead to arguments or excitement
- Setting a time to get up in the morning
- Keeping the bedroom for sleeping, only allowing activities in there that make your child feel sleepy
- Keep the bedroom quiet and at a steady temperature

If you are still having problems with your child’s sleeping, please ask us for advice. There are plenty of other methods to try, which we can tailor to you and your child’s needs.

Behaviour problems
Children who have had treatment for a brain tumour can also develop behaviour changes or problems. This is often due to combination of a hospital stay, the tumour itself and the treatment needed. Children might lose skills as a result of treatment and be functioning at a level of a younger child with associated behaviour. If the child had developed movement skills before treatment, there will need to be a period of readjustment. Children will need to learn new skills and re-learn others. The frustration this can cause often leads to difficult behaviour.

Common difficulties that we hear about include:

- Inability to concentrate
- Misunderstanding or forgetting instructions
- Tiring easily
- Difficulties learning new information, planning complex tasks or organisation
- Being easily distracted

Parents may find it hard to discipline their child, particularly if they are not sure which behaviour problems are caused by the tumour and which are expected for a child of that age. There are some strategies that can help:

- Provide clear guidelines and routines
- Accept that some difficult behaviour or behaviour changes are out of the child’s control
- Some behaviour may seem immature but are appropriate given the child’s new developmental level
- Reduce attention given to poor behaviour and praise good behaviour
- Anticipate situations that the child may find stressful and organise to minimise stress or allow rest breaks
**Balance and coordination problems (ataxia)**

A child with ataxia might be unsteady on his or her legs, walking with feet wide apart and holding on to stop falling over. If his or her arms are ataxic, he or she might have a tremor that gets worse when carrying out fine tasks, such as doing up buttons, writing or tying shoe laces. Ataxia happens when the cerebellum or balance centre of the brain is not working properly. Please see the diagram on page 3.

Surgery to remove a cerebellar tumour helps this in most children but in some children this improvement is very gradual, taking many months. Therapy from physiotherapists and occupational therapists can help children to re-acquire any skill that have been lost and learn ways of overcoming any that remain. This can be a ‘one-off’ session with recommendations for the child, family and school. Telling the school about your child’s school and teachers can help them understand if the child is having particular difficulties. For example, children who have problems with handwriting may benefit from using a computer or having extra time during tests and exams.

Although the majority of children with cerebellar tumours regain their coordination skills, some have moderate difficulties with fine motor tasks such as handwriting and a few have more severe permanent problems with walking balance. Some parents notice that these problems get worse for a while when the child is feeling unwell with a bad cold or flu.

**Epilepsy**

Epilepsy is the tendency to have seizures (fits). Seizures happen when the electrical currents in the brain build up to very increased levels with an unusual or irregular pattern. The type of seizure varies from child to child. Some may have tonic-clonic seizures (grand mal seizures) often start with the child crying out and then falling down unconscious. Their body stiffens and then their limbs start to twitch. Saliva may collect in the mouth and they may empty their bladder. Afterwards, the child will be sleepy or confused.

In a partial or focal seizure only one part of the brain is affected. The child may suddenly turn their eyes or head to one side and may stiffen or twitch the limbs on that side. The child may also make lip-smacking or gulping movements during the seizure.

Brain tumours can cause any type of epilepsy, but especially partial or focal seizures. On average, one child in ten with a brain tumour develops epilepsy. It is more likely to develop if the tumour is in the cerebral hemispheres or temporal lobes of the brain. Please see the diagram on page 3. Brain tumours cause epilepsy by altering the way that normal brain cells signal to each other using small electrical currents. If the cells do not work properly, there may be sudden and irregular electrical currents, which cause seizures.

