Irish Cancer Society

Understanding

Brain and spinal cord tumours in children

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Brain and spinal cord tumours in children

This booklet is about brain and spinal cord tumours in children and teenagers. It includes information on:

- Signs and symptoms of a tumour
- Types of tumours
- Treatment options
- Coping with your child's diagnosis
- Support for you
- After-care and follow-up

Important information

Personal details

Place hospital sticker here

Hospital contacts

CHI Temple Street

Hospital phone number

Consultant

Clinical nurse specialist

Medical social worker

Neuropsychologist

CHI Crumlin

Hospital phone number

Consultant

Clinical nurse specialist

Medical social worker

Psychologist

Radiotherapy hospital

Hospital phone number

Radiotherapy department

Consultant

Clinical nurse specialist

Local hospital

Hospital phone number

Paediatric unit

Consultant

Contents

Introduction

Every year in Ireland, an average of 45 children and teenagers are diagnosed with a tumour of the brain or spinal cord. Brain tumours are the most common tumours seen in children, and account for 2 in 10 new cases of childhood cancer every year. Your child may be treated for a tumour that is not cancerous, as not all brain tumours are a form of cancer.

Coping with this type of diagnosis is very stressful for families. We have written this booklet to provide you with information about the types of tumours we diagnose and treat.

There are many different types of tumours and each patient is unique. This means that even the same type of tumour can affect children in different ways, and the treatments may not be identical. The medical and nursing staff looking after your child will provide you with information specific to your child. There are also helpful online resources, which we have included at the back of this booklet.

The signs and symptoms of a tumour depend on the location of the tumour in the brain or spinal cord. The management of brain and spinal cord tumours may include surgery, radiotherapy, chemotherapy, targeted therapies and/or observation strategies. Not everybody needs all of the different types of treatment and your child's individual treatment plan will be discussed in detail with you.

About the brain and spinal cord

What do the brain and spinal cord look like?

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

The brain and spinal cord make up the central nervous system (CNS), and they are bathed in a special type of fluid called cerebrospinal fluid (CSF), which is produced by cells within the brain.

About the brain

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 (also called the cranium). Beneath the skull are three layers of membranes called meninges.

Parts of the brain

The brain is divided into regions that control specific functions. A tumour in a particular area of the brain may affect the actions it controls. It is important to remember that all the areas are interconnected and are working together at all times.

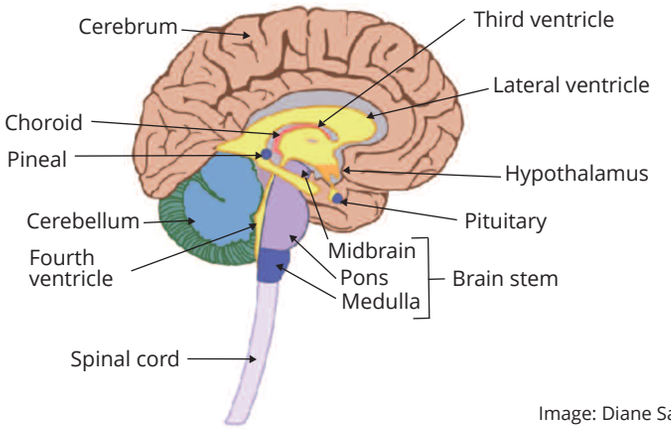
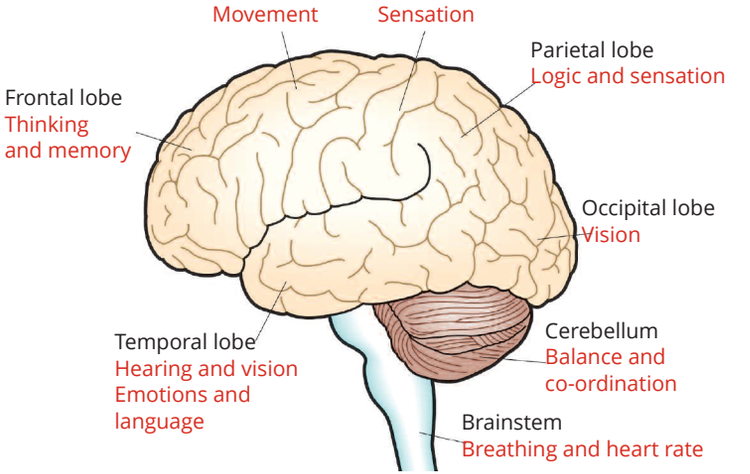


Image: Diane Sauveroche

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 receives messages from the left side and controls left-sided movement. 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 cause changes in behaviour/character, emotional difficulties, 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 heartbeat, 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, shoulders and tongue muscles.

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

Deep brain structures

This area is deep within the centre of the brain and includes the pituitary gland, hypothalamus, optic nerve pathway (nerves that travel from the back of the eyes), thalamus and pineal gland. The area containing the optic chiasm, pituitary and hypothalamus is often referred to as the sellar/suprasellar region. Tumours within this region may cause eyesight problems or hormonal (endocrine) problems.

Tumours affecting the thalamus may result in weakness, tremors in the arms and legs, abnormal positioning. A tumour affecting the deep brain structures may block the flow of CSF causing headaches, nausea and vomiting.

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, and the ability to 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, vomiting (sometimes early morning vomiting), double vision, uncoordinated movements, clumsiness, slurred speech, head tilt 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 the circulating CSF is blocked and the chambers/ ventricles swell. This results in raised pressure inside the head.

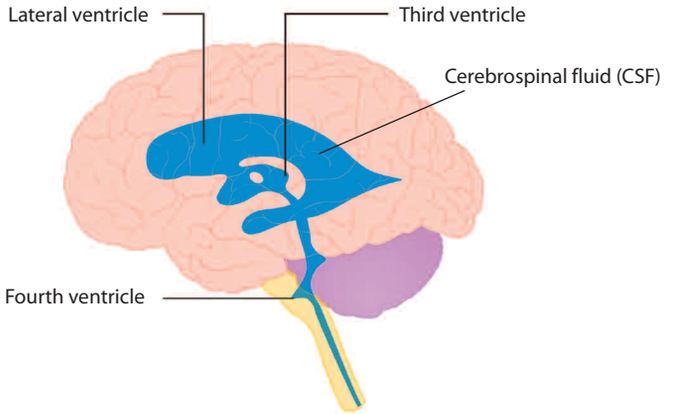
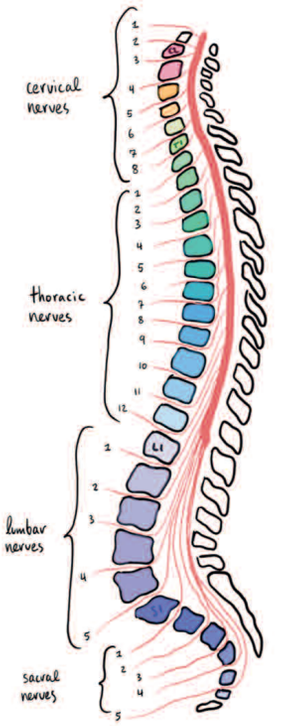


Image courtesy Cancer Research UK / Wikimedia Commons

A tumour may cause hydrocephalus because it either presses on part of the CSF pathways or grows within the system itself. Hydrocephalus is often treated before a biopsy of the tumour is performed. (See more about hydrocephalus on page 52.)

About the spinal cord

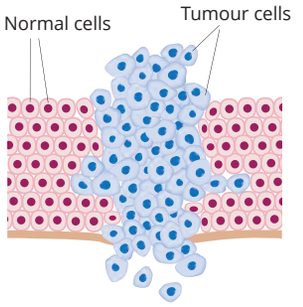
The spinal cord is protected inside the bones of the spine. These bones are called vertebrae. The spinal cord contains bundles of nerves that carry messages between the brain and the rest of the body. It communicates movements and sensations between the brain and the rest of the body through a network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



By David Nascari and Alan Sved - Own work, CC BY-SA 4.0, https://commons.wikimedia.org/w/index.php?curid=82049731

What is a tumour?

Our bodies are made up of billions of tiny building blocks called cells. Each cell has a specific role to play and contains our own DNA. Our cells are constantly dying off and being reproduced by new versions of themselves. This process sometimes results in cells with "mistakes" in them. This is common and happens in all of us. Our immune system usually destroys cells with mistakes.



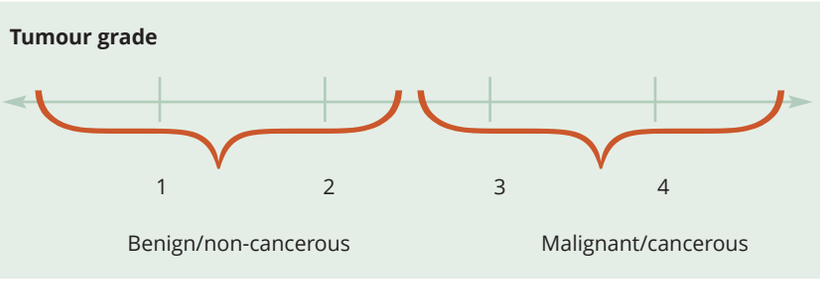
However, for a variety of complex reasons, sometimes a cell with a mistake in it can escape from the immune system. This can result in the cell dividing and multiplying in an uncontrolled way and forming a tumour. If this happens in the brain it is called a brain tumour. If it occurs in the spine it is a spinal tumour. The name of each specific tumour depends on the exact type of cell that grew out of control initially.

People use many different words for tumours, which can be confusing. A tumour is an abnormal group of cells forming a lump or mass. Often people may refer to a tumour as a lump or mass. A tumour may be benign (not cancerous) or malignant (cancerous). The only way of knowing with certainty if a tumour is benign or malignant, is by removing a piece of it or all of it and examining it in the laboratory. This is a complex process that involves numerous steps. This is why it can take 7-10 days (and sometimes longer) to know a precise diagnosis.

