

Helping Hand

*A guide for parents of children
with a brain tumour*





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Introduction

Every year in Ireland about 35 children are diagnosed with a brain tumour. This booklet is written for you, the parent, to provide you with information about the brain and spinal cord, the types of brain tumours and different types of treatment.

There are many different types of brain tumours and each child is different. The medical and nursing staff looking after your child will give individual information about your child's condition. The first signs of a brain tumour can vary a good deal. Children can have various symptoms, most commonly headache, vomiting and drowsiness as a result of increased pressure in the skull. Treatment for brain tumours can vary too and may include surgery, radiotherapy, chemotherapy or any combination of all three.

Your child's doctor will explain the exact facts about your child's tumour to you. This book adds to the information you receive from the medical and nursing staff.

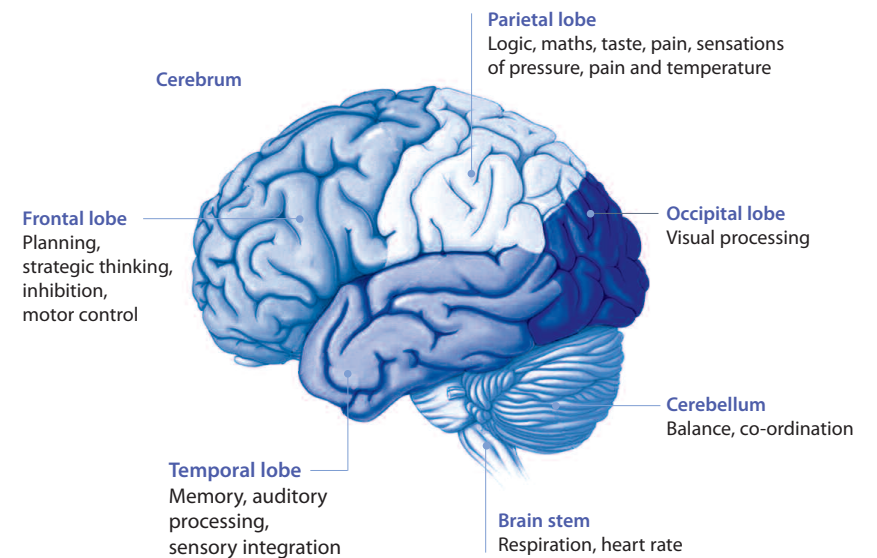
Please ask any questions or discuss any concerns you may have with the medical and nursing team.



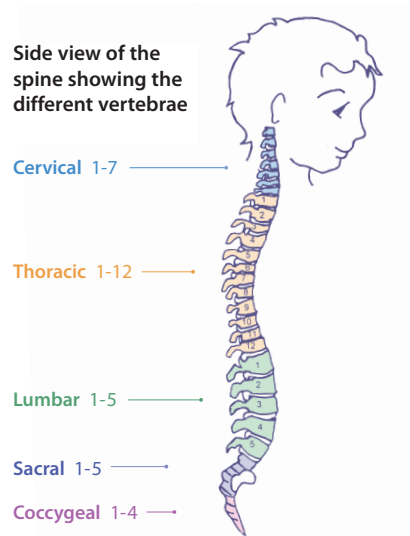
The brain

Understanding the brain and how it works is the first step in learning about the possible effects a brain tumour may have on your child.

The brain and spinal cord make up the central nervous system (CNS). The brain is the control centre for all body functions such as breathing, blood pressure, movement, behaviour, feelings, memory, speech and the senses (hearing, sight, taste, touch and smell). There are three main sections of the brain—the cerebrum, the cerebellum and the brain stem. The brain is protected by the skull or cranium, which keeps it from being crushed. Beneath the skull are three layers of membranes called meninges.



Areas of the brain



The spinal cord is protected inside the bones of the spine. These bones are called vertebrae. The spinal cord contains bundles of nerves that carry messages between the brain and the rest of the body. It communicates movements and sensations between the brain and the rest of the body through a network of nerves called the peripheral nervous system (PNS).

Parts of the brain

The brain is divided into regions that control specific functions throughout the body. A tumour in a particular area of the brain is likely to have an impact on the actions it controls. The following paragraphs describe the major areas of the brain to help you understand them in more detail. But it is important to remember that all the areas are interconnected and working together at all times.

Cerebrum

The cerebrum is the largest section of the brain, divided into two connected sides called the left and right hemispheres. The left hemisphere receives messages from the right side of the body and controls right-sided movement. The right hemisphere controls left-sided movement and receives messages from the left side. Each person has a dominant hemisphere, usually the left. As a result, people who are right handed have a dominant left hemisphere. Each cerebral hemisphere is divided into four lobes, which are named after the bones of the skull that cover them—left and right frontal, parietal, temporal and occipital lobes. A tumour in the cerebrum may show changes in behaviour/character, emotional problems, seizures (fits), slurred speech, weakness on one side, poor memory or eyesight problems.

Brain stem

The brain stem is found at the base of the cerebrum and connects the spinal cord to the cerebrum. It acts as a relay station between the brain and the rest of the body. It controls vital functions such as the rate and force of the heart beat, blood pressure, and the basic rhythm of breathing. The nerves of the brain stem also control smell, hearing, vision, eye movement, facial sensations, taste, swallowing, sneezing, coughing, as well as movement of the face, neck, shoulder and tongue muscles.

The first signs of a tumour in this region may be a squint, abnormal eye movements, clumsy walking, swallowing problems, speech difficulties, weakness on one side, occasional headaches or vomiting.

Midbrain

This is an area deep within the centre of the brain, including the pituitary gland, optic nerve pathway, the thalamus and pineal gland. Tumours within this region may show as headaches, eyesight problems, nausea and vomiting, personality changes or problems with growth.

Cerebellum

The cerebellum is a much smaller section of the brain, lying beneath the cerebrum in the back of the skull. Parts of the cerebellum carry signals that allow precise voluntary movements, maintain balance and posture. A tumour in this region may show signs of increased pressure within the skull due to hydrocephalus (discussed in more detail below). Symptoms may include headaches, early morning vomiting, double vision, uncoordinated movements, clumsiness, slurred speech, and weakness on one side.