Although a seizure is frightening to watch, the child is not in pain and will have no memory of what happened. The most useful things to do if a child is having a seizure are:

- Move anything away that might injure the child
- Do not attempt to restrain the twitching movements
- Do not put anything in the child’s mouth to stop them biting their tongue
- After the seizure has stopped, put the child on their side in the recovery position
Call medical help if
• the child has been injured during the seizure
• they have trouble breathing after the seizure
• if one seizure is immediately follow by another one
• if the seizure is lasting longer than usual

Successful treatment of the tumour may stop the epilepsy, but in some cases, the epilepsy continues. Anti-epileptic medicines can help to prevent the build up of sudden and irregular electrical currents. Most medicines come as tablets or suspensions and need to be taken twice a day. These medicines have side effects, which your doctor will discuss with you. Some children need to be given medicine when they are having a seizure. You will be taught how to give these medicines, as they need to be given into the bottom (rectal) or the side of the mouth (buccal).

Most children with epilepsy can lead a normal day-to-day life, with few restrictions. However, there are a few special precautions to take, depending on the child’s age, type of epilepsy and any other medical problems.

Riding a bicycle is fine but busy roads and traffic should be avoided.

Swimming is allowed but someone who can rescue them and carry out first aid if a seizure happens must accompany them.

Climbing is not a good idea in case they have a seizure leading to a serious fall.

Computer and video games are safe for most children with epilepsy.

Bathing is fine, but younger children should always be supervised in the bath. Showering is safer for children, but if you do not have a shower, keep the bath water shallow and the bathroom door unlocked.

Having seizures will not in itself cause any damage to your child’s brain. Sometimes injuries can occur during the fall and twitching movements. Very occasionally, a seizure may go on for much longer than usual, which may require emergency treatment in hospital.

Feeding problems

Children with brain tumours can lose their appetite or more rarely, may have an increase in their appetite. Their weight gain might be abnormal, such as failing to gain weight even with an increased appetite or gaining weight excessively. Some children lose the ability to chew or swallow food properly. These problems may lead to aspiration, or food going ‘down the wrong way’ into the lungs instead of the stomach. Vomiting occurs more frequently in children with brain tumours, and they may also develop reflux, where food and stomach acid travels back up the food pipe into the throat or mouth. They may also develop difficulties in feeding due to physical problems. Although we do not yet know how many children with brain tumours develop feeding problems, in our experience, about two-thirds of children have some kind of feeding problems.
The reason why children with brain tumours develop feeding problems for a number of reasons:

- The brain tumour may be located in an area controlling chewing and swallowing, particularly the brainstem. Tumours located elsewhere may affect the muscles used for chewing and swallowing.

- The brain tumour may be located in an area that controls appetite, particularly optic pathway tumours, which affect the hypothalamus.

- Some children with brain tumours have difficulty controlling their arm and hand movements or may not be able to sit correctly, which will interfere with feeding. If children have poor vision or hearing due to the tumour, this can also cause feeding problems.

- Some children may have communication difficulties, making it hard to tell parents when they are hungry or what they would like to eat.

- Brain tumours in very young children can get in the way of a child's normal development of feeding and appetite.

- Chemotherapy can affect a child's appetite, causing nausea and vomiting in some cases. Radiotherapy causes sleepiness that might interfere with normal feeding patterns. Constipation due to medicines or different eating habits will also result in lack of appetite in many children.

- Many children with brain tumours have a hormone imbalance as well, which can affect their appetite.

Various tests will be needed to discover the reason for the feeding problems, including speech therapy assessment, swallowing tests, pH testing, gastroscopy and electromyogram. Once the results of these tests are known, staff will be able to advise ways to improve a child's feeding and appetite.

**Follow up**

Once treatment has been completed, your child will need to be seen regularly by the medical teams caring for him. This will involve clinical examinations by your child's neurosurgeon, routine scanning and/or reviews by the oncologist and/or radiotherapist and also by the endocrine team for growth assessment. The number of appointments will be kept to a minimum and where possible, different appointments will be arranged for the same day.

The first follow-up appointment is usually arranged for six to eight weeks after the completion of treatment. A scan will be performed around this time and the consultant will see your child. An interval before scanning allows any disturbance within the brain resulting from treatment to settle down. Scanning too early may produce 'false pictures' giving inaccurate results and should be avoided.

