

Helping Hand

A guide for parents of children with a brain tumour





2015 edition compiled by

Jane Garland, Clinical Nurse Specialist, Our Lady's Children's Hospital
Miriam Hunter, Neuro-Oncology Clinical Nurse Specialist, Beaumont Hospital

2005 edition compiled by

Fionnuala Edmonds, Staff Nurse, Beaumont Hospital
Jane Garland, Clinical Nurse Specialist, Our Lady's Children's Hospital
Liz O'Donoghue, Clinical Nurse Specialist, Our Lady's Children's Hospital
Tracy O'Sullivan, Neuro-Oncology Liaison Nurse, Beaumont Hospital

Editor

Tara Droog

Cover illustration

Kayleigh and Catriona Clancy

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Introduction

Every year in Ireland about 45 children are diagnosed with a brain tumour. This booklet is written for you, the parent or guardian, 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 due to increased pressure in the skull. The signs and symptoms of a brain tumour depend on the area of the brain affected by the tumour. 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.

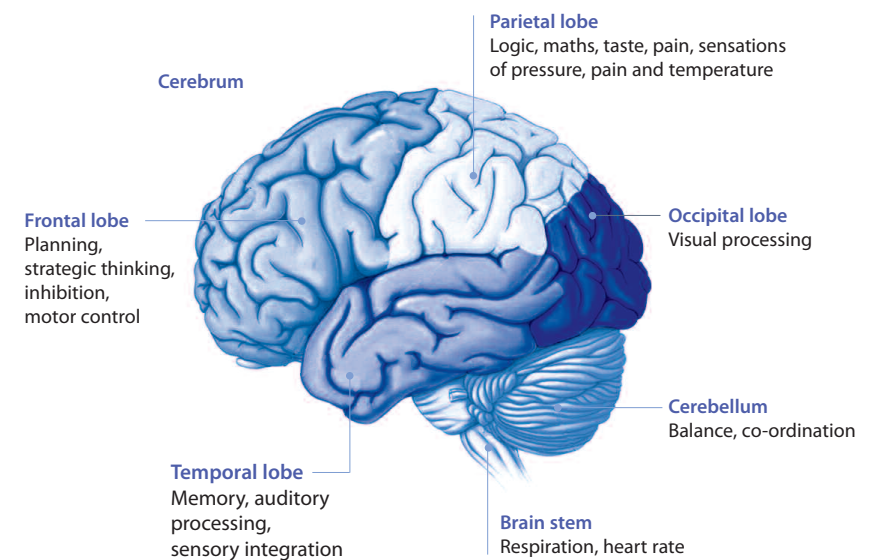
Please ask any questions or discuss any concerns you may have with the medical and nursing team.



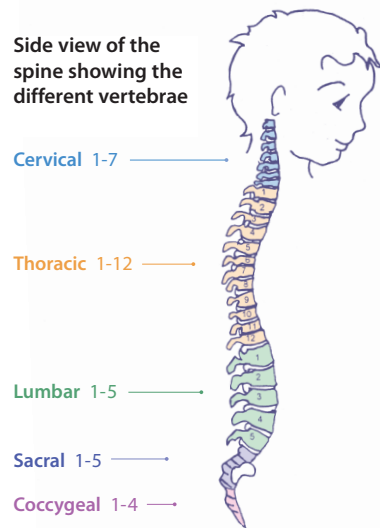
The brain

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 affect 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 and 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, tremors in the arms and legs, nausea and vomiting, personality changes or hormone problems (involving growth, water balance, age of puberty).

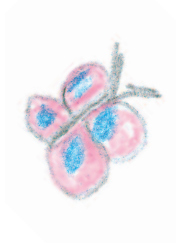
Cerebellum

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 or a build-up of fluid within the ventricles (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 made 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 a group of cells grow abnormally causing problems with normal cell function.

Grades of tumours

Most types of brain tumours are graded on a scale of 1 to 4 by the World Health Organization (WHO). Grade 1 is considered very slow growing, while grade 4 grows quicker or more aggressively. The grades can tell how malignant the tumour is.

A malignant tumour is generally a high grade tumour where the cells divide quickly and behave differently to normal cells.

Malignant brain or spinal tumours are growths that invade and destroy nearby tissue and may spread to other parts of the brain and spine.

Low grade tumours are made up of cells that grow abnormally but fairly slowly. These types of tumours are less likely to spread into other brain or spinal spaces.

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 (secondaries). This can also be called **tumour seeding** or **tumour spread**. An MRI scan and analysis of some cerebrospinal fluid (CSF) will help find out if the tumour has spread.

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 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, ependymoma 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).

Low-grade astrocytomas or non-malignant astrocytoma: These may be removed completely but sometimes it may not be possible. They will often contain a cyst filled with fluid rather than solid tissue. Pilocytic astrocytoma is an example of a common low-grade brain tumour found in children.

If your child's tumour is low grade and has been completely removed, the chance of it returning is small. But these tumours can be unpredictable so your child will be followed closely in the outpatient neuro-oncology clinic. If the tumour is low grade but cannot be surgically removed, your child will be referred to an oncologist. If the tumour is causing symptoms, chemotherapy and/or radiotherapy may be considered in these cases.

High-grade astrocytomas or malignant astrocytomas: These can be difficult to remove completely as they tend to grow quickly and creep into nearby normal brain tissue. The symptoms will depend on the area of the brain involved. They are usually treated by surgery followed by radiotherapy and/or chemotherapy.

Ependymoma

An ependymoma begins in the cells that line the ventricles of the brain and spinal cord. Ependymoma tumours vary from low grade to high grade. The low grade generally can be removed by surgery, while the high grade may involve two surgeries or more to completely remove the tumour. Full surgical removal is the main treatment for these tumours. Depending on your child's age, he or she may also be treated with radiotherapy and/or chemotherapy. This is to prevent the tumour spreading or from coming back.

Oligodendroglioma

This type of tumour is fairly uncommon in children. It starts in the oligodendrocyte cells, usually in the upper lobes of the brain (cerebral hemispheres). Treatment involves surgery to remove part of the tumour, or the entire tumour if safe to do so. Radiotherapy and/or chemotherapy are treatment options after surgery.