The ventricles and cerebrospinal fluid

The brain and spinal cord are surrounded by fluid called cerebrospinal fluid (CSF). This fluid is produced and reabsorbed in four hollow chambers within the brain called **ventricles**. Hydrocephalus occurs when there is a blockage in this system and the chambers swell. A tumour may cause hydrocephalus because it either presses on part of this system or grows within the system itself. Hydrocephalus is usually treated before tests on the tumour are done.

What is a brain tumour?

The body is made up of millions of cells which grow and multiply and allow the body to work normally. A tumour occurs when some cells grow abnormally causing problems with normal cell function. Some types of tumours are graded according to how malignant they are – the rate at which they grow. Grade 1 is considered very slow growing while grade 4 grows quickly.

The cells of slow-growing tumours are similar to other cells. They tend to grow slowly and stay in one place. The cells of fast-growing tumours are very different to normal cells; they grow quite quickly and may spread to other places in the brain or spine.

What are metastases?

Metastases are seeds of tumour that have spread from the original site (primary) and settled in a different location in the brain or spinal cord. It can also be called **seeding** or **spread**. Depending on the type of tumour, a scan may be done to find out if seeding has occurred within the central nervous system. It may not cause any symptoms, but if found your child's treatment may be slightly different.

What causes a brain tumour?

Very little is known why brain tumours occur. Children with some inherited conditions may have an increased risk of developing brain tumours. However, the cause is mostly unknown.



Types of brain tumours

This section gives a general overview of the types of brain tumours commonly found in children. It includes information on the type and behaviour of these tumours, a description of where the tumours occur and the treatments generally used. The doctor who examines the brain tumour cells in the laboratory is called a pathologist. The medical and nursing team caring for your child will provide specific and individual information about your child's tumour.

Glioma

Gliomas develop from the glial (supporting cells) in the brain and make up more than half of all primary brain tumours. Gliomas may be named after the part of the brain in which they are found or after the type of cells that they contain. The pathologist grades glioma tumours by the appearance of the cell under the microscope. Grade 1 and 2 are called low-grade (slow growing) gliomas, while grade 3 and 4 are considered high grade and grow quickly. Some common types of gliomas include astrocytoma, oligodendroglioma and mixed glioma.

Astrocytoma

Astrocytomas are the most common brain tumours found in children. This tumour is graded 1 to 4 depending on the rate of growth (grade 1 is slow growing and grade 4 grows rapidly). Some low-grade astrocytomas may be removed completely but in other cases this may not be possible.

If your child's tumour is low grade and has been completely removed, no further treatment is usually necessary. Your child will be followed up in the outpatient clinic for some time, but the chance of recurrence is small.

If the tumour is low grade but has not been completely removed, your child may be referred to the neuro-oncology clinic for further treatment.

High-grade astrocytomas are difficult to remove as these tumours tend to grow more quickly and move into surrounding normal brain tissue. They will often contain a cyst, which is filled with fluid rather than solid tissue, and can be found in any area of the brain. As a result, symptoms and prognosis will depend on the area of the brain involved. Radiotherapy and/or chemotherapy are usually used to treat children with a high-grade astrocytoma.

Ependymoma

An ependymoma begins from cells that line the ventricles of the brain. It is most commonly found in the cerebellum but can occasionally occur in the cerebral area. They account for a small number of childhood brain tumours (usually in the 5–15 year olds). They can be low grade but the majority are high grade and can spread to the spine. Treatment involves surgery to reduce the size of the tumour if possible, followed by radiotherapy and chemotherapy.

Medulloblastoma / Primitive neuroectodermal tumour (PNET)

Medulloblastoma tumours start from cells in the cerebellum. A medulloblastoma, which can also be called PNET, is a common type of brain tumour. It is a high-grade tumour and can spread to other areas of the brain or the spinal cord. Treatment is surgery followed by chemotherapy and/or radiotherapy. Radiotherapy is only done with special caution in younger children.

Oligodendroglioma

This type of tumour is uncommon in children and is usually slow growing. It starts in the oligodendrocyte cells and is usually found in the cerebral hemispheres. Treatment involves surgery to remove some or the entire tumour if possible. This is usually followed by radiotherapy and/or chemotherapy.

Germinoma

Germinoma is a high-grade tumour which usually spreads down the spine. These tumours also tend to grow in or near the pineal gland, which is found in the midbrain. Treatment involves surgery to remove the tumour if possible. Otherwise a biopsy or sample of the tumour may be taken to help diagnosis. Radiotherapy and chemotherapy are used following diagnosis. If seeding or spread has occurred radiotherapy to the whole brain and spine will most likely be necessary.

Craniopharyngioma

Craniopharyngiomas can be found in the region of the pituitary gland. Symptoms will depend on the position of the tumour near the hypothalamus, pituitary gland and optic nerves. Craniopharyngiomas tend to be diagnosed in children between the ages of 5 and 10 years. Treatment involves surgical removal if possible. Radiotherapy may be considered if complete removal is not possible. Due to the position of this tumour and the involvement of the pituitary gland, your child will have to attend the follow-up clinic in the long term because their growth may be affected.

Brain stem tumours

The brain stem is located at the base of the brain between the hypothalamus and the top of the spinal cord. This vital area of the brain contains many of the centres necessary for sustaining life, e.g. breathing. As a result tumours within this area are very hard to treat.

Surgery may not be possible due to the delicate structures surrounding the tumour, although sometimes surgery may be done to remove more easily reached areas of the tumour. A biopsy may be done to make a definite diagnosis. Radiotherapy is usually the best treatment to try to control the growth of this tumour.

Tumours of the optic nerves

Tumours of the optic nerves are generally known as low-grade astrocytomas. Because the location of the tumour involves the visual pathways (nerves that carry vision information to the eyes) and is situated near the hypothalamus, usually surgery is not possible. A close watch of the tumour may be done with scans over a period of time and treatment may be delayed until symptoms develop, e.g. a change in vision. Radiotherapy and/or chemotherapy may be given to control the growth of the tumour at that time.

Spinal cord tumours

Spinal cord tumours can be low grade or high grade, and are described according to their position. Spinal tumours may be located within the nerves of the spinal cord or inside the coverings of the spinal cord yet outside the cord itself. They may also occur in the bone of the spine.