Subsequent appointments for scanning and for clinical examinations will be arranged from this time. Depending on the type of tumour your child has, these will be arranged from three to six monthly. These check-ups will decrease in frequency and scanning will not be required at every follow-up appointment.

As the length of time from treatment extends, the risk of the tumour re-growing reduces, and a time will come when the doctors feel your child can be discharged from their care. There is usually a minimum period of five years follow-up (where necessary). This is variable, however, and will be decided by the consultant involved. Endocrine follow-up usually continues for a longer period because assessment and treatment may be necessary into early adult life.
Going home

It is a hard task for parents to relax about their child's health following the diagnosis of a serious illness. It is important to recognise that many of the symptoms that may have presented when the brain tumour was diagnosed, such as headache, vomiting and tiredness, are also symptoms of many of the common childhood illnesses. Your GP should be asked to examine your child if you are concerned and he may well be able to diagnose a common disorder. If there is any doubt, please contact your nurse specialist who will arrange for your child to be seen either at your local hospital or in outpatients if necessary. Please make phone contact with the hospital first before travelling from home.

It is appreciated that returning to 'normality' at the end of treatment is quite a daunting prospect. Your clinical nurse specialist, ward staff and social workers, among others, are all there to help you prepare for your return home and back into your community. Please talk about your fears and concerns. Constructive emotional help and practical advice is available for you, to help you towards regaining your confidence. Don't be afraid to ask for help! This is important for your child too!

Following discharge, your nurse specialist will remain in telephone contact and will be able to help with any questions or problems that arise once you are home. Links with community teams will be made as necessary and contact is always made with the health visitor, where applicable, and the GP. The nurse specialists will meet you and your child when you return for follow-up appointments and can help with any arrangements if necessary.

Once your child has finished treatment it is important that you have a telephone contact number for the nurse specialists, social worker or ward staff, to help ease your feelings of isolation. Please do not sit at home worrying. No question or fear is 'too silly' or 'too simple' to be asked and it usually can be easily resolved. The care of you and your child does not have to stop at the end of treatment.

Recurrence

The treatments described, all have the potential to cure. However, certain tumours, particularly those that are more malignant, can show a great resistance to treatment, and although they appear to make a good response initially, they may re-grow. Re-growth (recurrence) can occur at any time following treatment for up to five years or longer. If the tumour does re-grow the child will probably, but not necessarily, present with similar symptoms to those when the original tumour was diagnosed.

When a recurrence is diagnosed the medical team will speak with you about the possible treatments available.

There are times, sadly, when the decision is made either to discontinue any further treatment that has been established, or to withhold it completely. Any such decision will not be made without first discussing it with the child's parent(s), members of staff involved in his treatment and care, and the child himself if appropriate. When 'active' treatment is discontinued, families are included in all discussions on the care of their child and the support they need. The nurse specialists, GP, local hospital and community teams may all be involved, and links with the main treatment centres will be maintained. 'Active' treatment will then be replaced with 'palliative' treatment. This means that medical teams will focus on controlling any symptoms that may develop, such as headaches or sickness, in order to establish good quality living for as long as possible. Care will be directed at preserving the child's dignity and individuality, and at providing practical and emotional support to the child and his family. This can all be achieved within the home environment when desired.
You may become more aware of coverage by the media on the subject of brain and spinal tumours. Please be wary of what you read. Much of what is reported in the press is either inaccurate or grossly over-exaggerated. Do, however, talk over any issues that arise with the consultants caring for your child. They are able to discuss the treatments that have been reported and can help you decide if they are appropriate for your child.

All the doctors involved in your child’s care want the very best treatment for him. They will not withhold any information that may be beneficial to you and your child. The neurosurgeons, radiotherapists and oncologists, who care for your child, regularly communicate with each other and also with others in their field elsewhere in the country and worldwide. They therefore ensure that your child is receiving the best possible treatment.