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. For example, breathing. As a result tumours within this area are very hard to treat.

Surgery is only considered if the tumour involves more easily reached outer parts of the brain stem. If possible, 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. Steroid medication such as dexamethasone plays a major role in temporarily controlling symptoms for this tumour by helping to relieve swelling. Surgery to relieve hydrocephalus may also be necessary. See page 24 for more information about hydrocephalus and surgery.

Tumours of the optic nerves

Tumours of the optic nerves are generally known as low-grade astrocytomas or optic gliomas. 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. Your child's doctor will monitor their progress using scans taken over a period of time. Treatment may not be needed until your child develops symptoms. For example, if vision gets worse. Chemotherapy may be given to control the growth of the tumour at this time.

Tectal glioma

A tectal glioma is a low-grade glioma (LGG) in the tectum, which can be thought of as the roof of the brain stem.

The cause of these tumours is unknown. Symptoms can vary but some of the most common include the symptoms of hydrocephalus. For more information, see page 24.

Apart from surgical treatment for increased pressure (see page 24), the majority of children will be watched closely and will have frequent scans – every three months to start. Children will also make regular visits to the neuro-oncology outpatient clinic for check ups. Chemotherapy or radiation therapy are generally not needed for tectal gliomas that remain stable.

However, if your child's tumour is seen to be getting bigger or if more symptoms are developing, a biopsy may be considered (see page 23). This will help doctors decide if your child should receive treatment.

Spinal cord tumours

Spinal cord tumours can be low grade or high grade, and are described depending on their location. Spinal tumours may be found 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. Spinal cord tumours are largely gliomas.

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.

Malignant embryonal tumours

Medulloblastoma / Primitive neuroectodermal tumour (PNET)

Medulloblastoma tumours begin in cells found at the back of the brain in the cerebellum. Similar tumours that do not begin in the cerebellum are called primitive neuroectodermal tumour (PNET) or non-cerebellar PNET. Medulloblastoma is a high-grade tumour and the most common type of childhood brain cancer.

It is an aggressive tumour and can spread to other areas of the brain or spinal cord, or recur after treatment. Because of this, it is treated with surgery followed by chemotherapy and radiotherapy. Radiotherapy is recommended with special caution in younger children, especially during the first 3 years of life. This is because a child's brain is continuously developing at this very young age. But each child's situation is unique. Your child's specialist will advise you about radiotherapy and the most suitable type, and when it would be safe to give.

Hydrocephalus: Due to its location, the medulloblastoma can block the normal flow of fluid (CSF) within the brain. This build-up of fluid can raise the pressure within the brain, which is called hydrocephalus. It is treated by neurosurgery to relieve or bypass the obstruction, usually using shunts. This is then followed by surgery to remove as much tumour as possible. See page 24 for information about shunts.

Atypical teratoid/rhabdoid tumour (ATRT)

This type of tumour is generally seen in younger children and is fairly rare. It is a challenging malignant tumour that can be hard to treat. Surgery, chemotherapy and radiotherapy are all part of the treatment options.

Pineoblastoma

This type of tumour is rare. It starts in the pineal gland, a small organ located near the middle of the brain. Pineoblastomas can be treated by surgery, radiotherapy and chemotherapy.

Mid-brain tumours

Germ cell tumours

These tumours tend to grow in or near the midline structures of the brain, for example, the pineal gland. Certain germ cell tumours release chemicals that can be found in the blood or cerebrospinal fluid (CSF). These chemicals are called markers. If, after a MRI brain scan, a germ cell tumour is suspected, a blood sample and a sample of cerebrospinal fluid (CSF) can be taken to check for markers. These can also help diagnose the type of tumour without doing a biopsy.

Surgery can be difficult in these cases. It might only be done to relieve any build-up of CSF in the brain. If the markers are normal, a biopsy is usually done to find out the tumour type and help decide on treatment.

Germinoma: This is the most common type of germ cell tumour found in children. A biopsy or sample of the tumour may be taken to help diagnosis when blood and CSF markers are normal. Both radiotherapy and chemotherapy work very well on these tumours. Surgery may also be considered after radiotherapy/chemotherapy, or if the tumour is not responding to treatment.

Craniopharyngioma

Craniopharyngioma is a benign tumour found behind the pituitary gland in the midbrain. The symptoms will depend on where the tumour is near the hypothalamus, pituitary gland and optic nerves. These tumours tend to be diagnosed in children aged between 5 and 10 years. The type of treatment given will depend on your child's needs.

Treatment options: The tumour is usually removed by surgery if possible. The neurosurgeons will decide which type of surgery is best for your child. For example, the tumour might be removed through your child's nose. Radiotherapy may be considered if it is not possible to completely remove the tumour by surgery.

Relieving pressure: If your child has a build-up of pressure in a craniopharyngioma cyst, they may need surgery to relieve it. Sometimes an Ommaya reservoir, or a device through which fluids can be removed from the cyst, is placed under the skin in surgery. See page 25 for more about an Ommaya reservoir.

Hormone changes: The pituitary gland is the master gland of the body and responsible for the release of regulating hormones. Craniopharyngioma and its treatment can sometimes interfere with the normal hormone changes that happen as your child grows. More than likely, your child will need their hormones watched closely during childhood and adolescence. This means that they will need to have blood tests. They will have to attend a follow-up clinic after surgery. Here their vision and hormones (endocrine) will be checked and any issues about their general growth and development.



How is a brain tumour diagnosed?



The first stage of diagnosis starts when your child is checked out by your GP or local hospital. This is usually because your child has had a specific symptom or some vague ones that need to be investigated.

Tumours of the brain are generally first discovered on a brain scan. They are seen as an abnormal mass or lesion. Once a brain tumour is suspected, your child is referred to the paediatric neuro-oncology team based in Dublin. Neurosurgery is an important part of the care of brain tumours in children.