The cause of these tumours is unknown. Symptoms depend on the position of the tumour in the spinal cord. They may often cause symptoms by pressing on the nerves, including back and neck pain, numbness or weakness in one or both arms or legs. Tumours in the lower part of the spine may cause loss of bladder or bowel control. Treatment depends on the position of the tumour. Surgery will usually be done, either to biopsy or remove the tumour or to relieve pressure. Radiotherapy and chemotherapy may also be needed, depending on the type and grade of the tumour.



How is a brain tumour diagnosed?

A diagnosis is usually made following a medical assessment, a brain scan and laboratory results. These tests are usually carried out at Beaumont Hospital, Dublin. At the hospital St Raphael's Ward is where your child will stay.

Who will we meet in Beaumont Hospital?



Consultant Neurosurgeon

The neurosurgeon supervises the medical and surgical care of your child. He/she will provide you with information about your child's surgical treatment, type of tumour and other possible treatments needed. A team of doctors will look after your child, including the consultant, registrar and senior house officer.

Registrar and Senior House Officer

These doctors will undertake many of the tests and treatments and will be on hand in the ward for any problems that may arise.

Clinical Nurse Manager

The clinical nurse manager coordinates the care of your child during his/her stay in the ward. They are mainly responsible for ensuring that your child receives the safest and highest quality of nursing care possible.

Neuro-Oncology Liaison Nurse

The neuro-oncology liaison nurse provides emotional support, detailed information and advice about tumours and their treatment. The liaison nurse coordinates referral to the oncology team in Our Lady's Hospital for Sick Children and accompanies parents when meeting the oncology consultant. They will also link with the community team (GP and public health nurse) for children being discharged directly to the community. As a result they provide a link to Beaumont Hospital for parents and health professionals.

Staff Nurses

Staff nurses are experienced paediatric nurses who look after the physical, psychological, social and emotional needs of your child and your family. The paediatric nursing staff will encourage you to be as involved as much as possible in your child's care.

Healthcare Assistant

The healthcare assistant helps the nurse and your family to care for your child.

Anaesthetist

The anaesthetist is a doctor who puts your child to sleep for surgery and monitors him/her while asleep. They are responsible for pain management immediately after the operation. They may visit your child on the ward the night before or on the morning of the surgery.

Paediatrician

The paediatrician is a doctor who specialises in child health and illness. He/she will review your child daily on the ward and provide specialist paediatric advice.

Dietician

Dieticians look after the nutritional needs of your child during their hospital stay.

Medical Social Worker

Medical social workers deal with all social issues and practical needs of your child and family. They can also help you and your child cope with the emotional aspect of the diagnosis.

School Teacher

In Beaumont there is a hospital school for children to attend. The teacher may also visit your child at the bedside. We encourage children to attend the school as much as possible.



A CT scanner

MRI scan

An MRI scan is a type of X-ray that gives more information about the position of the tumour. Your child will need to lie still on a table in a special X-ray tunnel for 30 minutes or longer. You should prepare your child in advance for this scan as the machine is very noisy (hammering sound) and they may find it difficult to lie still in the tunnel. Very



An MRI scanner

Tests to diagnose a brain tumour

CT scan

A CT scan is a detailed X-ray which looks at the whole brain. The CT scanner is shaped like a large polo mint and has a table which sits inside the ring shape. Your child will need to lie still on this table. A special dye will usually be injected into their vein to give a clearer picture of their brain. A CT scan usually lasts about 15–20 minutes. For this reason younger children may be sedated or given a general anaesthetic.

young children are given a general anaesthetic for this type of scan. Older children who are prepared in advance tend to cope very well, but parents or guardians can also remain in the room with them during the scan. Because the scan uses magnets all metal objects (jewellery, clips or pins) will have to be removed. The scan cannot be done if your child has any metal devices implanted in their body, e.g. a pin for a broken leg.

What other tests might my child need?

Ophthalmology (eye) and hearing exam

Various eye and hearing tests may be done as part of the assessment for certain tumours.

EEG

An EEG or electroencephalogram is a test that measures the electrical activity in the brain. The test may be done for your child if their tumour is causing seizures or fits. It involves placing small electrodes on their scalp, which transmit and record electrical brain activity onto a graph for the doctors to read. This test does not hurt, although children may complain about the sticky gel in their hair. The gel is used to help keep the electrodes in place.

Angiogram

An angiogram looks at the blood vessels around the tumour. It provides the doctors with more information on tumours that may be near major blood vessels. This test usually takes place in the X-ray department. It can be done under general anaesthetic or awake with local anaesthetic. A dye known as 'contrast' is first injected into a vein in your child's groin. Then many X-rays are taken as the dye circulates in the bloodstream towards the blood vessels surrounding and going into the tumour. The dye allows the blood vessels to be seen on the X-ray. An information leaflet about this test is available to parents on St Raphael's Ward.



What type of treatment will my child need?

Depending on the type and location of the brain tumour, your child will need neurosurgery and possibly chemotherapy and radiotherapy as well. Remember to ask the medical and nursing staff as many questions about these treatments as you wish.

Some symptoms of brain tumours may need to be treated as soon as possible. This is before your child can receive surgery, chemotherapy or radiotherapy. If your child develops brain swelling or seizures they will need to take medication straight away.

What medications will my child need?

Dexamethasone

Your child may be given a steroid drug called dexamethasone. This drug works by relieving the swelling caused by the tumour on the surrounding brain tissue. Dexamethasone does not reduce the size of the tumour and cannot stop its growth, but by relieving the swelling, your child's symptoms will hopefully improve or disappear. Steroids are a temporary measure and may be used at different stages of your child's treatment. Some side-effects that you may notice in your child include an increase in appetite, weight gain and changes in behaviour, e.g. 'moodiness'.

Anticonvulsant (anti-seizure) medication

With certain tumours, seizures (fits) may occur. If your child has had seizures the doctor may prescribe an anticonvulsant medication to reduce the risk of further seizures. Your child will need to take the medication daily. More detailed information about seizures, anticonvulsant medication and safety precautions will be given if your child develops seizures.



Neurosurgery

Neurosurgery can be done for three reasons:

- To try to remove the tumour. This is called **excision/debulking**.
- To find out what type of cells are in the tumour. This is called a **biopsy**.
- To treat hydrocephalus. This is done by inserting a **shunt**, which is an external drainage system.