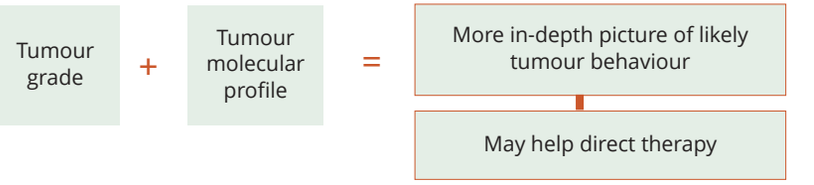
Email: supportline@irishcancer.ie

Tumour grades

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 tumours grow more rapidly or more aggressively. The grades provide some information as to how malignant/cancerous the tumour is. In general, a grade 1 or 2 tumour is considered benign (non-cancerous), and a grade 3 or 4 is considered malignant (cancerous). This grading system is not the only thing taken into consideration when determining how aggressive a tumour is likely to be, but it forms part of the picture.



In recent years, scientific advances have allowed doctors to obtain more information about a tumour based on the "molecular" profile. The results of these tests sometimes take some time. However, in addition to the tumour grade, they provide further information about the type of tumour and behaviour of the tumour. This can occasionally guide treatment.



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 a sample of cerebrospinal fluid (CSF) will help find out if the tumour has spread (metastasised).

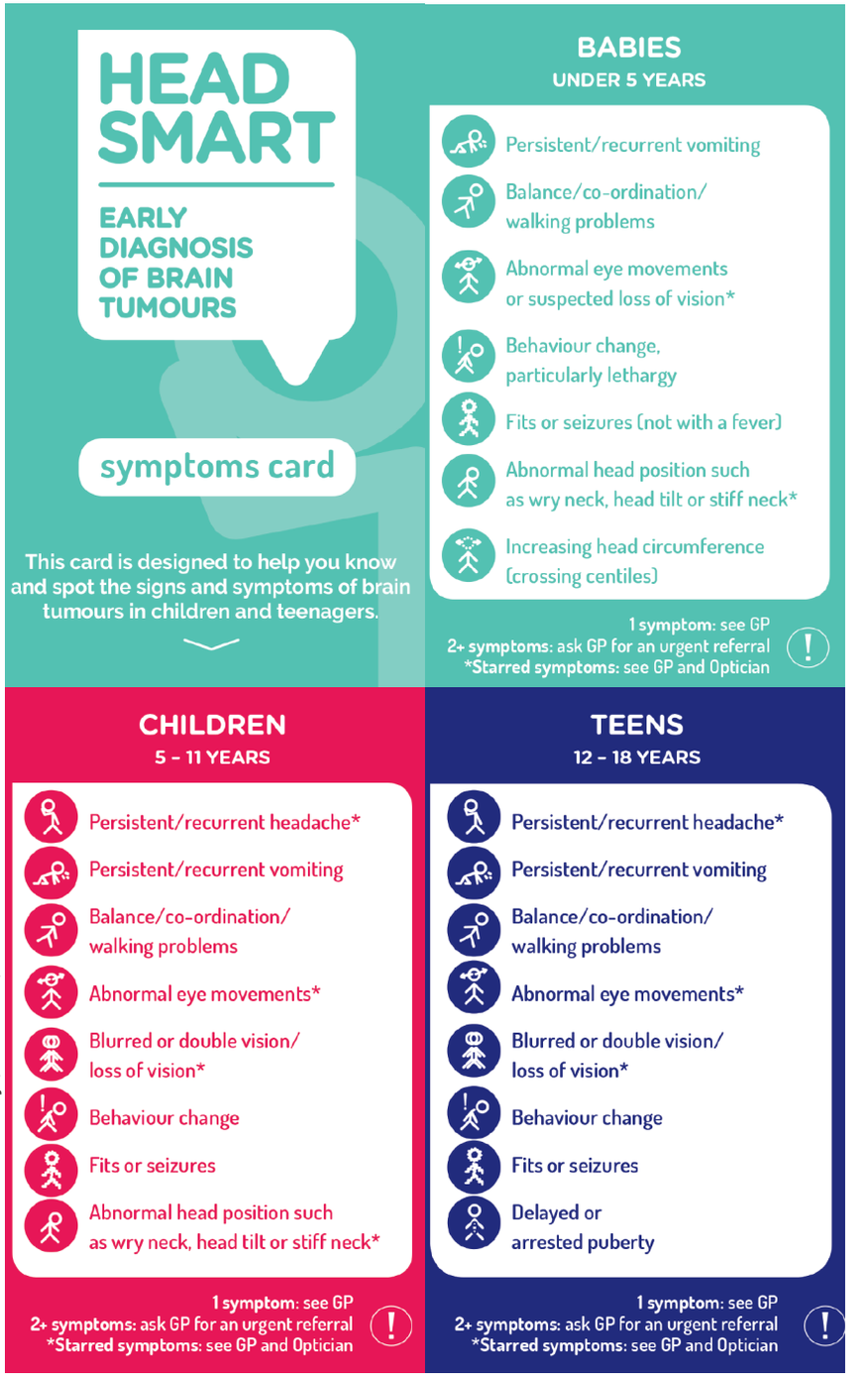
Signs and symptoms of brain and spinal cord tumours

The first signs of a brain tumour are variable and depend on many factors including the precise location of the tumour, the structures the tumour is putting pressure on and the age of the child. It is very common for the initial signs and symptoms to be mistaken for more common childhood illnesses, such as a tummy bug or migraine. We sometimes meet children or teenagers who have brain tumours and are completely well, but were having a scan of their head for another reason. This is called an incidental finding.

Spotting the signs and symptoms

The symptoms card (opposite) is part of the HeadSmart campaign in the UK, developed by the Brain Tumour Charity to raise awareness of brain tumour symptoms in children and teenagers. The information is based on data collated across the UK.

Note: *This symptoms card is a UK publication. If you are concerned about any of these symptoms, contact your GP. If you are very concerned about your child, go to the emergency department at your hospital.*



Source: The Brain Tumour Charity (HeadSmart)

What causes brain and spinal cord tumours?

It is understandable that carers have countless questions when a child is diagnosed with a brain tumour. Families wonder why this has happened; could it have been prevented; are other family members at risk; is the tumour life threatening? As more information about your child's tumour becomes available, all the details will be explained to you. Although new scientific discoveries and additional treatment options do sometimes become available, there are still many unknowns with regard to why your child developed a brain tumour. This will be discussed more in the clinical trials section, see page 65.

The cause of childhood brain tumours is unknown in the majority of cases. A small number are linked to rare genetic conditions. These include neurofibromatosis, tuberous sclerosis or Li-Fraumeni syndrome. If your oncologist believes your child may have one of these conditions, they will discuss this with you and explore the option of genetic testing for other family members.

Children, teenagers or young adults who have been exposed to radiotherapy in the past have an increased risk of developing tumours in the previously irradiated site. Some radiation-induced tumours are benign, and some may be malignant.

Diagnosis and tests

How is my child's tumour diagnosed?

The first stage of diagnosis starts when your child is seen by your GP or local hospital. This is usually because your child has symptoms that you are concerned about.

Childhood brain tumours are generally first discovered on a brain scan, for example, a CT scan or MRI. They are seen as an abnormal lump or mass. Once a brain tumour is suspected, your child is referred to the paediatric neuro-oncology team based in Children's Health Ireland (CHI) at Temple Street in Dublin.

Neurosurgery is an important step in looking after children or teenagers with suspected tumours of the brain or spinal cord. The neurosurgeon will often be the first specialist from the neuro-oncology team (see page 21) to meet your family. They will discuss the symptoms you have noticed in your child and explain the possible causes of these symptoms. The neurosurgical team usually does further tests to confirm the tumour type.

Meet the team

The care of children, teenagers and young adults with tumours of the brain or spinal cord involves a large team of specialists. We work together very closely to:

- Safely make an accurate diagnosis
- Create and deliver a tailored treatment plan
- Provide follow-up care after treatment
- Support the family throughout their journey

Members of the National Children's Cancer Service (NCCS), based in CHI at Crumlin, Dublin, together with the National Department of Neurosurgery (based in CHI at Temple Street) collaborate to form the paediatric neuro-oncology multidisciplinary team. This expert team includes neurosurgeons, paediatric oncologists, clinical radiation oncologists, radiologists, neuropathologists and a dedicated nursing team.

The team works closely with social workers, psychologists, physiotherapists, occupational therapists, speech and language therapists, dietitians, school and complementary therapists, all of whom provide a fundamental aspect of our service. Many other teams are involved as required – they are not all listed here.

Consultant neurosurgeon

The neurosurgeon is a specialist surgeon who operates on brain and spinal cord tumours. They 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.

Each child has a named neurosurgeon (based at CHI, Temple Street). This is often the person who performs the first surgery.

Consultant oncologist

Each patient will have a named paediatric oncologist, based at CHI, Crumlin. This is the doctor who will explain your child's diagnosis, direct and coordinate treatment and oversee follow-up care.

Consultant radiation oncologist

If a patient requires radiotherapy, they will be referred to one of our clinical radiation oncologists (based in St Luke's Hospital, Rathgar in Dublin). This initial consultation often takes place in CHI, Crumlin.

Clinical fellow

You may meet a clinical fellow. This is an experienced doctor, who is pursuing more in-depth training in the neurosurgical/oncology specialty.

Registrar and senior house officer

These doctors will carry out many of the tests and treatments. They will be available in the ward for any medical problems that may arise.

Advanced nurse practitioner (ANP)

The ANP is a senior member of the nursing team and is available to children having neurosurgery and/or 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.

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. CHI, Temple Street also provides dedicated consultation from a paediatrician with expertise in rehabilitation, as required.

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 your child receives the safest and highest quality of nursing care possible. The neurosurgical nurse coordinator is also available in CHI, Temple Street to give support and information about neurosurgery.

Staff nurses

Staff nurses are experienced 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 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. The neurosurgical ward in CHI, Temple Street is called St Gabriel's and the oncology ward in CHI, Crumlin is called St John's Ward.

Neuro-oncology clinical nurse specialist

The neuro-oncology clinical nurse specialist (CNS) is based in the neurosurgical centre. They provide emotional support, information and advice about tumours and their treatment. After the first surgery, the journey to full diagnosis and treatment takes a number of weeks. The CNS will first visit you while your child is a patient in the neurosurgical centre and will explain and organise next steps for your child. They will give you the relevant contact details and arrange your first meeting with the oncology team in CHI, Crumlin. They will also be involved in your child's follow-up appointments at the neuro-oncology outpatient clinics (in Crumlin).