The neurosurgeon will often be the first specialist from the neuro-oncology team to meet your family. He or she will discuss with you the symptoms you have noticed in your child and explain what the possible causes of these symptoms are. Further tests to confirm the tumour type will usually be done in the neurosurgical ward in Beaumont Hospital or the Children's University Hospital at Temple Street.

Who will we meet in the neurosurgical hospital?



Consultant Neurosurgeon

The neurosurgeon is a specialist surgeon who operates on brain and spinal cord tumours. He or 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 carry out many of the tests and treatments. They will be on hand in the ward for any problems that may arise.

Anaesthetist

The anaesthetist is a doctor who puts your child to sleep for surgery and monitors them while asleep. They are responsible for managing pain 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. They will review your child on the ward and provide special paediatric advice as needed.

Clinical Nurse Manager/ Neurosurgical Nurse Co-ordinator

The nurse manager organises the care of your child during their stay in the ward. They are mainly responsible for making sure that your child receives the safest and highest quality of nursing care possible. The neurosurgical nurse co-ordinator is available in the Children's University Hospital, Temple Street. She or he gives support and information about neurosurgery in younger patients. His or her contact details will be available in this treatment centre.

Staff Nurses

Staff nurses are experienced neuro-surgical paediatric nurses who look after the needs of your child and your family while you are in hospital. The nursing staff will encourage you to be as involved as much as possible in your child's care and will guide you and support you during your child's stay in hospital. A member of the nursing staff is available on the ward to help and advise you 24 hours a day. If you have concerns after your child's discharge, you can telephone the ward for advice. If needed, the nursing staff can direct your query to the team member most able to help.

Neuro-Oncology Clinical Nurse Specialist

The neuro-oncology clinical nurse specialist (CNS) is based in the neurosurgical centre. She or he gives emotional support, information and advice about tumours and their treatment. After the first surgery, the journey to full diagnosis and treatment can seem slow at times. The CNS will first visit you while your child is a patient in the neurosurgical centre and will explain and organise the sometimes difficult treatment facing your child. Contact details will be given to you and are listed at the end of this booklet. He or she will arrange your first meeting with the oncology team in Our Lady's Children's Hospital in Crumlin. They will also be present to follow up your child at the outpatient appointments at the neuro-oncology outpatient clinics (Hoops).

Healthcare Assistant

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

Speech and Language Therapist

Quite often children with brain tumours may have communication or swallowing difficulties. The speech and language therapist (SLT) will assess, advise and help your child with these problems.

Dietitian

The dietitian looks after the nutritional needs of your child during their hospital stay. If your child has weight loss during their admission or finds it hard to swallow food or liquid, the dietitian can assess and give advice on suitable foods or liquid feeds for your child. This will help their weight gain and growth throughout treatment and during follow-up.

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 deal with the emotional aspect of the diagnosis.

School Teacher

Each hospital has a Department of Education-registered school which children can attend. The teacher may also visit your child at the bedside. We encourage children to attend the school as much as possible. This will help normalise the hospital environment for your child and continue your child's learning. The hospital school can also liaise with your child's school to help support your child when returning to school.

Physiotherapist

The location of your child's tumour may cause problems with limb weakness, posture, balance and difficulties with coordination. A physiotherapist ('physio') will assess your child's abilities and provide therapy, advice and aids to help with normal movement. This can help to make your child as independent as possible.

Occupational Therapist

The occupational therapist (OT) can work with your child to improve their independence and quality of life. They will help your child achieve functions such as feeding, dressing, writing and generally cope with all the activities needed for daily living. The OT works alongside the physiotherapist to assess and help your child improve physical and fine motor skills. They can identify any equipment your child may need at home, such as special seating or cutlery.

Psychologist

A clinical psychology service is available to your child in the neurosurgical centres. The psychologist can help your child cope with behavioural and emotional difficulties due to the brain tumour itself or from the effects of treatment. Psychologists are highly experienced in assessing children's cognitive or learning abilities and they also offer confidential psychological therapy. They can make sure your child comes through their treatment with healthy emotions and develop skills to make the journey easier.

Tests to diagnose a brain tumour

CT scan

A CT scan is a detailed X-ray which looks at the whole brain. It can be used to look for swelling, bleeding and fluid problems. 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.



A CT scanner



An MRI scanner

MRI scan

An MRI scan is a type of X-ray that uses a very strong magnet and radio waves to give 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 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. If your child wears dental braces, this may make the MRI image less clear. You may be advised to have them temporarily removed for the scan. You will also need to tell staff if your child has had any metal devices implanted in their body in the 6 weeks before the scan. For example, a metal pin for a broken leg. The device may not yet be secure and staff may need to take special safety measures.

What other tests might my child need?

Ophthalmology (eye) and hearing exam

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

Lumbar puncture

A lumbar puncture involves taking a sample of fluid surrounding the spinal cord for examination. The fluid, known as cerebrospinal fluid (CSF), can diagnose some types of tumours, or show if the tumour has spread.

In a lumbar puncture, a fine needle is carefully inserted into the lower back to take a sample of fluid. This is usually done under sedation or general anaesthetic.

Biopsy

In some situations when it is not possible to remove the tumour, doctors may need to remove a small piece of the tumour to find out exactly what it is. This can be done in two ways: by open surgery or by stereotactic biopsy. Your child will be given an anaesthetic for the procedure and it will be done in the operating theatre.

With a stereotactic biopsy, a piece of the tumour tissue is taken by using a fine needle. The tumour sample is then sent to the laboratory to be analysed by the neuropathologist.

A neuropathologist is a specialist doctor who examines tissue and cells in the laboratory. He or she will make a diagnosis based on the tissue sample. Once a diagnosis has been made all members of the neuro-oncology team can work together to ensure that your child gets the most appropriate treatment.

Bloods tests

Certain tumours called germ cell tumours release chemicals that can be found in the blood. If a germ cell tumour is suspected, a blood test can be taken to look for these chemicals. It is sometimes possible to diagnose the type of tumour in this way without the need for a biopsy.

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. A dye known as 'contrast' is first injected into a vein in your child's groin. This allows the blood vessels to be seen on X-ray. An information leaflet about this test is available to parents on the neuro-surgical ward.