Neurosurgery takes place at Beaumont Hospital.

Excision/debulking

The neurosurgeon will try to fully or partially remove the tumour. Excision means all the tumour is removed, while debulking involves removing part of it. The amount of tumour tissue that can be removed will be different for each child and depends on its position in the brain and the important structures around it. In the operating theatre your child's hair will be shaved at the wound site—but the doctors will be careful to remove as little hair as possible.

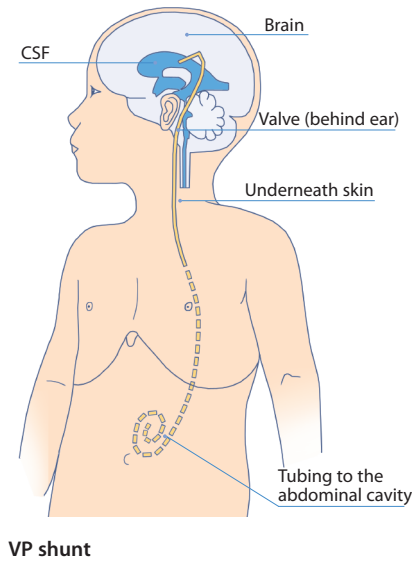
During surgery samples of the tumour will be sent to the laboratory to find out the type of tumour. How long the operation will last will depend on the size and position of the tumour.

Biopsy

If it is not possible to remove some or all of the tumour due to its position in the brain, a biopsy of the tumour may be done. Your child will be given an anaesthetic and a small area of hair will be shaved. A piece of the tumour tissue is got using a fine needle that has been passed into the tumour. Your child will have a small wound afterwards. The sample of tumour tissue is then sent to the laboratory to identify the type of tumour.

Shunt

Some tumours cause a blockage to the normal flow of fluid through the brain. The fluid in the brain and spine is called cerebrospinal fluid (CSF). The blockage in turn causes a build-up of pressure known as hydrocephalus. Hydrocephalus may need to be treated before any treatment of the tumour can take place. To relieve pressure a temporary tube called an external ventricular drain (EVD) may be inserted to drain this fluid from the brain into a bag at your child's bedside.



However, for most children a more permanent tube called a ventricular peritoneal shunt (VP shunt) will be inserted. The VP shunt will need to be placed under the skin so that the CSF can bypass the blockage caused by the tumour. This will reduce the pressure symptoms caused by a build-up of fluid. Information booklets about VP shunts are available for parents on St Raphael's Ward.

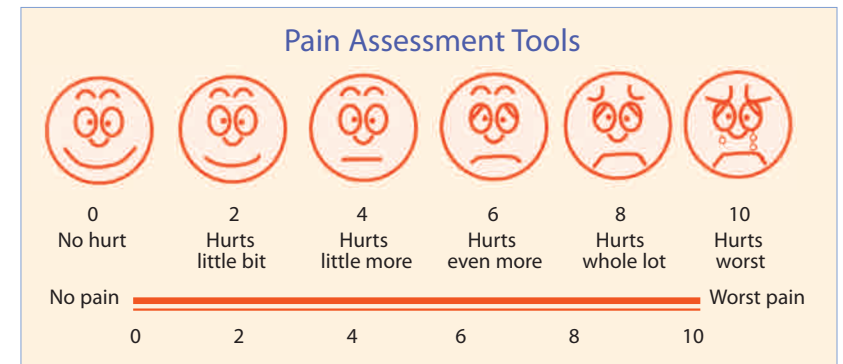
What happens before surgery?

The neurosurgeon will fully explain the type of surgery needed for your child. He/she will also explain the possible risks involved. Once the benefits and risks have been fully discussed the neurosurgeon will ask you or a guardian to sign a consent form allowing the surgical team to go ahead with the planned operation for your child.

Your child will need some blood tests done as routine preparation for surgery. A numbing cream (topical anaesthetic) will be placed on the

skin from where the blood tests will be taken to try to make it as painless as possible. The anaesthetist will examine your child on the evening before surgery.

In order to help manage your child's pain after surgery, the nursing staff will show you both a children's pain scale. This is a chart of smiley faces and sad faces which can help your child explain how they are feeling after the operation. Older children can also use a scale of 1–10. This can help the nurses and doctors decide how much pain medication your child needs. By introducing this before the operation, we hope it will help your child to become familiar with it, and use it effectively after the surgery.



Your child should have a bath or shower the evening before surgery. Also before surgery your child will need to fast. Fasting means **nothing to eat or drink**. The nurse and anaesthetist will tell you what time your child should fast from. A snack will be offered beforehand. Once your child is fasting, food and drinks should be removed from the bedside to reduce temptation.

Depending on their age, your child may have to wear a theatre gown during surgery. Because the gowns are open at the back, this will be put on just before leaving the ward.

Can I accompany my child down to theatre?

Both parents may accompany the child down to the theatre reception area with the nurse. However, only one parent/guardian will be allowed into the theatre. You will have to wear a special theatre hat, gown and shoes. Once your child is asleep you will be asked to leave and the theatre staff will look after your child. Older children may wish to go down alone, but this can be discussed beforehand.

What can I do while my child is in surgery?

We suggest that you use this time by taking a short walk, having something to eat, taking a nap or by simply going to the parent's accommodation and relaxing. Your child will need you both physically and emotionally when they return from surgery, so looking after yourself while they are in theatre will help both you and your child. Leave your mobile phone number with the nurses or let them know where to find you, so that they can keep you updated on the situation.

What will happen after surgery?

Following surgery, your child will be monitored in the theatre recovery room until they are awake. This may take from 2 to 3 hours. Parents/guardians are not allowed into the recovery room.

Observation

When your child is awake, they will usually be moved to the high dependency area on the ward. Sometimes if your child has been in theatre for a long time they may be moved to the intensive care unit (ICU). Once your child has returned from surgery, parents/guardians are encouraged to stay, to provide support and attend to their needs as you normally would. The nurse will monitor your child's blood pressure, heart rate and oxygen level. They will also need to check their awareness level and arm and leg movements very often. This means waking your child frequently, talking to and questioning older children or subtly observing babies.