Oncology clinical nurse specialist

The oncology clinical nurse specialist will meet you if your child requires chemotherapy or radiotherapy. They will offer you support in dealing with your child's diagnosis and throughout your child's treatment. They will give you a folder called ***Passport*** which contains all the information you will need while your child is receiving therapy. 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. Throughout your child's treatment they will be available to you to provide ongoing teaching, advice and support.

Healthcare assistant

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

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 you and your child with these challenges.

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 difficult to swallow food or liquid, the dietitian can assess and give advice on suitable foods or liquid feeds. This will help their weight gain and growth throughout treatment and during follow-up. If a child has challenges swallowing safely, or is unable to eat or drink for a prolonged period of time, a naso-gastric tube is sometimes considered to allow nutritional support to be given safely.

Medical social worker

Medical social workers help to support the practical needs of your family during this time of uncertainty. They can also help you and your child deal with the emotional and social aspects of the diagnosis. This will include the following:

- Offering short-term counselling
- Helping you to find ways to talk with your child about their illness
- Helping siblings cope
- Finding ways to deal with the impact of the illness on your everyday life – work, school, family/relationships
- Advising on financial issues: Coping with cancer can bring financial worries. You may have extra costs like travel or extra heating, or parents sometimes have to miss work or even give up their job to care for their child. These can be discussed with the medical social worker and planning done to deal with the issue rather than let it cause unnecessary stress.

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, as much as possible, to attend the school. 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/or 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 with feeding, dressing, writing and generally coping 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 centre and oncology centre. The psychologist can help your child cope with behavioural and emotional difficulties due to the brain tumour itself or from the effects of treatment.

They can help support your child on their journey through treatment with healthy emotions and help develop skills to make the journey easier. A child's ability to engage with psychology services varies from child to child. Younger children (for example, under 5) may benefit more from play therapy.

Neuropsychologist

Neuropsychologists are highly experienced in assessing children's cognitive or learning abilities.

Play therapist

Play therapists are available to your child. They use play as a "tool" to support a child in dealing with many of the strong emotions they may be feeling due to their diagnosis or treatment.

Complementary therapist

Complementary therapy is available in CHI, Crumlin. Our complementary therapist is a nurse specialist who provides her expertise to patients and their carers. Some of the therapies provided include reflexology and massage.

What tests will my child need?

Various tests will be done to give the doctors more information about your child's illness. These may include:

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 doughnut 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 scan uses a small dose of radiation.

MRI scan

A magnetic resonance imaging (MRI) scan uses radio waves and a powerful magnet linked to a computer to take detailed pictures of the brain and spine. These pictures can show the difference between normal and abnormal tissue. The MRI scans the brain and the spine. Your child will need to lie still on a table in a special tunnel-like machine for 30 minutes or longer. You should prepare your child in advance for this scan as the machine is very noisy (hammering sounds) and they may find it difficult to lie still. Very young children are given a general anaesthetic or sedation 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.

As 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.

What other tests might my child need?

Blood tests

A variety of blood tests will be performed prior to surgery. This allows the team to prepare your child for surgery appropriately. Some children may need a blood test for tumour markers (chemicals made by some tumours), if a germ cell tumour is a possibility.

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/metastasised. 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 to minimise discomfort.

Biopsy

In some situations, when it is not possible to remove the tumour, the doctors may need to remove a small piece of the tumour to help them diagnose and to decide on a treatment plan. Your child will be given an anaesthetic for the procedure and it will be done in the operating theatre. This can be done in two ways: by stereotactic biopsy or by open surgery. The neurosurgeon will decide on the most appropriate type of biopsy.

- **Stereotactic biopsy/keyhole biopsy:** A piece of the tumour tissue is taken by using a fine needle. This procedure is done by computer/ navigation guidance.
- **Open surgery/craniotomy:** This type of biopsy involves making a larger surgical cut (incision), so the surgeon can see the tumour and get a sample.

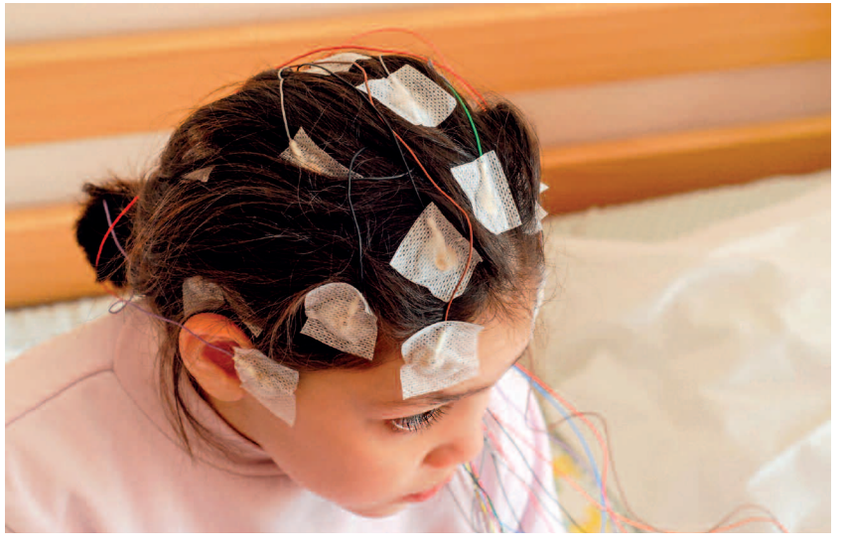
The tumour sample is then sent to the laboratory to be analysed by the neuropathologist. They will make a diagnosis based on the sample.

On average, a result can take 7 to 10 days. Sometimes the results may take longer to process depending on the complexity of the analysis. Specialist molecular results often take weeks to months to obtain as they are performed in batches.

Once a diagnosis has been made, all members of the neuro-oncology team work together to ensure that your child gets the most appropriate treatment in a timely way. In general, children need to recover from their surgery prior to starting other therapies.

EEG

An electroencephalogram (EEG) 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. This is not required for every child.



Angiogram

An angiogram looks at the blood vessels in and around the tumour. This test is not required for every child. 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 neurosurgical ward.

What medications might my child need?

Sometimes brain tumours cause symptoms that require urgent treatment – even ahead of surgery, chemotherapy or radiotherapy. If your child develops brain swelling or seizures certain medications are given promptly. These include:

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. In 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, temper tantrums, moodiness and sleep problems. While on steroids your medical and nursing team will be monitoring for other potential side-effects, such as high blood pressure and high blood sugars.

Anticonvulsant (anti-seizure) medication

Some tumours may cause seizures or fits. Fits may have been a symptom of your child's brain tumour before diagnosis, or they can happen after diagnosis or 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.

Types of brain and spinal cord tumours

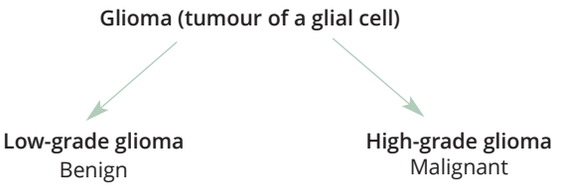
Types of brain and spinal cord tumours

This section gives a general overview of the common types of brain tumours found in children and teenagers. 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 tumour cells in the laboratory and provides the diagnostic “name” of the tumour is called a neuropathologist. 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 in children. Gliomas may be named after the part of the brain in which they are found (for example, optic pathway glioma) or after the type of cells that they contain (for example, pilocytic astrocytoma). The neuropathologist grades gliomas by carefully examining the appearance of the tumour cell under the microscope, (see more on tumour grading on page 13). If a glioma has a particular molecular abnormality, this may provide additional information about its behaviour, as well as occasionally guiding therapy. The amount of information provided by molecular markers is evolving all the time. Some children with gliomas may have an underlying condition which predisposes them to such tumours, for example, neurofibromatosis or tuberous sclerosis. Your doctor will tell you if they think that’s the case.



Low-grade gliomas

Low-grade gliomas are the most common type of brain tumour seen in children, representing 30-50% of all brain tumours. These tumours are typically grade 1 and 2, when examined under the microscope. These are considered benign and are typically slow-growing tumours. These tumours typically cause symptoms by putting pressure on surrounding structures in the brain. The treatment of choice is to surgically remove as much of these tumours as is safely possible. Sometimes these tumours contain a cyst filled with fluid rather than solid tissue.

If your child's tumour has been completely removed, the chance of it returning is small. Your child will be monitored closely in the outpatient neuro-oncology clinic at regular intervals, as occasionally these tumours can re-grow and need further treatment.

If the tumour is causing symptoms or growing, further surgery, chemotherapy and/or radiotherapy may be considered. If a low-grade glioma continues to grow despite surgery, chemotherapy, and/or radiotherapy; experimental or targeted therapies may be used. The treatment of a low-grade glioma is a constant balance between maximising the wellbeing of the patient and minimising the side-effects associated with treatments.

High-grade gliomas

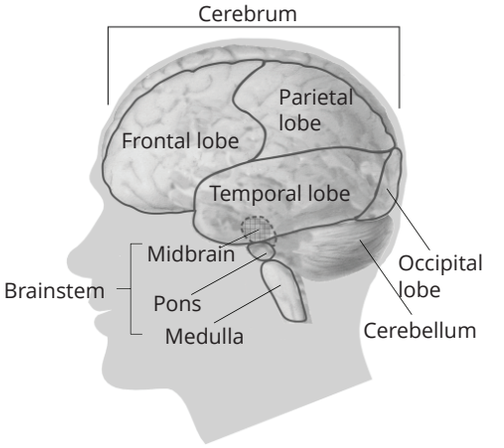
High-grade gliomas represent 8-12% of childhood brain tumours. These are malignant and tend to behave aggressively and grow rapidly. These tumours can be difficult to remove completely, as they tend to grow quickly and invade nearby normal brain tissue. The symptoms will depend on the area of the brain involved. They are usually treated by surgery followed by radiotherapy and/or chemotherapy. Types of high-grade glioma include glioblastoma multiforme (GBM) and anaplastic astrocytoma.