What type of treatment might my child need?

Depending on the type and location of the brain tumour, your child may 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. For example, moodiness and sleep problems.

Anticonvulsant (anti-seizure) medication

With certain tumours, seizures (fits) may occur. These fits may have been a symptom of your child's brain tumour before diagnosis, or they can happen after diagnosis and during treatment. 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



The neurosurgeon is usually the first person from the neuro-oncology team to see your child. The neurosurgeon is a specialist surgeon who operates on brain and spinal cord tumours. 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 relieve raised intracranial pressure.

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.

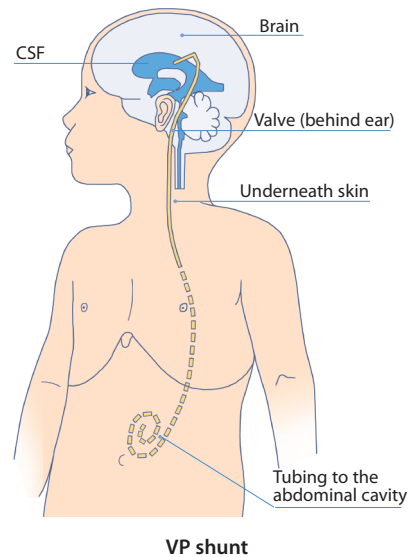
Biopsy

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. This means that a small piece of the tumour is removed to find out exactly what it is. Your child will be given an anaesthetic and a small area of hair will be shaved. A piece of tumour tissue is taken 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.

Relieving raised intracranial pressure

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. Symptoms of hydrocephalus include headache, vomiting, fatigue, memory problems and vision changes. 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.



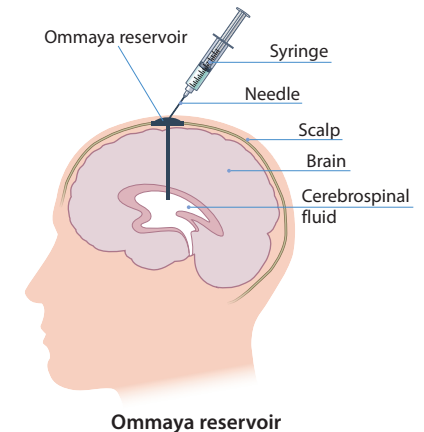
If a more permanent solution is needed, a tube called a ventricular peritoneal (VP) shunt will be inserted. The VP shunt will need to be placed under the skin so that the CSF can bypass the blockage caused by the tumour. This will reduce the pressure symptoms caused by a build-up of fluid.

Endoscopic Third Ventriculostomy (ETV)

An endoscopic third ventriculostomy (ETV) is sometimes used as an alternative to a VP shunt. This involves endoscopic surgery (using an endoscope). A small hole is made in the fluid chambers of the brain, which creates a new drainage route for the CSF. This allows the fluid to bypass the blockage caused by the tumour and relieve the pressure caused by hydrocephalus.

Ommaya reservoir or other devices

An Ommaya reservoir or similar device may sometimes be used for cyst-forming tumours such as craniopharyngiomas. The reservoir, or a device through which fluids can be removed from the cyst, is placed under the skin in surgery. A tube or catheter is passed through the skull into the fluid compartment in the brain and a dome or port placed under the skin of the skull. Fluid can then be removed from the cyst by attaching a needle and drawing the fluid back in a syringe. Local anaesthetic cream can be used on the skin before the needle is put in.



What happens before surgery?

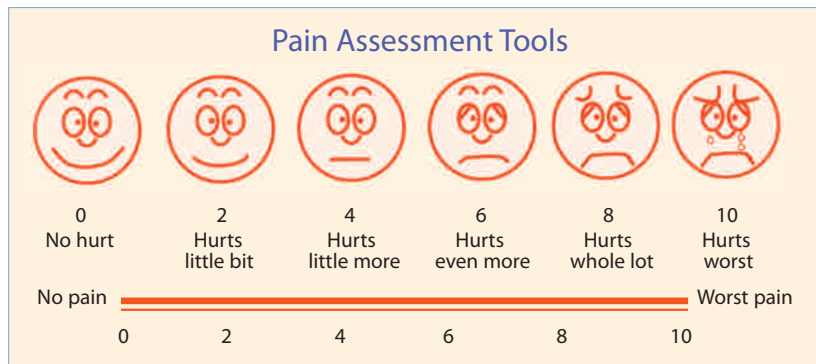
Your child's neurosurgeon will fully explain the type of surgery needed for your child. They will also explain the possible risks involved. Once the benefits and risks have been fully discussed the neurosurgeon will ask you or a guardian to sign a consent form allowing the surgical team to carry out your child's operation.

Your child will need some blood tests done as routine preparation for their 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.

Your child should have a bath or shower the evening before surgery. Your child will also 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.

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.



Can I accompany my child to theatre?

A parent or guardian may accompany the child to the theatre reception area with the nurse. One parent or guardian will usually be allowed into the theatre. (Sometimes this may not be possible and the nursing staff will explain why.) 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. Sometimes if your child has been in theatre for a long time or if your child is very young, they may be moved to the intensive care unit (ICU).

Observation

When your child is stable, they will usually be moved to the high dependency area on the ward. Once your child has returned to the ward, 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 an age-appropriate pain scale for your child, to help them tell us how much pain they have. 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. or intravenously, through a drip or pump. Your child may require morphine through the first stage of recovery. A specialist nurse for pain control can also be consulted if necessary. 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 ask the nurse first. The nurse must check that your child's ability to swallow safely has returned. 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

Head wounds will generally have dissolvable stitches in place to close the wound and help it heal together. These stitches can take up to six weeks to dissolve completely. Often you will find parts of the stitches on your child's pillow as they start to dissolve. Normally the wound heals over a period of 1 to 2 weeks. Your child's hair will gradually grow back to cover the scar.