Pain management

Your child will receive medication for pain during the operation and in the recovery room to help keep them comfortable on return to the ward.

The nursing staff will use the special children's pain scale, which your child will have seen before surgery, to guide your child's pain management. The nurse will also take into consideration your concerns and their assessment of your child. Your child will receive regular pain medication, usually as a tablet, liquid or suppository. Our aim is to keep your child as comfortable and pain-free as possible following surgery.

Nutrition and hydration

Your child will need intravenous fluids (a 'drip') after the operation to prevent dehydration. Sometimes a central line may also be used. A central line is a special type of 'tube' which is placed in a large blood vessel in the neck or groin. It is usually used for children if there are difficulties taking blood or putting in ordinary 'drip' lines. These lines are put in while your child is in theatre. If your child has an upset stomach or is vomiting, medication can be given through the drip or by suppository to relieve it.

Once your child is fully awake you may give them water or flat 7-Up, but check with the nurse first. After a while they can take something light to eat if they feel able for it. The fluids given through the drip can be stopped once your child is taking enough to drink.

Wound

Your child may have a small drain coming from the wound, draining away blood that has gathered there after surgery. This reduces bruising and swelling. The drain is held in place with a stitch and usually removed 24 hours after surgery. Removal may cause slight discomfort but pain medication will be given as necessary.

Head wounds will have stitches, metal clips or dissolvable stitches in place to help the wound heal together. These are generally removed 7–10 days after surgery. Pain medication will be given to avoid

discomfort. Normally the wound heals over a period of 1 to 2 weeks. Your child's hair will gradually grow back to cover the scar. Once stitches or metal clips have been removed and the nurse is happy that the wound is healing well, your child's hair can be washed.

Getting up and about

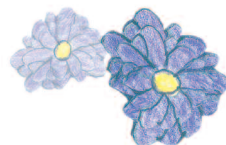
We suggest that you bring in T-shirts or pyjama tops with a wide neck or ones which are buttoned up the front to avoid contact with the wound. This avoids discomfort when your child is dressing. At first your child will be advised to stay in bed following surgery. Once the doctor gives permission your child can be gradually encouraged to get up and walk about (painkillers will be given by the nurse beforehand to avoid pain).

Some children or teenagers are very conscious about their self-image. Boys may wish to wear baseball caps to cover the wound or shave the rest of their hair off. Girls may wish to wear a cap, bandana or similar band to cover the wound.

Following surgery and bed rest, constipation may be a problem. Once your child's appetite has returned a high-fibre diet is encouraged to prevent this problem.

When will we find out what kind of tumour our child has?

The pathologist usually needs between 5 and 7 days to fully examine the tumour before a final diagnosis can be given. This is a difficult time for you, your child, family and friends. Once the pathologist provides the final report, the consultant together with nursing staff will sit down with you to explain the diagnosis and if any other forms of treatment are needed.



Chemotherapy



Once a referral has been made by the neurosurgeon, an appointment will be made for you to visit the oncology department in Our Lady's Hospital for Sick Children (OLHSC) in Crumlin. You and your child will see the paediatric oncologist and radiation oncologist at OLHSC. During this meeting the doctors will discuss with you the best treatment plan for your child. Some children will need chemotherapy or radiotherapy or both.

The neuro-oncology liaison nurse from Beaumont Hospital will usually accompany you to OLHSC for this first visit, otherwise a clinical nurse specialist (CNS) or medical social worker from OLHSC will meet you and sit in on the meeting. Many parents find it useful to make a list of questions prior to this visit and the liaison nurse in Beaumont Hospital can help with this too. It is natural for you to be quite shocked and anxious during this first meeting, so it is helpful to have someone else with you to discuss and repeat the information afterwards.

Who will we meet in Our Lady's Hospital for Sick Children?



Consultant Paediatric Oncologist

Once a diagnosis has been made the paediatric oncologist is responsible for the overall care of your child. He/she will decide the best treatment for your child. Paediatric oncologists from all over the world meet regularly to discuss new developments in the treatment of childhood cancers. Rest assured that your oncologist is not working alone and your child will be receiving the most up-to-date treatment available.

Registrar and Senior House Officer

These doctors will carry out a lot of the tests and treatments for your child and will be on hand in the ward for any problems that may arise.

Clinical Nurse Manager

The clinical nurse manager coordinates the care of your child during his/her stay in the ward. He/she is mainly responsible for ensuring that your child receives the safest and highest quality of nursing care possible.

Staff Nurses

The staff nurses are experienced oncology nurses and understand your child's needs and your needs while in hospital and at home. They are available 24 hours a day whether your child is a patient on the ward, in the 'Home from Home' or at home.

Clinical Nurse Specialist — Parent Educator

The parent educator is a specialist nurse that will meet you shortly after your child is admitted to St John's Ward in OLHSC. They will teach you how to deal with the practical matters of caring for your child once he/she is discharged home. The parent educator will give you a folder/booklet called 'Passport' which contains a full list of all the information you will need while your child is undergoing chemotherapy treatment.

Clinical Nurse Specialist

A clinical nurse specialist will also be assigned to your child. At diagnosis they will meet you and assist you with planning your child's discharge from hospital. They can link up with your public health nurse, GP and your local hospital too. Throughout treatment the clinical nurse specialist will be available to you for advice and support. He/she will be in regular contact with the neuro-oncology liaison nurse from Beaumont Hospital to ensure that everyone is kept up-to-date.

Research Nurse

If your child is part of a drug or treatment clinical trial, the research nurse will talk to you and your child and explain the treatment plan that your child will commence. They will also answer any of your questions about the treatment your child is about to have.

Play Specialist

The play specialist will meet your child on admission to the ward. They have specialised dolls and books to help explain to your child about chemotherapy, surgery and radiotherapy. This helps your child deal with what is happening to them.

Dietician

If your child is to receive chemotherapy, he/she may lose their appetite and certain types of drugs can change the taste of foods. A dietician will monitor your child's weight and progress and will give you advice on how to maintain your child's best weight.

Dentist and Dental Nurse

A dentist and dental nurse will see your child on their first admission to St John's Ward and will be able to advise you on mouth care for your child during their treatment.