Second opinions

As you know your child is being treated at Great Ormond Street Hospital by the neuro-oncology team, a group including specialist doctors that include paediatric neurosurgeons, radiotherapists, oncologists, endocrinologists and neurologists. The treatment plans we recommend follow nationally agreed guidelines but we also discuss the management of individual patients with other experts either here in the UK or abroad. This means that the treatments we recommend are similar to those used in other major children’s brain tumour centres in Europe and the United States and the results of treatment are also similar.

Not everyone wants or requires a second opinion but some families feel that they would like to seek one for their peace of mind. No doctor should be insulted by your requesting to consult another team about your child’s life and well being. Second opinions from other specialist centres in the UK can be obtained and are available on the NHS at no extra cost. If you want to arrange a second opinion yourself, the team can advise you on the most appropriate centre and you can arrange for copies of your child’s scans, for a nominal fee.

Homeopathic and complementary therapies

Some families consider alternative medicine and therapies such as homoeopathy, aromatherapy, reflexology and massage. It is recognised that the intention in using complementary therapy is to support your child through their treatment, not provide cure. Doctors do not condemn people who investigate these options but would like you to let them know if your child is receiving any other treatment(s).
Keeping things normal

This is an incredibly difficult time for you all. Trying to establish some semblance of normality during the traumatic time you are going through must seem almost impossible. But there are many people around who are willing to support you as you strive to do the best you can for your child and the rest of the family.

Talking to your child

The psychological and emotional needs of your child are of concern both to you and to all the staff involved with his treatment and care. An important fact that all medical and nursing staff will recognise is that you know your child best. We will aim to work alongside you in your care of your child. Our experience can help by providing you with advice on ways in which to talk with, and manage, your child. There is a psychologist available to you while your child is an inpatient, please discuss with the nurse or doctor caring for your child if you require this.

Each child is unique. A child’s age, basic development, religious beliefs, cultural influences and past experiences of serious illness, all combine to influence his ability to understand what is happening to him. It is important that a child is given adequate preparation for procedures and treatments whenever possible. This preparation need not be complicated if the child is unable to understand much detail. Simple explanations as to what will be done, what it will be like and why it is necessary, may be all that is needed. You are probably the best judge as to how soon before an event it is best to prepare your child, but be wary of leaving it too late and therefore not having enough time. Nursing staff and/or play specialist are always willing to be involved in this if you are finding it understandably difficult. Do ask if there are things you do not understand fully.

From diagnosis onwards your child has the right to know as much as he wants to know. This may only be simple and basic questioning of the immediate present, or it could be more complex searching for a greater understanding. Honesty is essential. It is usually possible to answer all questions truthfully, simplified if necessary. If you are uncertain about things yourself, ‘I don’t know but I will tell you when I do’ is quite acceptable as long as you do return with an answer when you have it. Anticipate likely difficult questions and talk them through with a member of staff ahead of time. Never tell an untruth, however tempting. A child will rapidly lose trust in any adult he realises is not answering him accurately and may well stop asking. He will also question this apparent ‘secrecy’, and become more anxious. You should be aware that your child might hear the words ‘tumour’ and ‘cancer’ even if you as a family do not use them. Headstrong, the children’s section of the Brain and Spine Foundation has recently published information that helps children with brain tumours understand their condition and encourages them to talk openly about it. Your nurse specialist will be able to direct you to these resources, but their website can be found at the end of this booklet.

Family needs

It is so important during this critical time in all your lives that you strive to maintain your normal patterns of communication with your child. Discuss with your partner or other family members how you want to talk with your child and ensure you are consistent with each other. Do talk this difficult issue over with the ward staff or your nurse specialist. They can listen to your concerns and guide and reassure you.

In time you will find that you are more able and ready to give your child more detailed explanations, if he requests them, concerning his illness, the need for treatment and what that involves. Initially everything happens very quickly. You will find it difficult yourself
to listen to everything that is being said and understand it, as well as trying to explain things to your child. You will, however, gradually gain a better understanding, the pace of things will slow down and it will become easier to talk with your child.