In some cases, head wounds will have stitches or metal clips to close the wound. These are usually removed 7-10 days after their operation. Once the nurse is happy that the wound is healing well, your child's hair can then 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 normal diet with high-fibre content 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. Together we will make an appointment for you at Our Lady's Children's Hospital, Crumlin (OLCHC) to discuss the best treatment or surveillance plan for your child.



Referral to Our Lady's Children's Hospital, Crumlin (OLCHC)

Once a referral has been made by the neurosurgeon, an appointment will be made for you to attend the Haematology Oncology Outpatients Department at Our Lady's Children's Hospital, Crumlin (OLCHC). You and your child will see the paediatric oncologist and during this meeting the doctor will discuss with you in detail the best treatment plan for your child. Some children will require chemotherapy or radiotherapy or both. If radiotherapy is a treatment option for your child, you will be given an appointment to meet the radiation oncologist, also in OLCHC.

The neuro-oncology clinical nurse specialist from the neurosurgical centre will usually accompany you to OLCHC for this first visit. If they are not available, a clinical nurse specialist (CNS) or medical social worker from OLCHC will meet you and sit in on the meeting. Many parents find it useful to make a list of questions before this visit and the neuro-oncology clinical nurse specialist in the neurosurgical centre 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 Children's Hospital, Crumlin?



Consultant Paediatric Oncologist

Once a diagnosis has been made the paediatric oncologist is responsible for the overall care of your child. He or 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 examine your child daily during their stay in hospital and carry out a lot of tests and treatments for your child. They will also be on hand in the ward if any problems arise.

Advanced Nurse Practitioner

The advanced nurse practitioner (ANP) is a senior member of the nursing oncology team and is available to children having chemotherapy. The ANP works alongside the medical and nursing team to coordinate your child's investigations and treatment. They provide comprehensive assessments of your child, referring to other members of the team as appropriate.

Clinical Nurse Manager

The clinical nurse manager coordinates the care of your child during their stay in the ward. They are 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

The clinical nurse specialist will first meet you at diagnosis and they will support you in dealing with your child's diagnosis and the treatment that they will go through. They will give you a folder called 'Passport' which contains a full list of all the information you will need while your child is having chemotherapy. They will help you to plan for your child's discharge from hospital and teach you how to deal with the practical matters of caring for your child at home. They will link you up with your public health nurse, GP and your local hospital too. Throughout your child's treatment, the clinical nurse specialist will be available to you to provide ongoing teaching, advice and support. They will also be in regular contact with the neuro-oncology CNS from Beaumont/TSCUH to ensure that everyone is kept up-to-date about your child's care.

Bone Marrow Transplant (BMT) Nurse Specialist

Depending on your child's treatment plan they may need high-dose chemotherapy with stem cell rescue. This means that your child will be treated with very high doses of chemotherapy over 3 or 4 days followed by a reinfusion of their own stem cells to aid recovery. They will receive 3 or 4 of these cycles depending on their age.

The BMT nurse specialist will work with your child's consultant to plan and organise this phase of their treatment. They will organise tests before treatment starts and before each cycle. They will also keep you up-to-date and answer any questions you may have about your child's treatment.

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 your child's treatment plan. 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 can help your child deal with what is happening to them.

Dietitian

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

Physiotherapist

The position of your child's tumour may cause problems with limb weakness, posture, balance and co-ordination. A physiotherapist will assess your child's abilities and provide therapy, advice and aids to encourage normal movement and independence.

Occupational Therapist

The occupational therapist (OT) works with patients to improve independence and quality of life. The OT uses therapeutic activity and a problem-solving approach to help each child reach their potential to function independently. Treatment can include functional rehabilitation for children who have a neurological impairment as well as facilitating independence in daily activities, such as feeding and dressing. They also give recommendations for home adaptation and equipment.

Dentist and Dental Nurse

A dentist and dental nurse will see your child when they are first admitted 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. For example, what will I tell my child, relatives and school? 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.

School Teacher

There is a dedicated school teacher and classroom in the oncology unit. The teachers, both primary and post-primary, can also teach your child at the bedside. Going to school helps to normalise the hospital environment. It also ensures that your child's education continues while they are undergoing treatment. The hospital teacher can liaise with your child's school. This ensures that your child is doing the same work as their classmates and reduces the isolation that he or she might feel. The hospital school is also a designated exam centre. Children doing the Junior or Leaving Certificate can be facilitated to sit the entire exam, or even one subject, at short notice.



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 the Haematology Oncology Unit 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. For some tumours, chemotherapy is injected directly into the cerebrospinal fluid surrounding the brain and spinal cord. This is called intrathecal chemotherapy. An Ommaya reservoir is used to give the chemotherapy. See page 25 for more information on Ommaya reservoirs.

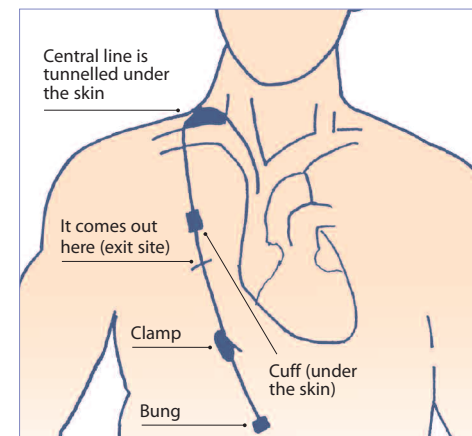
Intravenous chemotherapy

If your doctor decides that your child should have intravenous chemotherapy, your child will be admitted to OLCHC as an inpatient. Chemotherapy drugs can be given directly into the vein using the following devices:

- 1 Hickman[®] ('Freddie') line
- 2 Portacath

1 Hickman[®] ('Freddie') line

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



Left and below: Hickman line

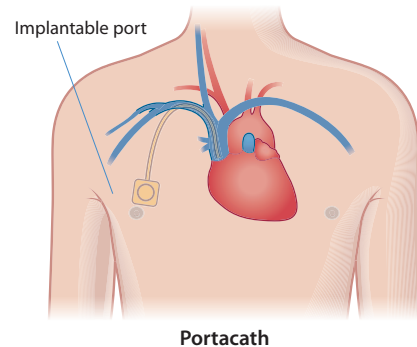


During your child's first admission to hospital, the Hickman line will be inserted and your clinical nurse specialist will start teaching you about the line and side-effects of treatment. The length of this first stay can vary depending on your child's diagnosis and treatment plan.