Brain stem tumours

The brain stem is located at the base of the brain between the deep brain structures and the top of the spinal cord. This vital area of the brain contains many of the control centres necessary for sustaining life, for example, breathing, blood pressure and heart rate. As a result, tumours within this area can be challenging to treat. Brain stem tumours are usually gliomas and often one of two types:

- Low-grade glioma, for example, pilocytic astrocytoma
- High-grade glioma called a diffuse intrinsic pontine glioma (DIPG), so called because it originates in the pons of the brainstem
- DIPG tumours are part of a family called diffuse midline gliomas (DMGs). They often have a specific molecular abnormality called a histone mutation. DMGs don't only occur in the pons and may also occur higher up in the brain, for example, in the thalamus

If safe to do so, initial surgical treatment is focused on relieving hydrocephalus (fluid in the ventricles) if present. Or sometimes the steroid dexamethasone is used to treat the swelling (see page 31). A biopsy is performed (if considered safe to do so) to achieve a diagnosis. The treatment path followed depends on whether it is a low-grade glioma or a high-grade glioma (for example, DIPG). Low-grade gliomas are typically treated as outlined in the glioma section (see page 36). DIPG tumours are usually treated with radiotherapy, in an attempt to reduce tumour size, associated pressure effects and symptoms. Your child's treating team will explain in detail the diagnosis, prognosis, treatment pathway, and will advise you of the option to participate in clinical trials, if available (see page 65).



Optic pathway gliomas

Tumours of the optic pathway are generally low-grade gliomas. As the location of the tumour involves the visual pathways (nerves that carry visual information to the eyes), surgery is usually not performed to remove the tumour. If safe to do so, a biopsy is sometimes done. Your child's doctor will monitor the tumour closely with regular medical reviews, MRI scans and visual assessments. (An ophthalmologist is the doctor who specialises in these visual assessments). This is called an observation strategy.

If the tumour is growing or causing a major symptom for your child, for example, causing vision to deteriorate, your child's doctor will discuss the merits of starting treatment with chemotherapy. Occasionally radiotherapy or targeted therapies are used, depending on the situation.

Tectal glioma

A tectal glioma is a low-grade glioma of the tectum (the roof of the brain stem). Symptoms may vary, but most commonly include symptoms of hydrocephalus (headache, vomiting, sleepiness, changes in eye movements). Treatment is aimed at surgically relieving the hydrocephalus and does not always include a biopsy or surgery to remove the tumour.

The majority of children will then be observed closely and have scans and medical reviews at regular intervals. Chemotherapy or radiotherapy are seldom required 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 or other treatments may be considered.

Embryonal brain tumours

Embryonal tumours develop from cells that are left over from the early stages of our development. While there are different types of embryonal tumours, the most common type is medulloblastoma.

Medulloblastoma

Medulloblastomas are the most common malignant (cancerous) brain tumours in childhood. In Ireland, at least 10 children are diagnosed with a medulloblastoma annually. These tumours often occur in or close to the cerebellum, frequently blocking the flow of CSF and causing hydrocephalus. Initial steps in looking after children with a medulloblastoma include:

- Surgical procedure to relieve hydrocephalus if present; sometimes a ventriculo-peritoneal (VP) shunt is needed, see page 53
- Removing as much of the tumour as is safely possible
- Post-operative MRI scan – to find out if there are tumour cells anywhere else in the brain or spine and also to see if there is visible tumour left at the main tumour site
- 10-14 days after the surgery, a lumbar puncture to allow CSF testing to find out if there are any tumour cells floating in the CSF. Your child will be sedated/under anaesthetic for this to minimise discomfort
- Bone marrow aspirates (liquid samples) and biopsies (if there is evidence of disease spread)

The treatment of medulloblastoma depends on many factors including:

- Age of child
- Whether the tumour has spread or is in one place
- Whether the tumour has been totally removed or not
- The specific molecular subtype of medulloblastoma

- Whether the child has an underlying condition which predisposes them to the development of a medulloblastoma (small minority of patients)
- How well the child is after the diagnosis and surgery

In general, treatment of a medulloblastoma involves a combination of:

- Surgery
- Radiotherapy to the primary tumour site and craniospinal axis (in children over the age of 3-4)
- Chemotherapy

There have been a lot of scientific advances related to medulloblastomas in recent years. This has allowed doctors to learn more about the molecular subtypes of medulloblastomas, for example, WNT, SHH, group 3 and group 4. In some cases, this helps to guide treatment decisions. Sometimes the treatment decisions are complex and unique to your child. However, the aim is always to maximise the chance of a long-term cure while minimising the chance of treatment-related side-effects. Your medical team will be able to discuss this with you in more detail.

Posterior fossa syndrome

Posterior fossa syndrome (PFS), or cerebellar affective syndrome, can be a complication following surgery to the posterior fossa area of the brain (see diagram on page 8). The symptoms of PFS may persist for several months and in some cases can affect timing or sequence of post-surgical treatment. Your neurosurgical team will explain this syndrome to you in more detail before surgery.

Atypical teratoid/rhabdoid tumour (ATRT)

This is a rare type of embryonal tumour, which predominantly occurs in younger children; 2 out of 3 cases are in children under the age of 3 years. This tumour can occur anywhere in the brain or spine. Initial steps in looking after children with ATRT include:

- Surgical procedure to relieve hydrocephalus if present; sometimes a VP shunt is needed, see page 53
- Biopsy or removing as much of the tumour as is safely possible
- Post-operative MRI scan – to find out if there are tumour cells anywhere else in the brain or spine and also to see if there is visible tumour left at the main tumour site
- 10-14 days after the surgery, a lumbar puncture to allow CSF testing to find out if there are any tumour cells floating in the CSF. Your child will be sedated/under anaesthetic for this to minimise discomfort
- Abdominal ultrasound – to examine the kidneys

The treatment of ATRT depends on many factors including:

- Age of child
- Whether the tumour has spread or is in one place
- Whether the tumour has been totally removed or not
- Whether the child has an underlying condition which predisposes them to the development of rhabdoid tumours (minority of patients)
- How well the child is after the diagnosis and surgery

In general, treatment of ATRT involves a combination of:

- Surgery
- Radiotherapy to the primary tumour site
- Radiotherapy to the craniospinal axis (if there is metastatic disease) – in children over the age of 3-4
- Chemotherapy

If we see – very rarely – that there are additional tumours outside the brain and spinal cord, for example, kidney tumours, we become concerned that a child may have a condition that predisposes them to the development of rhabdoid tumours. If the medical team is concerned that a "rhabdoid predisposition syndrome" is a possibility for your child, this will be discussed in detail with you, as not all children are affected.

Pineoblastoma

These are malignant tumours which arise in the pineal region in the brain, which sits in the centre of the brain between the two hemispheres. The pineal gland produces a substance called melatonin, which helps control our sleep cycle. In the minority of children, a pineoblastoma may be associated with an inherited mutation in the RB1 gene.

Initial steps in looking after children with a pineoblastoma include:

- Surgical procedure to relieve hydrocephalus if present. Sometimes a VP shunt is needed, see page 53
- Biopsy or removing as much of the tumour as is safely possible
- Post-operative MRI scan – to find out if there are tumour cells anywhere else in the brain or spine and also to see if there is visible tumour left at the main tumour site
- 10-14 days after the surgery, a lumbar puncture to allow CSF testing to find out if there are any tumour cells floating in the CSF. Your child will be sedated/under anaesthetic for this to minimise discomfort

In general, treatment of a pineoblastoma involves a combination of:

- Surgery
- Radiotherapy (in children over the age of 3)
- Chemotherapy

Other embryonal tumours

Many other rare malignant embryonal tumours exist. Examples include CNS-neuroblastomas, CNS-ganglioneuroblastomas, medulloepitheliomas, embryonal tumour with multi-layered rosettes (ETMR) and CNS-embryonal tumour NOS (not otherwise specified). In general, these tumours also require treatment with a combination of surgery and chemotherapy, with/without radiotherapy (depending on the age of the child).

Ependymoma

An ependymoma is a tumour that begins in the cells (ependymal cells) that line the ventricles of the brain and spinal cord. Ependymoma tumours vary from benign low-grade tumours to malignant higher-grade tumours. In recent years, new molecular discoveries have been providing us with more diagnostic and prognostic features of ependymomas.

The low-grade benign ependymomas (often seen in the spine) generally can be removed by surgery.

Initial steps in looking after children with higher-grade malignant ependymomas involve:

- Surgical procedure to relieve hydrocephalus if present. Sometimes a VP shunt is needed, see page 53
- Removing as much of the tumour as is safely possible (this sometimes requires more than one procedure)
- Post-operative MRI scan – to find out if there are tumour cells anywhere else in the brain or spine, and also to see if there is visible tumour left at the main tumour site
- 10-14 days after the surgery, a lumbar puncture to allow CSF testing to find out if there are any tumour cells floating in the CSF. Your child will be sedated/under anaesthetic for this to minimise discomfort

Treatment of a malignant ependymoma involves a patient-specific treatment pathway:

- **Surgery (removing as much of the tumour as is safely possible):** This sometimes requires more than one procedure
- **Radiotherapy:** Radiotherapy only to the site of the primary tumour, in children over the age of 18 months. If the ependymoma has spread (rare at diagnosis), and the child is over 3 years, craniospinal radiation may be considered
- **Chemotherapy:** Various chemotherapy combinations are sometimes considered depending on the age of the child, whether all the tumour was removed and whether the disease has spread

Germ cell tumours

These tumours tend to grow in or near the midline structures of the brain, for example, the pineal gland or pituitary gland. Certain germ cell tumours release chemicals that can be found in the blood or cerebrospinal fluid (CSF). These chemicals are called tumour markers. If, after an MRI brain scan, a germ cell tumour is suspected, a blood sample and a sample of CSF can be taken to check for markers. In some cases, these tumour markers allow us to diagnose the type of tumour without doing a biopsy. There are different type of germ cell tumours but they are grouped into two main categories called germinomas and non-germinomatous germ cell tumours. These tumours are generally sensitive to chemotherapy and radiotherapy, but occasionally a surgical procedure is needed to remove parts of the tumour.