Children of any age are usually aware of anxiety surrounding them in stressful situations. They also, like you, may be angry, frustrated, frightened and questioning. Do not be surprised if you see abnormal behaviour patterns: aggression, temper tantrums or sullenness. Children have less ability to voice their feelings than adults and are more likely to express themselves through their behaviour. This expression will most likely be directed at the people they trust the most, that is, their parent(s), as they know you will not turn away from them however poor their behaviour. Allow them to vent their feelings, support them as much as possible, and enable them to talk with you about their situation. There are people who can help you and your child cope and deal with these feelings. Do tell a nurse or doctor if you are finding this area of your child's illness difficult.

Another aspect of dealing with your child's behaviour is discipline. The majority of parents have a great struggle with this issue when their child is ill. As your child recovers from the initial effects of his illness and treatment, you will be faced with the need to re-establish your normal family structures of discipline.

The desire to abandon all normal guidelines is strong. We strongly advise that you discipline your child as normal. This is because children actually prefer the security of the boundaries they are used to. They will cope better with their illness and all that it entails if they recognise the usual limits set by you, and see that you intend to maintain them. Children respond to 'normality', whatever that is for each individual child and family. To be receiving special attention from you, and treatment that is different from usual, will make him much more aware of and frightened by the threatening situation he is in.

Consideration of yourselves and any other children in the family is important. You all will benefit when normal patterns of communication and discipline can be re-established within the family structure.

**Brothers and sisters**

As a parent(s) you will feel overwhelmed by everything you have needed to handle. You may be physically and emotionally drained having had to give round the clock care to your sick child in hospital. Other children in the family may have unavoidably been left out when they too desperately need emotional support.

Brothers and sisters often experience fear, grief and confusion, coupled with anger jealousy and guilt. They may not want to upset you further and may keep their feelings inside. It is advisable to tell your other children as much as they can understand about their sister and brother's condition and plans for treatment as soon as possible and in ways that are age-appropriate. As with your child, using the correct terms such as ‘brain tumour’ will be helpful as avoiding terms can make the subject ‘taboo’ and everything feel all the more frightening.

Reassure your children that they are in no way responsible for the tumour and that it isn’t ‘catching’. It may be helpful to explain that the doctors and nurses do not have all the answers but are doing their very best to help their sick brother or sister. If practical, your other children could attend hospital appointments with you. Involving your other children will help them to feel useful.
School

Whenever possible part-time education is maintained throughout the weeks of treatment. If your child is receiving treatment on an outpatient basis it may be possible to attend school either before or after the treatment session. If your child is an inpatient, there are hospital teachers who will assist with a few hours of teaching each day. The hospital teachers will link up with children's schools where appropriate.

Although tiredness often affects the child's ability to do much schoolwork, they are nonetheless usually keen to continue their education. It helps them start to regain their concentration skills and prevents them from falling too far behind their classmates. Keeping in touch with the school and with school friends during the early period of treatment may also help to lessen any possible hurdle of returning to school later on, especially if symptoms such as hair loss are apparent.

Returning to school fulltime following treatment needs to be carefully managed. A gradual reintroduction is advisable as it is disappointing for a child to find that he is unable to cope, and have to take yet more time off. It may take up to half a term for your child to return to full-time education. For some it can be considerably faster. Be guided by their state of tiredness and behaviour. Most children are keen to return and only a few will try to delay it! If there are any problems with your child's return to school, do refer back to your nurse specialist, psychologist, or the doctors involved with your child's care.

CLIC Sargent

The CLIC Sargent social worker/family support worker provides support to all children and their families who have a diagnosis of a malignant tumour, or are receiving treatment. The social worker/family support worker can offer help in many ways by providing practical support, including benefit advice such as DLA and Carers Allowance, as well as assistance with housing needs, letters to employers to explain your changes in circumstances, and referrals to local social services to request support at home. The CLIC Sargent social worker/family support worker can also provide financial assistance. In addition to practical support we can provide emotional support to the child and their siblings, as well as to the parents, grandparents and extended family where necessary. The CLIC Sargent social worker/family support worker can also help you to apply for holidays with CLIC Sargent and other organisations, and to apply for special wishes for your child. The CLIC Sargent team are willing to assist in any way possible to make life a little easier through this difficult time.