Depending on your child's treatment plan they will be admitted to the haematology/oncology day unit or the inpatient unit regularly over the next few months.

2 Portacath

A portacath or port is a totally implantable venous access device (TIVAD), which is placed under the skin. Like the Hickman line, it also gives easy access for all the intravenous chemotherapy and blood tests. The portacath is a thin, soft plastic tube with a rubber disc (port) at the end. Under general anaesthetic, the tube is inserted into a vein in the chest and the port lies under the skin on your child's upper chest. A special needle is put into the port in the hospital to allow the drugs to be given and blood to be taken.



Advantages of a portacath

- Reliable access for all intravenous chemotherapy
- Increased comfort and reduced anxiety for children
- Lower infection rate than external Hickman lines
- Less noticeable than external Hickman lines
- Your child's physical activity is not restricted
- Your child can shower and swim as normal

Disadvantages of a portacath:

- A needle is required to access the device and this may cause anxiety
- There is a risk of needle dislodgement
- There will be scarring and a small bulge where the port is located

Oral chemotherapy

If your child is to receive oral chemotherapy (by mouth), this can be given at home. After your first meeting with the paediatric oncologist your child will then be seen as an outpatient. At this meeting you will also be introduced to 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 haematology oncology outpatients clinic (HOOPS) 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 area. They will give you written information about the drugs prescribed by the paediatric oncologist 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 updated about your child's progress. Your medical social worker will also be in touch to answer any questions that you may have.

What side-effects can we expect?

Each child is different but some of the 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.

While your child is taking oral chemotherapy, it is important that you watch their temperature. If it rises to 38.5°C you must contact the haematology/oncology unit in OLCHC immediately. You must also contact OLCHC if your child's temperature is between 38°C and

38.4°C on two separate occasions in 24 hours. **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.

G-CSF (granulocyte colony stimulating factor)

Children on certain chemotherapy protocols (treatment plans) need a medicine called granulocyte colony stimulating factor (G-CSF). This medicine stimulates the production of neutrophils in the bone marrow. Neutrophils are a type of white blood cell, important in the body's fight against infection. G-CSF will reduce your child's likelihood of becoming febrile neutropenic (developing a fever because of a low number of neutrophils). However, some children will still become febrile neutropenic and will need to be admitted to hospital for intravenous antibiotics. It is therefore essential that you monitor your child's temperature closely. If your child develops a temperature, you must contact St. John's Ward in OLCHC for advice.

G-CSF is given between chemotherapy courses. Your child will be given G-CSF once a day by injection under the skin (subcutaneous). G-CSF usually starts 24–72 hours after your child's chemotherapy finishes and stops 24–48 hours before the next course of chemotherapy is due. However this can change depending on your child's specific treatment plan. Your child's blood count will determine the number of days they receive G-CSF. While your child is on G-CSF they will have their blood count checked weekly. You will be advised by the nurse or doctor looking after your child when to start and when to stop the G-CSF.

If your child is receiving G-CSF before a stem cell collection, you should continue the daily G-CSF injections until the procedure has been completed.

Stem Cell Collection

Depending on your child's treatment plan, they may need high-dose chemotherapy with stem cell rescue. This means that your child will be treated with very high doses of chemotherapy over 3 or 4 days followed by a reinfusion of their own stem cells to help them to recover. They will receive 3 or 4 cycles depending on their age.

Where are stem cells?

Stem cells are blood cells at their earliest stage of development. They are mainly found in the bone marrow. It is possible to move them into the bloodstream so they can be collected.

How do you get stem cells from the bone marrow into the bloodstream?

A few days before your child's stem cell collection, they will be given chemotherapy based on their protocol, and daily injections of granulocyte colony stimulating factor (G-CSF). This will help your child's bone marrow to make lots of stem cells. These stem cells then spill out of the bone marrow into the bloodstream. Blood travelling around the body is called peripheral blood. Moving stem cells from the bone marrow into the peripheral blood is called 'mobilisation'. Your child will have regular blood counts during this time. When your child's consultant thinks their count is good enough, their stem cells will be collected.

How are stem cells collected?

The stem cells are collected in the Apheresis Unit. A machine called a cell separator is used. The machine spins and separates the stem cells from the other blood parts. The stem cells are collected into a bag and the remaining blood is then returned to your child. This takes 2–4 hours.

How many collections are needed?

Your child may need to have their stem cells collected over 2 or more days to get enough stem cells. If more collections are needed, daily injections of G-CSF must be continued until the final collection is done.

Radiotherapy



The medical paediatric oncologist or neurosurgeon will refer your child directly to the paediatric radiation oncologist. An appointment will be made for you and your child to meet the radiation oncologist in the oncology outpatients in OLCHC, 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 or 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 OLCHC 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 OLCHC or on your arrival at St Luke's Hospital 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.

Radiation Therapist

The radiation therapists are specially trained to give your child the radiotherapy and operate the machines used for treatment. They work closely with the doctors and other staff involved in your child's care and you meet them every day during treatment.

Medical Social Worker

The medical social worker will deal with any questions that you will want to ask. For example, what will I tell my child, relatives and school? 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.

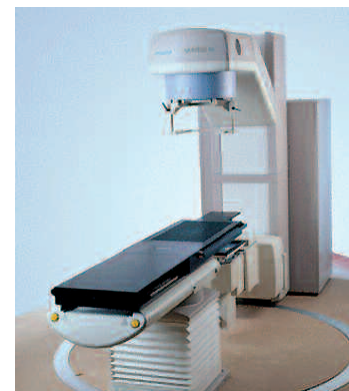
Anaesthetist

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.