Initial steps in managing children with germ cell tumours include:

- Surgical procedure to relieve hydrocephalus if present. Sometimes an endoscopic third ventriculostomy (ETV) or VP shunt is needed, see page 53
- Blood tumour markers and CSF tumour markers
- If tumour markers are normal or not diagnostic, a biopsy may be required to diagnose the suspected germ cell tumour
- MRI of brain and spine to find out if there are tumour cells anywhere else in the brain or spine, and to evaluate the tumour at the primary site
- A lumbar puncture 10-14 days after surgery to find out if there are any tumour cells floating in the CSF. Your child will be sedated/under anaesthetic for this to minimise discomfort
- Endocrinology review (hormonal assessment) may be required
- Ophthalmology review may be required

In general, treatment involves a combination of:

- Chemotherapy
- Sometimes surgery (if there is tumour left over after chemotherapy)
- Radiotherapy

Craniopharyngioma

A craniopharyngioma is a benign tumour found in the sellar/suprasellar region involving the deep brain structures. The symptoms will depend on whether the tumour is involving or pushing on the hypothalamus, pituitary gland or optic nerves. These tumours often have solid parts and cystic parts (look like cysts).

The type of treatment given will depend on your child's individual case.

Treatment options

Surgery: 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 can sometimes be removed through your child's nose.

Radiotherapy may be considered, in certain cases, for example, if the tumour has not been completely removed and is growing or causing symptoms.

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 (see page 53), or a device through which fluid can be removed from the cyst is surgically placed under the skin to allow cyst fluid to be removed periodically. If a craniopharyngioma tumour has blocked or interrupted the flow of cerebrospinal fluid, your child may have symptoms of hydrocephalus. Occasionally, urgent treatment for hydrocephalus is needed before the tumour itself is treated. See more about hydrocephalus on page 52.

Hormone changes: The pituitary gland is the master control centre for the body's hormones. A 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. Many children with craniopharyngiomas require hormone replacement therapy (medication). This means that they will need blood test monitoring and careful observation of their growth and pubertal development.

Vision: Children with a craniopharyngioma may have changes to their vision. This is monitored closely, and if deteriorating, may be an indication that further treatment needs to be considered.

Spinal cord tumours

Spinal cord tumours are relatively rare in children and teenagers, representing less than 5% of all tumours of the central nervous system. There can be any of the previously described tumours in the spinal cord, but the most frequent types diagnosed include gliomas (particularly low-grade gliomas) and ependymomas.

Spinal tumours may be found within the nerves of the spinal cord, or inside the coverings of the spinal cord or even outside the cord itself. They may also occur in the bone of the spine.

Symptoms depend on the position of the tumour in the spinal cord. These tumours may often cause symptoms by pressing on the nerves, including back and neck pain, or 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 of the spinal cord tumour depends on what type of tumour it is. Surgery will usually be performed, to allow biopsy/diagnosis or removal of the tumour or to relieve pressure on the spinal cord itself. Further treatment is dependent on tumour type.

Other tumours

It is outside the scope of this booklet to describe every type of brain and spinal cord tumour. Other rare tumour types do occur in infants, children, teenagers and young adults, for example, choroid plexus tumours and meningiomas. Your medical team has experience in treating these tumours and will discuss them in detail with you.

Treating brain and spinal cord tumours

What types of treatment are available?

Your child will have their diagnosis and treatment plan recommended by the neuro-oncology multidisciplinary team, which includes experts from all relevant disciplines.

The paediatric oncologist will discuss this treatment plan in detail with you and answer all of your questions. Each child's treatment plan is unique to them, but will be based on "standard of care". This means that the treatment plan which is recommended will be based on available scientific evidence and expertise, and is the "best way we know how" to treat a particular tumour type.

Sometimes there is an opportunity to enrol on a clinical trial (see page 65 for more on clinical trials). Selecting treatments for children with brain and spinal cord tumours is always a very careful balance – that is, we aim to pick treatment which maximises our chance of cure or disease control but minimises the chances of long-term side-effects.

These decisions are often straightforward, but sometimes require complex discussion. Please be reassured that your medical team is committed to answering all of your questions, as we know this is a very worrying time for your family.

Neurosurgery

Neurosurgery is an important part of the care of brain and spinal tumours in children. The neurosurgeon is a specialist surgeon who operates on brain and spinal cord tumours. These tumours are often referred to as central nervous system (CNS) tumours.

Neurosurgery is generally done to:

Obtain a diagnosis by removing a little piece of the tumour for analysis. This is called a biopsy (see below)

Relieve raised intracranial pressure or decompress pressure caused by a brain or spinal tumour

Remove the tumour, or part of it. This is called debulking or resection

Biopsy

A biopsy is performed when a diagnosis needs to be made before deciding on a treatment plan for your child. A biopsy means that a small piece of tumour is removed in surgery to find out exactly what kind of tumour it is. See page 29 for more on biopsy.

Relieve raised intracranial pressure

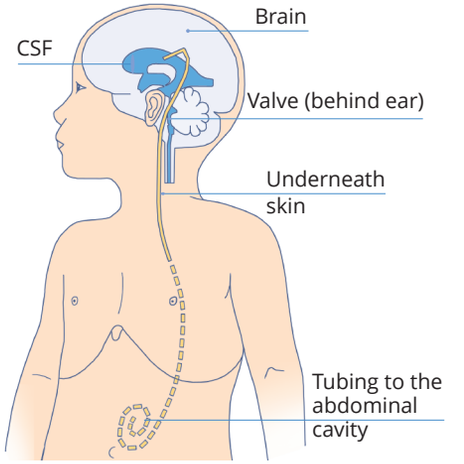
Hydrocephalus

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 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.

VP shunt

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.

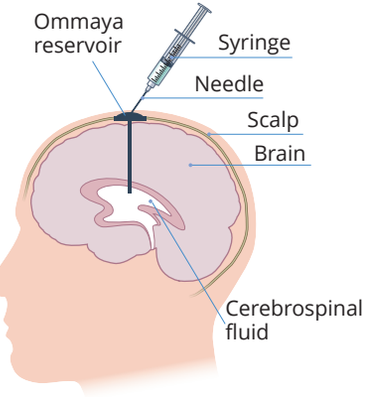


Endoscopic third ventriculostomy

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

Ommaya reservoir

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.



An Ommaya reservoir can also be used for the delivery of certain chemotherapy drugs into the CSF. (See page 57 for more on giving chemotherapy.)

Remove the tumour

Surgery is used to try to remove as much of the tumour as is safely possible. The amount of tumour that can be removed will be different for each child.

There are two words you may hear used to describe the neurosurgical operation: **resection** and **debulking**.

Gross total resection means that all of the tumour has been removed; subtotal resection means most of the tumour has been removed and partial resection or debulking means part of the tumour has been removed. Recent advances in equipment to help the surgeon navigate around the tumour have made neurosurgery more accurate and safer.

In some cases, being able to completely remove the tumour surgically greatly improves chances of survival and of cure. When complete removal is not possible, other types of therapy such as chemotherapy and radiotherapy still remain as treatment options. Some tumours do not need complete resection and are treated with chemotherapy and radiotherapy, for example, germinomas.

Intraoperative monitoring and tumour mapping is often used to help guide maximal safe tumour resection. The aim of this is to remove as much of the tumour as safely as possible, while trying to minimise post-surgery neurological deficit. There are some instances where it is necessary to remove all of the tumour and certain neurological deficits are expected as a result of this post-surgery. The surgical team will discuss these possibilities with you.

Sometimes surgery has to be done as an emergency. When a child presents to an emergency department unconscious, with a tumour causing acute pressure on the brain or loss of power in the spine, the neurosurgeon often has to make the decision to operate immediately to relieve the symptoms, increasing the child's chances of survival.

Your neurosurgeon will fully explain the type of surgery needed for your child and its benefits and risks before asking you to sign a consent form before surgery.

Once surgery is complete the neurosurgeon and team will meet you and explain the details of your child's operation.

It is useful to leave your mobile number with the nurses so that you can be updated while your child is in surgery.

Following surgery your child will be monitored in the theatre recovery room and generally will be moved directly to the intensive care unit (ICU) for close observation. After brain tumour surgery, a post-operative MRI may be taken on the way to ICU or sometimes a MRI is necessary during surgery. If this happens your child will be still under general anaesthetic and unaware of the procedure. An early MRI is required to gain a baseline image of how much of the tumour was removed during surgery.

Histology/pathology result

A histopathology report is often called a biopsy or pathology report. Following your child's surgery it will take on average 7-10 days (and sometimes longer) for the neuropathologist to send back a report from the laboratory on the tumour sample received during surgery.

This report will describe features of the tumour tissue and confirm if your child's tumour is low grade or high grade, benign or malignant. The specific features found while examining the tumour tissue under the microscope will mark the start of a full diagnosis for your child and enable further treatment planning.

See pages 29 and 35 for more on neuropathology.

Observation strategy

Brain or spinal cord tumours that are not causing significant symptoms for your child, and are believed to be slow growing are often observed closely. This involves regular outpatient visits and MRI scans to ensure that the tumour is not showing signs of growth. There are many children who are looked after in this way, and never require intervention. If the tumour starts to grow or cause symptoms for your child, the team will discuss the next steps with you.

Chemotherapy

Chemotherapy is a term used to describe many different types of medicines used to treat tumours (both cancerous and non-cancerous). Chemotherapy affects cells that are rapidly dividing, like tumour cells. The aim of giving chemotherapy is to stop or slow down tumour growth. If a tumour has been removed completely, we often still give chemotherapy, with the aim of "mopping up" tiny tumour cells that are left over. There are many different types of chemotherapy drugs which may be used alone or in combination with others, depending on the type of tumour being treated.

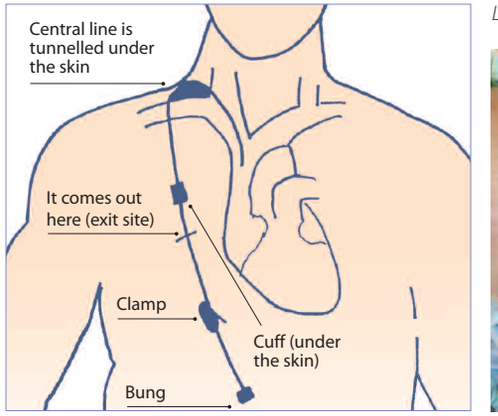
Who decides which chemotherapy drugs to use?