Holidays

It is possible to take holidays during treatment and if necessary, your specialist nurse can set up direct access with the nearest children's unit. It is recommended that you seek travel insurance before travelling abroad. It is generally safe for your child to fly three months after surgery. Some headaches may be experienced during take off and landing due to pressure changes within the aeroplane. There is no additional concern if your child has a VP shunt, but it will be useful for you to identify the nearest children's neurosurgical centre, just in case there is a problem.

Sport

Most sports can be safely started once your child has recovered, although contact sports that may result in blows to the head should be avoided. You should check with your nurse specialist if you are worried. Swimming is encouraged when wounds from surgery or skin from radiotherapy have healed. Your child should not swim unsupervised, especially if there is a risk of seizures.
Members of the team

Nurses
- Ward staff – includes care assistants, student nurses, staff nurses and senior staff nurses
- Sister (female) or charge nurse (male) – are responsible for the running of the ward
- Clinical nurse specialists – coordinate treatment teams and centres, linking up with community team, and provide continuing support once treatment has finished
- Modern matron – senior nurse responsible for a number of wards
- Research nurse – neurooncology

Doctors
- Paediatrician – based at your local hospital, and specialised in medical treatment of childhood illnesses
- Neurosurgeon – a surgeon who specialises in disorders of the brain and spinal cord
- Radiotherapist – doctor who prescribes and plans radiotherapy
- Oncologist – a doctor specialised in the treatment of malignant diseases, such as cancer
- Neurologist – a doctor specialised in the diagnosis and treatment of disorders of the nervous system
- Ophthalmologist – a specialist in the diagnosis and treatment of disorders of the eye
- Endocrinologist – a specialist in the treatment of disorders affecting the hormone-secreting glands, and growth and development
- Radiologist
- Histopathologist

Other members of the team
- Dietician – expert in food and nutrition
- Occupational therapist – provides therapy to restore function and ability to participate in activities of daily living
- Physiotherapist – expert in rehabilitation
- Play specialist – specialises in providing appropriate occupation for the child, and can enable him to express any concerns through the medium of play
- Psychologist – specialises in developmental, behavioural and educational issues
- Psychotherapist – specialises in offering psychological support to the family
- Pharmacist – prepares and dispenses medicines
- Radiographer – gives prescribed radiotherapy treatment and carries out x-rays and other scans
- Social worker – provides practical aid and emotional support
- Speech and language therapist – specialises in issues related to speech and feeding
Glossary

Glossary explanations listed below are given in relation to brain tumours only.

**A**

Alopecia – loss of hair
Anaemia – a reduction in the quantity or quality of red cells in the blood
Analgesic – medicine used to reduce pain
Analysis – using laboratory techniques to establish the nature of a specimen (piece) of tumour
Anorexia – loss of appetite
Anticonvulsant – medicine used to prevent/treat fits
Antiemetic – medicine used to prevent/treat vomiting
Ataxia – clumsy, uncoordinated limb movements

**B**

Benign – slow growing; does not spread into surrounding areas
Blood brain barrier – the brain’s natural barrier to protect it from harmful substances
Brainstem – the lowest part of the brain, which acts as a pathway for messages between the brain and spinal cord, and controls vital functions

**C**

Central nervous system (CNS) – relating to the brain, the spinal cord and the nerves, which originate within the brain
Cerebrospinal fluid (CSF) – fluid naturally made within the brain that circulates around the brain and spinal cord
Contrast – a dye given intravenously to enhance a scan
Cord contrast – the dye injected during CT or MRI scanning
Cranial cavity – inside the skull
Cranial nerves – twelve pairs of nerves, which originate in the brain
Craniotomy – an operation performed on the skull where a portion of bone is removed to gain access to the brain and is then put back
Cyst – a swelling filled with fluid, which is usually benign