Play Specialist

By using therapeutic play skills the play specialist can prepare your child for the process of radiotherapy so that they will understand and cope with the experience. This will help your child to become familiar with the equipment being used as well as what to expect when attending St Lukes Hospital. The play specialist can also advise parents on games to practice with the child before starting treatment and what items they can bring with them to help the child relax for the treatment. The play specialist will aim to provide your child with coping strategies so that your child will be able to lie still for the treatment and hopefully not require an anaesthetic. However, this will also depend on your child's age and developmental stage. This important resource helps many children cope with their daily treatment.

What is radiotherapy?



A radiotherapy machine

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. 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.

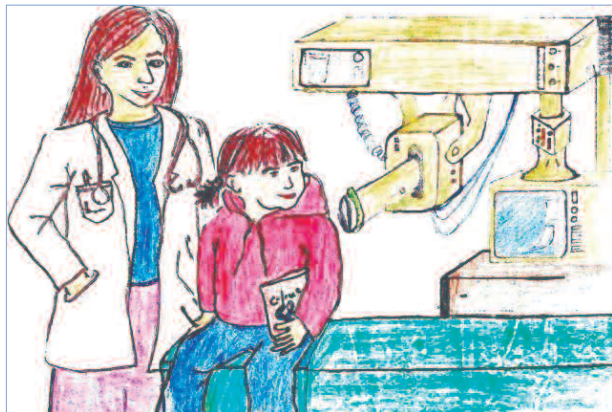
Are there different types of treatment?

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 before starting 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 they 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 near OLCHC 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 OLCHC, should you have any concerns about your child day or night. There is also accommodation available in Ronald McDonald House, located on the grounds of OLCHC.

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 OLCHC. 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 OLCHC, Beaumont or Temple Street 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 (such as 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.

Proton Therapy

Proton therapy is a specialised form of radiotherapy, given using a machine called a cyclotron. The cyclotron uses proton radiation rather than X-rays to kill the cancer cells. The proton beam is aimed directly at the cancer and causes very little damage to surrounding healthy tissues.

Some very rare cancers, such as tumours affecting the base of the skull or the spine, can be treated with high-energy proton therapy. There are plans to develop this treatment in the UK, but it is not currently available in Ireland. However, the Department of Health can arrange for children who need this type of radiation to have it at centres in Europe.

Sterotactic Radiosurgery (SRS)

Stereotactic radiosurgery is a form of radiation therapy that focuses high-powered X-rays on a small area of the body. Other types of radiation therapy are more likely to affect nearby healthy tissue. Only a very small number of children have tumours that are suitable for treatment with stereotactic radiosurgery.

Follow-up clinic

When treatment is finished, your child will be reviewed regularly at the Neuro-Oncology Clinic in OLCHC. At this meeting you will meet your child's medical oncologist, radiation oncologist, neurosurgeon and neuro-oncology clinical nurse specialist. This clinic is held on the 2nd, 3rd 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. You can also discuss your child's latest test results and make an action plan to meet your child's needs until the next clinic appointment.

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.



Coping with 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.



Important information

Personal details

Name: _____
Address: _____

Telephone: _____

Hospitals your child may attend

Neurosurgical hospital: _____
Hospital phone number: _____
Paediatric unit: _____
Consultant: _____
Clinical nurse specialist: _____

Oncology hospital: _____
Hospital phone number: _____
Paediatric unit: _____
Consultant: _____
Clinical nurse specialist: _____

Radiotherapy hospital: _____
Hospital phone number: _____
Radiotherapy department: _____
Consultant: _____
Clinical nurse specialist: _____

Local hospital: _____
Hospital phone number: _____
Paediatric unit: _____
Consultant: _____
Clinical nurse specialist: _____



Resources



Useful organisations and websites

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
Cancer Nurseline Freephone:
1800 200 700
Email: cancernurseline@irishcancer.ie
Website: www.cancer.ie

Beaumont Hospital

Beaumont
Dublin 9
Tel: 01 8093 000
Website: www.beaumont.ie

Our Lady's Children's Hospital, Crumlin

Crumlin
Dublin 12
Tel: 01 4096 100
Website: www.olchc.ie

St Luke's Hospital

Highfield Road
Dublin 6
Tel: 01 4065 000
Website: stlukesnetwork.ie

Temple Street Children's University Hospital

Temple Street
Dublin 1
Tel: 01 878 4200
Website: www.cuh.ie

Help and support in Republic of Ireland

Aoibheann's Pink Tie

A registered charity that provides practical assistance and support for families in need who have a child with cancer. They take referrals through St John's Ward at Our Lady's Children's Hospital, Crumlin.

Aoibheann's Pink Tie
c/o Spar
Dunboyne Shopping Centre
Dunboyne
Co Meath
Tel: 01 240 1332 / 086 353 3897
Email: lindaconnell@aoibheannspinktie.ie
Website: www.aoibheannspinktie.ie

ARC Cancer Support Centre

Two centres that offer a range of support, counselling and therapy services to adults diagnosed with cancer, to their families, to parents of children with cancer and to friends and carers. Offsite support for children can be arranged.

ARC Cancer Support Centre

ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Barretstown

A specially designed camp for children with serious illnesses and their families.

Barretstown
Ballymore Eustace
Kildare
Tel: 045 864 115
Email: info@barretstown.org
Website: www.barretstown.org

Bray Cancer Support Centre

A centre that provides a range of support services for children and young adults, including counselling, arts and crafts, and social outings. Parents can also avail of some services.

Bray Cancer Support Centre
36 Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Website: www.braycancersupport.ie

Cancer Support Sanctuary LARCC

A centre that offers various services such as children's play therapy, which is facilitated by a fully qualified children's play therapist.

Cancer Support Sanctuary LARCC
Coole Road
Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
CallSave: 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

CanTeen Ireland

A nationwide support group for young people who have or had cancer, and also for their siblings and friends.

CanTeen Ireland
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: info@canteen.ie
Website: www.canteen.ie

Childhood Cancer Foundation

A registered charity that raises awareness of childhood cancer, advocates for improved services and helps fund vital supports for parents and children.

Childhood Cancer Foundation
Main Street
Dunboyne
Co Meath
Tel: 01 554 5655
Email: info@childhoodcancer.ie
Website: www.childhoodcancer.ie

Children in Hospital Ireland

A voluntary organisation that works directly with children in hospitals to help them cope with illness and being in hospital.