Psychologist

Our aim is not only to make your child physically healthy, but also to ensure that they come through their treatment with healthy emotions and as happy as possible. Whether your child is receiving a combination of chemotherapy, surgery and radiotherapy or oral chemotherapy or radiotherapy alone, the expert help of a psychologist can be of great benefit to your child and family.

Medical Social Workers

Medical social workers can be of immense help to you. They can help you by discussing the diagnosis and any anxieties you may have. Also your social worker can deal with any questions you may want to ask, e.g. what will I tell my child, relatives and school? etc. They have a supply of books and information leaflets that can help you and your family come to terms with the diagnosis and treatment as well. Apart from providing counselling, your social worker can help with practical problems and can give you advice on your entitlements and how to get any of the services you need. Throughout your child's treatment, your medical social worker will be in contact with you as necessary, or you may contact them, if you wish.

What is chemotherapy?

Chemotherapy means treating the tumour with chemicals or drugs. There are many different types of chemotherapy drugs which may be used together or alone, depending on the type of tumour being treated.

Who decides which chemotherapy drugs to use?

Throughout the world paediatric oncologists work together to develop successful treatment plans, which are also called protocols. Children are entered into a protocol depending on their tumour type and age. The paediatric oncologist will explain to you in detail which protocol is suitable for your child and any possible side-effects linked with that treatment. Chemotherapy protocols are usually given over many months, with children attending St John's Ward at regular intervals either as a day patient or inpatient.

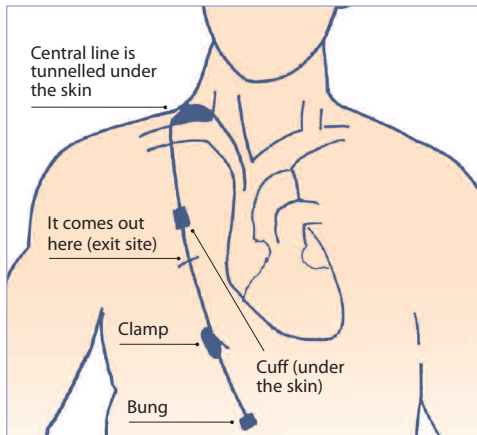
How is chemotherapy given?

Chemotherapy is usually given by drip (intravenously) or in tablet or liquid form.

Intravenous chemotherapy

If your doctor decides that your child should have intravenous chemotherapy, your child will be admitted to OLHSC as an inpatient.

A long-term narrow tube called a Hickman or 'Freddie' will be inserted into a major blood vessel in your child's chest under general anaesthetic. This gives easy access for all the intravenous chemotherapy, blood tests and protects your child from regular injections. Once you and your child are settled in the oncology unit in OLHSC, the play specialist or parent educator will show you and your child what a Hickman line or 'Freddie' line looks like and will help prepare your child for theatre. The parent educator will teach you about the Hickman line and how to care for it at home.



Left and below: Hickman line



The first admission to hospital is usually for at least one week to allow for the line to be inserted, chemotherapy to be given, and any teaching or advice about the line and side-effects of treatment to be given.

Depending on your child's treatment plan they will be admitted to the day unit or to St John's Ward regularly over the next few months.

Oral chemotherapy

If your child is to receive oral chemotherapy (by mouth), they will receive their treatment at home. After your first meeting with the paediatric oncologist your child will then be seen on an outpatient basis. You will be given the names of a clinical nurse specialist and a medical social worker who will be your main points of contact. The paediatric oncologist will control your child's chemotherapy dose and will make any changes necessary. Your child will be monitored regularly and will be seen at the oncology outpatients department where any necessary scans and tests will be arranged.

Your clinical nurse specialist will contact your local pharmacy and fax a special prescription to your pharmacist and HSE (former local health board). They will give you written information about the drugs that the paediatric oncologist has prescribed and any precautions and blood tests that will be necessary. They will be in regular contact with you about your child's medication and discuss any possible side-effects. Your local hospital, public health nurse and GP will be contacted too. Your medical social worker will also be in touch to answer any questions that you may have.

What side-effects can we expect?

Common side-effects of chemotherapy include nausea, vomiting, low immunity, infection, and hair loss. The oncologist will give you information about the expected and possible side-effects of the drugs used in your child's treatments. The clinical nurse specialist will also teach you how to manage the side-effects and give specific advice about your child's needs.

It is important that while your child is taking oral chemotherapy that you watch their temperature. If it rises to 38° Celsius you must contact St John's Ward (OLHSC) immediately. **Do not give your child paracetamol.** The nurses on the ward will advise you on what action to take. Your clinical nurse specialist will have given your child's details to your local hospital so that they will be fully up-to-date with your child's treatment. You should attend your local paediatric unit if your child develops any problems.



Radiotherapy

The medical paediatric oncologist or neurosurgeon will refer your child directly to the radiation oncologist. An appointment will be made for you and your child to meet the paediatric radiation oncologist in the oncology outpatients in OLHSC, to discuss radiotherapy treatment in detail. If your child needs radiotherapy – either as part of their treatment plan or as a single treatment – it will be carried out in St Luke's Hospital in Rathgar, Dublin.

Who will we meet in St Luke's Hospital?



Consultant Paediatric Radiation Oncologist

The paediatric radiation oncologist is responsible for your child's care during radiotherapy. He/she works with the neurosurgeon and paediatric oncologist to provide the most suitable treatment plan. Children are treated in St Luke's Hospital but follow-up is given in OLHSC at the Neuro-Oncology Clinic.

Liaison Nurse

The liaison nurse from St Luke's will meet you at your first visit to the Neuro-Oncology Clinic in OLHSC and will provide a link to St Luke's Hospital throughout your child's treatment. They will also provide suitable materials to help explain radiotherapy to your child.

Medical Social Worker

The medical social worker will deal with any questions that you will want to ask, e.g. what will I tell my child, relatives and school? etc. They will also have a supply of books and information leaflets that can help you and your family come to terms with the diagnosis and treatment. Apart from providing counselling, your medical social worker can help with practical problems and can give you advice on your entitlements and how to get any services you need.

Anaesthetist

Very young children (under 3 years of age) often need an anaesthetic each day for radiotherapy. The anaesthetist is the doctor responsible for your child's well-being while under anaesthetic.