Throughout the world paediatric oncologists work together to develop successful treatment plans, which are also called protocols. Children are treated on a specific 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 associated with that treatment. Chemotherapy protocols are usually given over many months, with children attending the oncology unit at regular intervals, either as a day patient or inpatient.

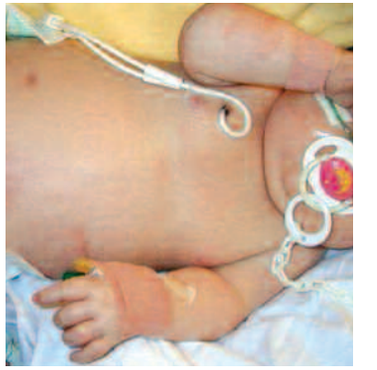
How is chemotherapy given?

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 sometimes used to give intrathecal chemotherapy (see page 53).

Chemotherapy drugs can be given directly into the vein using a central venous line.



Left and below: **Hickman line**



A Hickman®, Broviac or Freddie line is a type of central venous line. It is a long-term, narrow tube that is inserted into a large blood vessel in your child's chest under general anaesthetic. This allows 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 CHI, Crumlin, 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 this procedure. The clinical nurse specialist will teach you about the Hickman line and how to care for it at home. We use this type of central venous line most commonly in CHI, Crumlin. There is a Hickman app which is free to download and contains written information and video demonstrations. Your oncology nurse specialist will discuss this with you if your child needs a Hickman line.

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. 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 send 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 provide you with detailed 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.

High-dose chemotherapy and stem cell transplantation

Depending on your child's treatment plan, they may need high-dose chemotherapy with stem cell rescue. Not all children require this therapy. 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.

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 in CHI, Crumlin. 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.

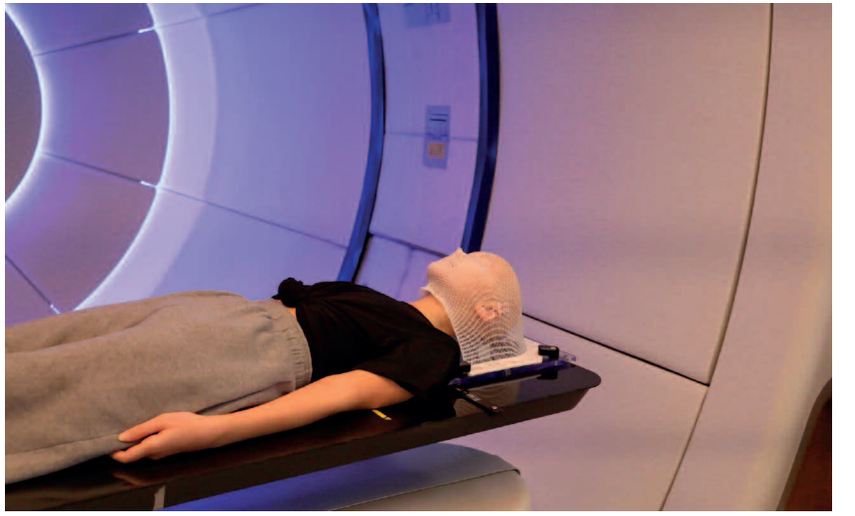
How many collections are needed?

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

Radiotherapy is a treatment that uses high-energy radiation to treat tumours. Treatment is similar to having an X-ray taken and is completely painless. It is usually directed very accurately at the tumour to destroy the cancer cells. Radiotherapy is given as a course of daily treatments, over a period of weeks. It is usually used in combination with surgery and/or chemotherapy. It is important for children to keep very still during treatments. The team will make a special mask to help children to keep their head in the correct position. Very young children may be treated under general anaesthetic, while older children may be prepared with play therapy and distracted during the treatment.

As part of preparation, your child will have a planning CT scan, which is loaded onto a special computer programme. The radiation oncologist uses this scan, along with any previous MRIs, to find the area they will treat, along with any important organs near to the treatment area. They then produce a radiotherapy dose map, which shows the dose of radiotherapy that should be given to all the relevant areas of the brain or spine.



There are different types of radiotherapy.

Photon radiotherapy: X-rays are most commonly used, often using a special technique known as intensity modulated radiotherapy (IMRT). This enables very accurate sculpting of the dose around the tumour while minimising the dose to the surrounding organs. This type of radiotherapy is available in Dublin.

Proton beam therapy: This radiotherapy uses protons instead of X-rays to treat tumours. It does not improve the chance of cure, but it might reduce the risk of long-term side-effects. It is not available in Ireland, but the HSE funds proton therapy for patients that are most likely to benefit from this option. This takes place in Essen, Germany.

We have a special online leaflet ***Guide for families with children receiving proton therapy abroad***. You can download the leaflet from the Irish Cancer Society website, **www.cancer.ie**

Your medical team will consider all aspects of care when selecting the best type of radiotherapy for your child – in particular, the risks of travelling and the risks of any potential delays in radiotherapy. They will discuss all of this with you in detail.

What are the risks and side-effects of radiotherapy?

The majority of children tolerate radiotherapy very well. The side-effects of radiotherapy vary depending on the area treated, the dose of radiotherapy required and the age of the child.

In the short term, potential side-effects may include hair loss, tiredness, nausea, loss of appetite, mouth ulceration and skin sensitivity or rash. These may worsen towards the end of the treatment course, and often peak a few weeks after treatment ends, before fading away.

In the long term, potential side-effects are very much dependent on the type of radiotherapy received, the age of the child during treatment, the areas of the brain and/or spinal cord treated and other factors such as the chemotherapy agents used and the presence or absence of hydrocephalus.

Please note that the following side-effects may not be relevant to your child. Your oncology team will discuss specific long-term risks related to your child. Some long-term risks may include: hormonal imbalances, which may impact on growth and pubertal development; potential hearing impairment; neurocognitive challenges (which can range from mild to significant learning disability, slower processing speeds, memory impairment); a risk of developing a second tumour (which can be cancerous or non-cancerous) and an increased risk of having a stroke in early adulthood.

Targeted therapies

In the last decade, scientific research has lead to new discoveries relating to paediatric neuro-oncology. Tumours that we thought were single entities (based on what they look like under the microscope) have turned out to be a complex family of related tumours, which often differ in the factor that is “driving” them to grow. This has allowed us to learn more about the likely behaviour of a tumour type, for example, different molecular subtypes of medulloblastoma.

In some instances, these discoveries have lead us to alter treatment plans for children. However, this is usually in the context of a clinical trial and are not front-line therapies at present. These targeted agents are sometimes available if your child’s tumour comes back (relapses) after standard treatment has been given. New information is becoming available all the time, and your medical team will be happy to discuss any potential role for targeted agents for your child’s tumour.

Clinical trials

(Information adapted from the leaflet 'Taking part in a clinical trial' by the Children's Cancer and Leukaemia Group – CCLG)

Many children and young people with brain and spinal cord tumours are treated on clinical trials. If there is a clinical trial that your child may be eligible for, your doctor will inform you. Taking part in a clinical trial is completely optional, and your child will be expertly cared for, regardless of whether they are included in a clinical trial or not. There are not always clinical trials “open” for recruitment, at any given time.

Always ask your child's doctor or other members of the team if you have any queries relating to treatment or participation in a trial.

What is a clinical trial?

A clinical trial is a medical research study involving people to find out the most effective treatment for a particular disease. Before a new treatment is available to all patients, it must be tested to be sure it is safe and effective. This is done through clinical trials.

The aims of clinical trials are to:

- Find out whether a new treatment or procedure is safe
- Find out whether a new treatment or procedure has any side-effects
- Test new medicines
- See whether a new treatment or procedure works better than the currently used treatment
- Find out which treatments have the least impact on patients’ everyday lives
- Find out which supportive care treatments can help reduce side-effects
- Find out the impact of the cancer and the treatment has on quality of life

Why are clinical trials important?

As we don't yet know the best way to treat every type of cancer, clinical trials help us to find better ways of treating the different kinds of cancer. Clinical trials allow us to test new treatments and ways of controlling symptoms, or to investigate new ways of preventing or diagnosing cancer. It is largely because of clinical trials that such progress has been made in the treatment of children's cancer over the last few decades.

Can anybody enter a trial?

There are very clear guidelines about which patients are eligible for a particular trial. Each trial will have specific rules about who can take part, such as the type of cancer, age of patient and stage of the disease. Your child's doctor will explain this to you.

What are we told about the trial?

Detailed information sheets are provided for patients and parents, and there will be opportunities to discuss the trial with the doctor or nurses, and to ask any questions. The information sheets will give you details about the treatment and any possible side-effects, as well as explaining what will happen to the data collected during the trial. A research nurse, or another member of the team, will be available to explain the trial in more detail, answer any questions you have, and talk through anything that is not clear from the information sheets.

Who is responsible for running the trial?

Clinical trials might be developed by hospital teams, research scientists or by pharmaceutical companies. The trials may be national or international. Your child's research team can include nurses, pharmacists, clinical trial practitioners and data managers who work across a huge variety of research projects. In Ireland, trials must be approved by the Health Products Regulatory Authority (HPRA) and a recognised ethical committee.

Taking part in clinical trials

In order to take part in the trial, it will be necessary to sign a consent form to confirm that you understand what happens in the trial and you agree for your child to take part. This will be signed by you as the parents or the patient themselves, depending on age.

What happens if we don't want to take part?

The doctor treating your child will respect your choice and your child will receive the best known and proven treatment.

What if we say 'yes', then change our minds?

Patients and parents can change their mind at any time. You do not have to give a reason if you do not wish to. Your child's doctor will respect your decision and your child will then receive the best known and proven treatment.

What are the benefits of taking part in a clinical trial?

- Your child may receive a new treatment that is only available in a clinical trial
- Your child's treatment will be the same, wherever you live
- National, or often international, experts in the particular tumour type will have worked together to develop the trial protocol
- There is considerable emphasis on patient safety and your child will be monitored closely
- Sometimes there may be no benefit for your child, but the results of the trial may help doctors improve cancer treatments for future patients

Are there any disadvantages?