**D**

Dexamethasone – a steroid used to reduce the swelling around brain tumours
Diplopia – double vision
Dysarthria – difficulty speaking, such as slurring
Dysphagia – speech disorder caused by a disturbance of the speech areas of the brain, which are usually on the left side. This may cause difficulty in producing words or understanding the speech of others

**E**

Endocrine system – a system of hormone-secreting glands within the body

**H**

Hemiplegia – a weakness of the face, arm and leg on one side of the body
Histology – the naming of a tumour having looked at it under the microscope
Hormone – a chemical substance produced in one part of the body and carried in the blood to cause activity in other parts of the body
Hydrocephalus – also known as ‘water on the brain’, it is commonly caused by a build up of cerebrospinal fluid in the brain. It is not always the result of a brain tumour.
<table>
<thead>
<tr>
<th>I</th>
<th>Intra-cranial pressure – the normal pressure within the brain</th>
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<tbody>
<tr>
<td>L</td>
<td>Lethargic – sluggish, drowsy</td>
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<td></td>
<td>Lumbar puncture – a needle is passed into the space between the bones in the lower spine and a sample of cerebrospinal fluid is withdrawn.</td>
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<td>M</td>
<td>Malignant – fast growing; can spread into surrounding areas</td>
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<td></td>
<td>Metastases – seeds of tumour that have spread away from the original tumour site. These seeds can settle and grow</td>
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<td></td>
<td>MRI – a scan produced by a strong magnetic field</td>
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<td>N</td>
<td>Nystagmus – involuntary, wobbly eye movements</td>
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<tr>
<td>O</td>
<td>Oedema – swelling of the area around the tumour due to the accumulation of fluid</td>
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<td></td>
<td>Ophthalmology – medical study of the eye</td>
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<tr>
<td></td>
<td>Ophthalmoscope – instrument used for examining the back of the eye</td>
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<td>P</td>
<td>Palliative – relieves symptoms but does not cure</td>
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<td></td>
<td>Palsy – paralysis, often used in association with damage to the facial nerve causing a one sided weakness</td>
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<tr>
<td></td>
<td>Papilloedema – swelling to the optic nerve at the back of the eye, seen on eye examination, which can indicate raised intracranial pressure</td>
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<td>R</td>
<td>Recurrence – the return of symptoms or the tumour itself</td>
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<td>S</td>
<td>Specimens – small pieces of tumour tissue removed at operation to enable analysis in the laboratory</td>
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<td></td>
<td>Stereotactic – specific surgical/radiotherapy technique, which enables very accurate location of treatment</td>
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<td></td>
<td>Steroids – artificial replacements of hormones that naturally occur within the body, given in medicine form. See also dexamethasone</td>
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<td>Strabismus – squint</td>
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<td>Subarachnoid space – the area between the two linings of the brain, containing cerebrospinal fluid</td>
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<tr>
<td>V</td>
<td>Ventricles – a series of interconnecting cavities in the brain, which are filled with cerebrospinal fluid</td>
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Further information
Available from your clinical nurse specialist
Tumours
- Cerebellar astrocytoma
- Ependymoma
- Medulloblastoma
- Optic pathway glioma
- PNET

Books for children
- All about tumours – Headstrong
- Mary has a brain tumour – Sargent

Websites and organizations
Brain and Spine Foundation (UK)
www.brainandspine.org.uk
American Brain Tumour Association
www.abta.org
Childhood Brain Tumour Foundation (USA)
www.childhoodbraintumor.org
Paediatric Brain Tumour Foundation USA
www.pbtfus.org
National Brain Tumour Foundation (USA)
www.braintumor.org
CancerBackup in association with the UK Childhood Cancer Study Group (UKCCSG)
www.cancerbackup.org.uk/info/child-brain.htm
Children Brain Tumour Research Centre
www.nottingham.ac.uk/~pdzmgh/cbtrc/
National Childhood Cancer Foundation (USA)
www.nccf.org