Children in Hospital Ireland
Carmichael Centre
Coleraine House
Coleraine Street
Dublin 7
Tel: 1890 25 26 82
Email: info@childreninhospital.ie
Website: www.childreninhospital.ie

CLIMB

A programme in the Tuam Cancer Care Centre. It is aimed at children aged 5–12 who are experiencing the impact of a sibling's cancer diagnosis. The centre also provides many services to parents and adult family members.

Tuam Cancer Care Centre
Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Cliona's Foundation

A registered charity that provides financial help for hidden costs in caring for critically ill children in Ireland.

Cliona's Foundation
Unit B3, Eastway Business Park
Ballysimon Road
Limerick
Tel: 061 400 640
Email: info@clionasfoundation.com
Website: clionasfoundation.com

Cork ARC Cancer Support House

A holistic centre that provides emotional support and practical help to those with cancer and their families. Open to adults diagnosed with cancer, parents of children with cancer, and adult family members and friends.

Cork ARC Cancer Support House
Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cuisle Cancer Support Centre

A centre that offers various services such as play therapy for children with cancer and for children whose parents have cancer.

Cuisle Cancer Support Centre
Block Road
Portlaoise
Co. Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support Group

A support group that provides a highquality holistic cancer support service to adults affected by cancer throughout the Midlands. It offers a wide range of supports and services, from Reiki and reflexology to creative writing and art classes.

Dóchas: Offaly Cancer Support Group
Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Hand in Hand

A group based in the west of Ireland that provides much-needed practical support for families of children with cancer.

Hand in Hand
Oranmore Business Park
Oranmore
Co Galway
Tel: 091 799 759
Mobile: 087 660 0103
Email: info@handinhand.ie
Website: www.handinhand.ie

Neurofibromatosis Association

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

Neurofibromatosis Association
Carmicheal Centre,
North Brunswick Street, Dublin 7
Tel: (01) 872 6338
Websites: www.nfaireland.ie or
www.nfauk.org

Sligo Cancer Support Centre: The Solas Centre

A centre that offers people with cancer and their families support, counselling, holistic therapies and healing workshops in a caring and tranquil environment. The centre offers a support group for children and young adults.

Sligo Cancer Support Centre
44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.sligocancersupportcentre.ie

South Eastern Cancer Foundation

A centre that offers support services to cancer patients, their families and their carers. The centre offers art psychotherapy for children and one-to-one support.

Solas Centre
South Eastern Cancer Foundation
Williamstown
Co Waterford
Tel: 051 304 604
Email: info@solascentre.ie
Website: www.solascentre.ie

Steppingup.ie

Steppingup.ie is a website full of transition information for young people, with long-term illnesses, moving to adult healthcare services.
Website: Steppingup.ie

Useful websites

Alex's Lemonade Stand Foundation

US children's charity that provides useful resources.
www.alexlemonade.org

Brain Tumour Ireland

Website: www.braintumourireland.com
Email: info@braintumourireland.com

Children's Oncology Group (COG)

Based in the US, the world's largest organisation for childhood and adolescent cancer research.
www.childrensoncologygroup.org

CLIC Sargent for Children with Cancer

UK children's charity that publishes a wide range of books, including storybooks.
www.clicsargent.org.uk

Headstrong

An Irish charity that focuses on youth mental health. Its Jigsaw programme gives young people somewhere to turn to and someone to talk to when in need.
www.headstrong.ie

www.jigsaw.ie healthtalkonline.org youthhealthtalk.org

Websites that contain information about cancer, and have video and audioclips of people talking about their experiences.
youthhealthtalk.org [for young people]

The Pituitary Foundation

Information on pituitary tumours and craniopharyngioma.
www.pituitary.org.uk

Reachout.com

For children and teenagers coping with stress, anxiety, bullying, suicide, depression, and other mental health and well-being issues.
<http://ie.reachout.com>

SteppingUP.ie

Irish website with information and support for young people with long-term illnesses moving from child to adult health services.
<http://steppingup.ie>

Stupid Cancer

Global support community for young adults with cancer.
<http://stupidcancer.org>

Teenage Cancer Trust UK

Cancer information and support forum for teenagers with cancer.
www.teenagecancertrust.org

TYAC (Teenagers and Young Adults with Cancer)

Information and support for teenagers and young adults with cancer.
www.tyac.org.uk

2bMe

For teenagers dealing with social and physical issues of being treated for cancer.
<http://lookgoodfeelbetter.org/2bMe/2bMe.html>

Useful contacts outside Republic of Ireland

Action Cancer

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Brain Tumour Association

Patient information site with children's information section.
Website: www.abta.org

Brain & Spine Foundation

LG01, Lincoln House
Kennington Park
1-3 Brixton Road
London SW9 6DE
Tel: 0044 20 7793 5900
Email: info@brainandspine.org.uk
Website: www.brainandspine.org.uk

The Brain Tumour Charity

Hartshead House
61-65 Victoria Road
Farnborough GU14 7PA
Tel: 0044 808 800 0004
Email: support@thebraintumourcharity.org
Website: www.thebraintumourcharity.org

Cancer Focus Northern Ireland

40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerhelp.org.uk

CLIC Sargent: Caring for Children with Cancer

Horatio House
77-85 Fulham Palace Road
London W6 8JA
Helpline: 0044 300 330 0803
Email: info@clicsargent.org.uk
Website: www.clicsargent.org.uk



Helping Hand has been produced by
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Department of Neurosciences,
Beaumont Hospital, Dublin 9



Department of Haematology/Oncology,
Our Lady's Children's Hospital,
Crumlin, Dublin 12



Saint Luke's Radiation Oncology Network
at St Lukes, Rathgar; Beaumont and
St James's Hospitals, Dublin



Neurosurgical Department,
Temple Street Children's University Hospital,
Temple Street, Dublin 1

Irish Cancer Society

43/45 Northumberland Road
Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Open Monday to Thursday 9am to 6pm

Friday 9am to 5pm

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