Your child's doctor will discuss with you any possible disadvantages. Depending on the design of the trial protocol:

- You may have to make more hospital visits
- Your child may have more tests carried out
- The new treatment, although expected to be better, may not actually be better
- Your child may experience side-effects that you or your doctor are not expecting, but this will be closely monitored
- Your child may not be able to have the drug treatment made up specially as a syrup, but will have to swallow tablets/capsules the same as other patients on the trial

Support for you

How will my child's illness affect me?

Having a child diagnosed with a brain or spinal cord tumour will affect you and the people close to you. Understandably, you will feel worried and stressed as you come to terms with the diagnosis and what it means for your child. You will no doubt worry that your child will suffer and that your family life is going to be completely disrupted. Some parents may also feel that they will lose their child.

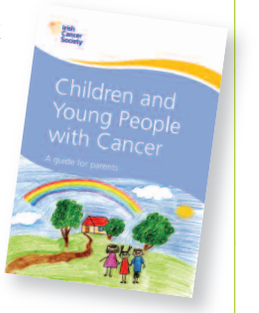
When first told the diagnosis, you may feel numb, confused, or unable to hear or remember information about your child's diagnosis or treatment. You may also feel overwhelmed by painful and powerful emotions. These reactions are normal – remember, the doctors and nurses are there to help you at this time.

There are also other people and organisations that can offer support (see page 81).

Support for you

If you are feeling anxious or overwhelmed and would like to speak to a nurse outside of the hospital environment, call the Irish Cancer Society Support Line on 1800 200 700 and ask them to arrange for you to speak to their Children's Cancer Nurse.

You can call just to chat things over or to ask for support and advice. You can also ask for a copy of the booklet ***Children and Young People with Cancer: A guide for parents***. Or you can download it from **www.cancer.ie**



The booklet has lots of information on:

- Coping with the impact of a diagnosis
- Feelings and emotions
- Practical support
- Looking after yourself

You and 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 is the best policy, as it helps prepare your child for the treatment ahead and why it is needed. Information needs to be given to a child in an age-appropriate way; this is something we can support you with.

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 sick child/teenager?

Once your child is admitted to hospital with a suspected brain or spinal cord tumour, we encourage parents to talk to them openly about it, including 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 frightening 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 even 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 reality. For this reason, we encourage openness so that all members of the family can support one another. Your medical social worker, play specialist and nursing staff will also help you find ways of talking to your child. Together with the doctors and nurses and many others (for example, psychologists, play specialist, speech and language therapist, dietitian, social workers, physiotherapist, occupational therapist), we will work together to ensure that you feel supported.

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 to an older child, whereas for younger children you could say, for example, "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, for example, 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.

Getting advice

If you require information and advice on coping with a child's cancer, the impact of a diagnosis, looking after yourself and practical support and would like to speak with a Children's Cancer Nurse or be referred to a trained parent volunteer, you can either:

- **Call the Irish Cancer Society Support Line on 1800 200 700 – 9am to 5pm Monday to Friday**
- **Email supportline@irishcancer.ie**

Will my GP and local hospital be informed?

Once a diagnosis has been confirmed, the consultant caring for your child will send a written summary letter outlining your child's diagnosis and proposed treatment plan to both your local hospital consultant and your GP.

What happens with school?

Cancer treatments will disrupt schooling. But your child's education should continue, because school gives a sense of life being normal or as normal as it can be.

Your child should be encouraged to go back to school, even just for a few hours or half a day.

Some children need extra support at school, especially those treated for brain tumours. Some children find it hard to concentrate or may need extra time to complete tasks.

A booklet is available for your child's teachers to help them understand your child's illness. This book is available from the medical social workers.

Your child may have concerns about how other children may react when they return to school. Experience has shown that if the other children understand what is wrong with your child, they are usually very supportive.

Many children with tumours of the brain and spinal cord continue to attend school. Your child's treating team will give you specific advice regarding this.

Email: supportline@irishcancer.ie

After treatment

Follow-up neuro-oncology clinic

When treatment is finished, your child will be reviewed regularly at the neuro-oncology clinic in CHI, Crumlin. You will meet your child's medical oncologist, radiation oncologist, neurosurgeon and neuro-oncology clinical nurse specialist, as required. This clinic is held on a Monday morning. Appointments are arranged by the medical oncology secretary on 01 409 2536.

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.

Finishing treatment can be a time of mixed emotions as feelings of relief and pleasure are mixed with uncertainty and worry. When a child has finished treatment, the treating team will provide an end-of-treatment summary. This outlines all the different treatments they received, including the names of any chemotherapy drugs used, surgical procedures undertaken and radiotherapy received.

Keep this end-of-treatment summary somewhere safe for easy access, should your child ever need to know the details of their treatment. For example, they may need it for an antenatal visit or pre-employment health check when starting a new job.

Long-term follow-up

As time goes on, the emphasis of follow-up appointments changes from checking the condition hasn't returned to looking for any late effects of treatment.

Long-term follow up is not just to offer support with medical problems. There can be other issues. Some survivors talk about experiencing job discrimination or difficulties obtaining health or travel insurance. This is a good reason for your child to know about their illness, its treatment and potential effects later in life. It is important to remember that although your child's experience will always be a part of them, it doesn't need to define the person they are.

Transition to adult services

A smooth and timely transition from the paediatric service to adult service is essential for follow-up of our patients over the age of 16. As your child approaches adulthood, it is important that long-term follow-up within a familiar structured clinical setting is available to them.

There is an adolescents and young adult (AYA) neuro-oncology clinic presently available to our patients in Beaumont Hospital.

Long-term follow-up at this clinic will be a planned event and discussed with you over time.

Support resources

Useful organisations and websites

Aoibheann's Pink Tie
A registered charity that provides practical assistance and support for families in need who have a child with cancer. It takes referrals through St John's Ward at CHI, Crumlin.

Tel: 01 240 1332
Email: info@aoibheannspinktie.ie
Website: www.aoibheannspinktie.ie

CHI Crumlin
Tel: 01 4096 100
St John's Ward
Tel: 01 4554 176
Website: www.olchc.ie

St Luke's Hospital
Tel: 01 4065 000
Website: www.stlukesnetwork.ie

CHI Temple Street
Tel: 01 878 4200
St Gabriel's Ward
Tel: 01 878 4680/1
Website: www.cuh.ie

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

Tel: 045 864 115
Email: info@barretstown.org
Website: www.barretstown.org

Brain Tumour Ireland
Brain Tumour Ireland gives information and support to people affected by a brain tumour. It also has a separate web section for families affected by a paediatric brain tumour diagnosis.

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

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

Tel: 01 872 2012
Email: info@canteen.ie
Website: www.canteen.ie

Childhood Cancer Foundation
Ireland's national independent body for childhood cancer. It raises awareness about childhood cancer, advocates for improved services and funds vital supports for affected families.

Tel: 01 554 5655
Email: info@childhoodcancer.ie
Website: www.childhoodcancer.ie

Irish Cancer Society

The Irish Cancer Society provides information and support to people affected by a child or adolescent cancer diagnosis.

- **Contact a Children's Cancer Nurse through the Support Line Freephone 1800 200 700**
- **Email supportline@irishcancer.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. It also provides ongoing support to their families.

Tel: 01 290 3510
Email: info@childreninhospital.ie
Website:
www.childreninhospital.ie

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

Tel: 061 400 640
Email:
info@clionasfoundation.com
Website: clionasfoundation.com

Hand in Hand
A national support service that provides much-needed practical support for families of children with cancer.

Tel: 091 799 759/087 660 0103
Email: info@handinhand.ie
Website: www.handinhand.ie

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.

Website: www.headstrong.ie

Irish Cancer Society
Support Line Freephone:
1800 200 700
Email: supportline@irishcancer.ie
Website: www.cancer.ie

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

Tel: 01 872 6338
Websites: www.nfaireland.ie *or*
www.nfauk.org

SteppingUP.ie
Irish website with information and support for young people with long-term illnesses moving from child to adult health services.

Website: http://steppingup.ie

Useful supports outside Ireland

Alex's Lemonade Stand Foundation
US children's charity that provides useful resources.
Website: www.alexslemonade.org

The Brain Tumour Charity UK
UK charity dedicated to funding research and raising awareness of brain tumours. HeadSmart is a Brain Tumour Charity campaign which, along with the Children's Brain Tumour Research Centre and the Royal College of Paediatrics and Child Health, is dedicated to raising awareness of the signs and symptoms of brain tumours in children and teenagers.

Website:
www.thebraintumourcharity.com

Children's Cancer and Leukaemia Group (CCLG)

CCLG is a network of 20 specialist centres for diagnosing and treating children's and teenage/young adult cancers throughout the UK and Ireland. CHI, Crumlin has one of the largest centres within the group. The group supports the 1,700 children who develop cancer each year in the UK and Ireland. CCLG's principal treatment centres work together to make sure families across the UK and Ireland have access to the best possible treatment and care.

Children's Oncology Group (COG)
Based in the US, the world's largest organisation for childhood and adolescent cancer research.

Website:
www.childrensoncologygroup.org

Children's Cancer and Leukaemia Group (CCLG)
The Children's Cancer and Leukaemia Group is a leading children's cancer charity in the UK and Ireland. (see panel)

Email: info@cclg.org.uk
Website: www.cclg.org.uk

CLIC Sargent for Children with Cancer
UK children's charity that publishes a wide range of books, including storybooks.

Website: www.clicsargent.org.uk

The Little Princess Trust
A charity which funds real hair wigs for children.

Website:
www.littleprincesses.org.uk

Reachout.com
For children and teenagers coping with stress, anxiety, bullying, suicide, depression, and other mental health and well-being issues.

Website: http://ie.reachout.com

Stupid Cancer
Global support community for young adults with cancer.

Website: http://stupidcancer.org

Teenage Cancer Trust UK
Cancer information and support forum for teenagers with cancer.

Website:
www.teenagecancertrust.org

TYAC (Teenagers and Young Adults with Cancer)
Information and support for teenagers and young adults with cancer.