Art Teacher

The art room is open to all children for entertainment and therapeutic recreation while they wait for treatment or before they go home. This important resource helps many children cope with their daily treatment.

What is radiotherapy?

Radiotherapy uses high-energy X-rays to damage tumour cells and prevent them regrowing. It is given in small doses (fractions) of treatment over several weeks. The aim is to give the highest dose to the tumour but give a very small dose to normal cells.



A radiotherapy machine

Radiotherapy affects normal cells and tumour cells within the area being treated as well as the surrounding tissues. However, normal cells are able to repair themselves after treatment better than tumour cells.

Radiotherapy is a painless treatment using high-energy X-rays that go deep inside the body. As there can be some damage to normal cells, side-effects may be seen during or after treatment.

Are there different types of treatment?

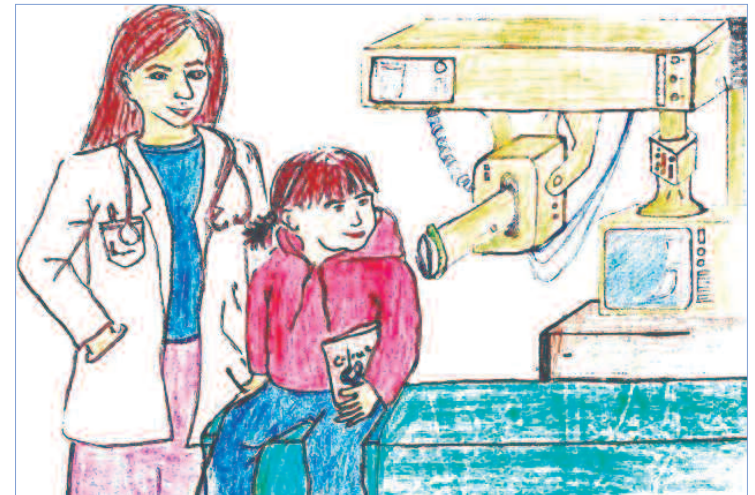
There are different types of radiotherapy used for tumours of the brain and spine. These include:

- Focal – this is radiotherapy to the original tumour area.
- Craniospinal – this is radiotherapy to the whole of the brain and spine.
- Boost – this is extra radiotherapy given to a specific or smaller area.

What is 'planning'?

Once you have met with the radiation oncologist and your child has been booked in for treatment, you will receive a letter or phone call asking you to bring your child to a planning appointment.

Planning of treatment is a vital part of radiotherapy with a number of experts involved in this process. For your child this will mean a number of visits to St Luke's prior to the start of treatment. Planning involves having a mask made, scans and a simulation of treatment (a practice session without using actual radiation).



While your child is having radiotherapy he/she may need to wear a mask to hold their head steady during the treatment. The mask is tailor-made to fit your child's head and to keep it in the same position each time they have treatment. This mask is made using mould/mesh before your child starts radiotherapy. Making the mask does not hurt but you can stay with your child while it is being done.

When your child is receiving radiotherapy, they will wear the clear plastic mask that has been made from their mould. Your child will wear the mask each day only during the treatment.

What is involved in radiotherapy?

The treatment will be every weekday (Monday to Friday) for about 6 weeks (30 days). Sometimes it is shorter, sometimes it is longer. During treatment your child will lie on the X-ray table for 10–15 minutes with the mask on, and they must stay still for this time. Radiotherapy is a painless procedure, however, very young children may be unable to stay still and may need a general anaesthetic each day.

Does my child stay in hospital for treatment?

Usually children attend St Luke's as an outpatient. If you do not live in Dublin there is accommodation available for you and your child in Cuan Aoibhinn, which is known as the 'Home from Home'. This is a house on the grounds of OLHSC solely for the children and families attending the oncology unit as an inpatient or outpatient. It has a direct phone line to the nurse's station on St John's Ward in OLHSC, should you have any concerns about your child day or night.

There is a small fee charged for staying in the home to cover cleaning and electricity bills. If you have any financial concerns please contact your medical social worker in OLHSC. If you are staying in Dublin for treatment, you can go home at the weekends and return on the Monday. Sometimes children may not have been discharged from OLHSC or Beaumont when they start radiotherapy. These children are transferred to St Luke's each day by ambulance.

What side-effects from radiotherapy can we expect?

Like any form of medical treatment, radiotherapy has both benefits and side-effects. These side-effects may be seen during treatment, shortly after treatment or a number of years after treatment. The radiation oncologist will explain all side-effects to you in detail before your child starts treatment.

Side-effects commonly seen during treatment

Skin reactions

Skin reactions occur to some degree in most patients, where the treated area becomes red or itchy. The radiation therapist or nurse will provide specific advice about skin care.

Swelling

Sometimes the treatment causes the brain to swell slightly. This is usually not noticeable because pressure on the brain has been eased by removing part of the tumour or by a shunt. But some children may develop headaches, nausea, vomiting or confusion during treatment. These symptoms are usually treated with steroids to relieve the swelling at the tumour site.

Hair loss

After about 3 weeks your child will lose their hair in the area being treated. It will start to grow back 3–4 months after your child's treatment finishes. However, it may be thinner than before and in some cases may not grow back at all.

Fatigue

Many children experience tiredness and fatigue during and after treatment. The effect of radiotherapy can continue for a number of weeks or months after your child's last treatment session and may cause ongoing fatigue. You may find this frightening as your child can spend long periods sleeping. You can help your child by encouraging them to drink when awake to prevent dehydration. You can also talk to your clinical nurse specialist about ways to manage fatigue at this time.



Long-term side-effects

Growth

Some effects of radiotherapy may not be obvious for a number of years. If the treatment area involves the pituitary gland then your child may not grow fully and may need to be seen by an endocrinologist (a hormone specialist) in the future.

Height

If the radiotherapy is aimed at growing bone (e.g. the spine) the growth of that bone may be slowed down. As a result, your child may not reach their full height potential.

Learning issues

It is possible for radiotherapy to affect the ability to learn, especially when very young children are treated. This problem may not be obvious for a number of years, with children showing difficulty learning new information and skills. Children may need to be referred to the educational psychologist for assessment and may require ongoing support in school.

Follow-up clinic

When treatment is finished, your child will be reviewed regularly at the Neuro-Oncology Clinic in OLHSC. At this meeting you will meet your child's medical oncologist, radiation oncologist and neurosurgeon. This clinic is held on the 2nd and 4th Monday of every month. Appointments are arranged by the medical oncology secretary on 01 4096 659.

At the follow-up clinic you get a chance to discuss any problems you may be having, or ask any questions that may have slipped your mind while your child was having treatment. It is important to attend these clinics so that your child's progress can be monitored. We try to keep these clinics as informal as possible and families generally find the follow-up clinics a great source of support.





Telling your family

The first question that may come into your mind when told the cancer diagnosis is what to tell your child and the rest of your family. Each family will have their own ways of dealing with the issue, however. In our experience we have found honesty the best policy as it helps prepare your child for the treatment ahead and why it is needed.

Many parents find it is best to tell close family and friends the truth as their support will be invaluable in the days ahead. If you are receiving a lot of phone calls it might be helpful to nominate one person to pass on the news to the rest of the family. Your medical social worker will also be happy to give you advice as will any member of the nursing or medical staff.

What do we tell our child/teenager?

Once your child is admitted to hospital with a suspected brain tumour we encourage parents to talk to them openly about it and the possible treatments the doctors suggest. Openness and honesty encourages trust and security, whereas secrecy can lead to isolation, fear and anxiety for your child.

Listening to your child is the best support you can provide. Your ability to listen and respond calmly will send out the message that even though their illness is difficult it is not too scary to talk about. Don't feel you have to know the answer to every question. Information should be given to your child using clear and simple language. Openness and honesty gives your child the chance to express their feelings and to share them with you, the rest of your family, or with the nursing/medical staff.

Teenagers are a unique age group – they are at a stage of development where they are striving to be independent. Very often they are more aware of their health problems than their parents realise. They may be experiencing feelings of confusion, fear of the unknown or fear of dying. By giving them information in a supportive and positive environment you can help them express their fears and worries.

Children and teenagers can sense the fears of parents and relatives. Often the fear of the unknown can be more frightening than the truth. For this reason we encourage openness and honesty so that all members of the family can support one another. Your medical social worker and nursing staff will also help you find ways of talking to your child.

What do we tell the other children in the family?

You may need support to speak to the rest of the family, so don't be afraid to ask someone to sit with you when doing so. Again use clear and simple language. The information can be changed to suit the age of your child. Full details can be given for the older child, whereas for younger children you could say, e.g. 'Your brother/sister has a lump in his head which the doctors need to take out.' Be truthful and remember it is acceptable to say 'I don't know'. Children respect honesty and will sense if you are lying or hiding something.

When breaking the news, do not start the conversation by saying something like 'You might be sad' or 'I have some bad news for you' or 'Please be brave and don't cry now'. Children have a remarkable ability to step outside any upset or grief. They can listen to your news and go out to play afterwards without a bother. So try not to instil negative thoughts in them – allow them time to understand and ask questions.

Expect and be prepared for a range of emotions which may follow, e.g. sadness, fear, anxiety and anger. Be prepared for curiosity, especially in younger children with simple questions like 'How big is it?' or 'What colour is it?' The details may need to be repeated at intervals over the course of your child's hospitalisation. After speaking to your other children, take a break and allow time to relax and reflect.

It is important to note that older children commonly hide their feelings and fears, as they will be very aware of your anxieties. Often they choose a close relative or friend to confide in instead because they may not wish to burden you with their concerns.

If you as parents are not available to talk to your other children (due to the distance of the hospital from your home), ensure that the person delivering the news is known and trusted by them. This prevents the possibility of them denying the news.



Resources



Ireland

Beaumont Hospital

Beaumont, Dublin 9
Tel: (01) 8093 000
Fax: (01) 8376 982

Our Lady's Hospital for Sick Children

Crumlin, Dublin 12
Tel: (01) 4096 100
Fax: (01) 4558 873

St Luke's Hospital

Highfield Road, Dublin 6
Tel: (01) 4065 000
Fax: (01) 4972 941

Irish Cancer Society

The national charity for cancer care, dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer.

43–45 Northumberland Road, Dublin 4
Tel: (01) 2310 500
Fax: (01) 2310 555
National Cancer Helpline: 1800 200 700
(Monday–Friday 9am–5pm;
Tuesdays 9am–9pm)
Email: info@irishcancer.ie
Website: www.cancer.ie

TCCUP (Teen and Children's Cancer United Parents)

For parents of children with cancer by parents of children with cancer. Supports parents by sharing common experiences, providing practical information and advocating on issues relating to childhood cancer.

Tel: (085) 7227 272
Website www.tccup.com

CanTeen Ireland

Teenage cancer support group for teens and young adults with cancer (aged 12 to 25). CanTeen has regular day and weekend meetings and publishes a range of teen information booklets.

Tel: (01) 8722 012 (mornings)
Website: www.canteen.ie

ARC Cancer Support Centre

Support services for parents.

ARC House, 65 Eccles Street, Dublin 7
Tel: (01) 8307 333

Neurofibromatosis Association

Information and support for parents of children diagnosed with neurofibromatosis (NF).

Carmicheal Centre,
North Brunswick Street, Dublin 7
Tel: (01) 8726 338
Websites: www.nfaireland.ie or
www.nfauk.org

UK

Brain and Spine Foundation

Child-centred resources available online or by post.

7 Winchester House, Kennington Park,
Cranmer Road, London SW9 6EJ
Website: www.headstrongkids.org.uk

CancerBACUP

Over 1500 pages of information, news and resources available online.

Website: www.cancerbacup.org.uk

The Pituitary Foundation

A website providing information on pituitary tumours and craniopharyngioma.

Website: www.pituitary.org.uk

Brain Tumour Action

Support groups for relatives and sufferers of brain tumours. Information and counselling provided. Online discussion forum and quarterly newsletter also available.

30 Woodburn Terrace,
Edinburgh EH45S, Scotland
Website: www.braintumouraction.org.uk

USA

ASTRO (American Society for Therapeutic Radiology and Oncology)

The patient/press information section of the ASTRO website provides the public with up-to-date information on radiation therapy as a treatment option for cancer.

Website: www.astro.org

American Brain Tumour Association

Patient information site; contains an interesting children's information section.

Website: www.abta.org