Website: www.tyac.org.uk

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **Survivor Support**
- **Support in your area**
- **Patient travel and financial support services**
- **Publications and website information**

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information. In relation to children with cancer, the nurse can offer advice about supports that are available. Or you can ask to speak to a children's cancer nurse. The Support Line is open Monday to Friday, 9am to 5pm. Or email us on supportline@irishcancer.ie or visit our online community at **www.cancer.ie**

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Local cancer support groups and centres

You can email daffodilcentreinfo@irishcancer.ie or visit **www.cancer.ie** to find your local Daffodil Centre.

Survivor Support

We have trained parent peer supporters available to provide emotional and practical support to you while your child is going through or has finished treatment.

If you would like more information on any of our services, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Patient travel and financial support

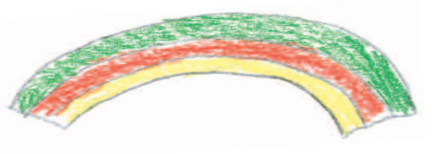
We provide practical and financial support for patients in need, who are undergoing cancer treatments. There are two funds available to children through the Society:

- **Travel2Care** is a fund, made available by the National Cancer Control Programme (NCCP), for patients who are having difficulty getting to and from their treatments while attending one of the designated centres of excellence or their satellites. The medical social worker in your child's hospital will apply on behalf of your family, if eligible.
- Our **Children's Fund** is a special fund to help families in financial hardship when their child is faced with a cancer diagnosis. The fund is for families who cannot meet a specific financial burden only because of their child's cancer diagnosis or treatment. This includes children who are having active treatment or receiving palliative care.

You can make three applications over the course of your child's treatment, with a 12-month interval between each application. The most that can be paid out is €1000 for the first application and €500 each for a second and third application. There is no automatic entitlement and each application is assessed on a case-by-case basis. As with Travel2Care, the medical social worker in your child's hospital will apply on your behalf.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our **website www.cancer.ie** or call our Support Line for free copies of our publications.



Local cancer support services

The Irish Cancer Society works with cancer support groups and centres across the country to ensure people affected by cancer have access to confidential support, including professional counselling. This includes parents of children diagnosed with cancer.

As a parent of a child with cancer you may like to avail of a variety of services including complementary therapies or peer support at your local cancer support centre.

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at **www.cancer.ie/cancer-information-and-support/cancer-support/find-support**

What does that word mean?

Acute Occurring suddenly over a short period of time.

Alopecia Hair loss.

Anaemia A reduced number of red blood cells.

Anaesthetic Drugs that put your child to sleep (general anaesthetic) or that numb a part of their body (local anaesthetic).

Antibodies Proteins created by the immune system when exposed to foreign proteins such as viruses and bacteria.

Atypical teratoid/rhabdoid tumour (ATRT) This is a rare type of embryonal tumour, which predominantly occurs in younger children. This tumour can occur anywhere in the brain or spine.

Audiogram A hearing test that is not painful. Your child wears headphones and responds to various volumes and tones.

Benign A tumour or growth that is not cancerous but may still cause problems.

Biopsy A small sample of tissue taken from the body to make a diagnosis.

Blood count A blood test to check the number of different cells in the blood. Sometimes it is called a full blood count or FBC.

Bone marrow The spongy material in the centre of large bones in the body, which makes blood cells.

Bone marrow aspirate/biopsy A test that takes samples of bone and bone marrow and examines them under a microscope. If bone is taken, it is called a trephine biopsy. If bone marrow is taken it is called an aspirate. The test is usually done in theatre.

Bone scan A test that can show if cancer is present in bones using a radioactive dye.

Cannula A short plastic tube put into a vein to deliver medication, fluids or a transfusion.

Craniopharyngioma A benign tumour found behind the pituitary gland in the midbrain.

CT scan A computerised axial tomography scan. It is a series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to X-ray machines. Sometimes a dye called contrast may need to be given before the scan to get a better picture.

Catheter A thin, flexible tube used to give fluid into the body or to drain fluid from the body. For example, a urinary catheter or a central line, such as a Hickman line.

Central nervous system (CNS) This refers to the brain and spinal cord.

Cerebrospinal fluid (CSF) Fluid made in the brain that surrounds the brain and spinal cord.

Chemotherapy Drug treatment that kills cancer cells.

Chromosome Structure in the nucleus of the cell that contains the genetic make-up of the cell.

Cyst An abnormal sac or closed cavity that is filled with fluid or semisolid matter.

Cyto- To do with cells.

Cytogenetics The study of chromosomes in cells.

Diffuse intrinsic pontine glioma (DIPG) is a high-grade glioma so called because it originates in the pons of the brainstem.

Echocardiogram (Echo) This is an ultrasound scan of the heart. It checks how well the heart is working.

Electrocardiogram (ECG) This tests the electrical activity of the heart muscle. Electrical sensors are placed on your child's chest for the test.

Electroencephalogram (EEG) This tests the electrical activity of the brain. It is not painful but will involve electrical sensors being attached to your child's head.

Electrolytes The minerals and salts in the body. For example, sodium, potassium and calcium.

Endocrine To do with hormones.

Endoscopic third venticulostomy (ETV) is a surgical procedure for treatment of hydrocephalus in which an opening is created in the floor of the third ventricle. This allows the cerebrospinal fluid to flow, bypassing the obstruction.

Ependymoma A tumour that begins in the cells (ependymal cells) that line the ventricles of the brain and spinal cord. Ependymoma tumours vary from benign low-grade tumours to malignant higher grade tumours.

External ventricular drain (EVD) is a device used in neurosurgery to treat hydrocephalus and relieve elevated intracranial pressure when the normal flow of cerebrospinal fluid (CSF) inside the brain is obstructed.

GCSF A growth factor called granulocyte colony-stimulating factor. This protein boosts the bone marrow making white blood cells, usually neutrophils.

Genetic A condition caused by abnormal genes (may be inherited).

Germ cell tumours These tumours tend to grow in or near the midline structures of the brain, for example, the pineal gland or pituitary gland. Certain germ cell tumours release chemicals that can be found in the blood or cerebrospinal fluid (CSF).

Glomerular filtration rate (GFR) is a test that shows how well the kidneys are working.

Haemoglobin (Hb) The substance in red blood cells that carries oxygen around the body, often referred to as Hb.

High-grade glioma (HGG) are malignant tumours that tend to grow rapidly.

Histopathology The study of body tissues.

Hormone A substance made by a gland and carried in the bloodstream to parts of the body where it has a specific effect on the way the body works.

Immune system The body's defence against infection, disease and foreign substances.

Immunology The study of the body's immune system, which fights infection.

Immunophenotyping A test to identify particular proteins in the cells to help find out which type of cell has become cancerous.

Immunosuppressive Lowering the body's ability to fight infection.

Intrathecal (IT) Into the spine, usually by lumbar puncture. See also lumbar puncture.

Intravenous (IV) Into a vein.

Low-grade glioma (LGG) Most common type of brain tumour in children. Slow-growing and benign.

Lumbar puncture (LP) This can be done to diagnose, prevent or treat disease. The fluid that surrounds the brain and spinal cord is called cerebrospinal fluid (CSF). During the test, some CSF is removed by putting a needle into the lower back and the fluid is then examined in the laboratory to diagnose if disease is present, and treatment can be given into the CSF to prevent or treat disease.

Lymph A clear fluid that is part of the body's defence against infection. It is carried around the body in a network of lymphatic vessels.

Lymphatic system Part of the circulatory system. It consists of a network of vessels that carry a clear fluid called lymph in the direction of the heart. Excess fluid (lymph) in the tissues is drained by the lymphatic system into the bloodstream. It also defends the immune system.

Lymph nodes Small bean-shaped structures found along vessels in the lymphatic system. They become enlarged due to infection or cancer.

Lymphocyte A type of white blood cell that fights infection.

Malignant A tumour or growth that is cancerous. If a tumour is malignant it grows uncontrollably and can travel to other parts of the body.

Medulloblastoma is the most common malignant (cancerous) brain tumour in childhood.

Metastases Tumours that have spread from the first (primary) tumour into another part of the body. Also known as secondary tumours.

MRI scan Magnetic resonance imaging scan. This uses radio waves and a powerful magnet linked to a computer to take detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.

Nausea Feeling sick.

Neuro- To do with the nerves or the nervous system.

Neutropenia or neutropenic Low levels of neutrophils.

Neutrophils White blood cells that fight infection.

Oedema Swelling caused by fluid.

Oncology The study and treatment of cancer.

Ophthalmology The study of the eyes.

Optic pathway gliomas Tumours of the optic pathway are generally low-grade gliomas.

Oral To do with the mouth.

Palliative Relief of a symptom (for example, pain) rather than cure of the disease.

Pineoblastoma These are malignant tumours which arise in the pineal region in the brain, which sits in the centre of the brain between the two hemispheres.

Platelet A type of blood cell that helps the blood to clot.

PRN Medicines to take when required.

Prognosis The expected outcome of a disease and its treatment.

Pulmonary To do with the lungs.

Pulmonary function tests Tests that measure how well the lungs take in and breathe out air, and also how well they move oxygen into the bloodstream. Your child breathes through a mouthpiece connected to a special machine called a spirometer.

Radiotherapy The use of high-energy X-rays to destroy cancer cells.

Red blood cell Blood cells that carry oxygen around the body. The part that contains iron, called haemoglobin, gives blood its red colour.

Refractory Resistant to treatment.

Relapse The return of a disease after previous treatment or during treatment.

Remission There is no evidence of the disease being present, using the available tests.

Renal To do with the kidneys.

Spinal cord tumours Spinal cord tumours are relatively rare in children and teenagers, representing less than 5% of all tumours of the central nervous system.

Stem cell Early, immature blood cell from which other blood cells are made.

Subcutaneous (SC) Under the skin, also referred to as subcut.

Tectal glioma A tectal glioma is a low-grade glioma of the tectum (the roof of the brain stem).

Therapy Treatment.

Thrombocytopenia Low levels of platelets in the blood leading to bruising and bleeding.

Total parenteral nutrition (TPN) Giving nutrients into a vein when a child is unable to take food in the normal way.

Ultrasound A test that uses sound waves to check the tissues inside the body.

Ventriculoperitoneal (VP) shunt A device/catheter that is inserted in order to remove excess fluid from the brain or tumour.

White blood cells Blood cells that defend the body against infection.

Questions to ask your child's doctor or nurse

Here is a list of questions that you might like to ask your child's doctor or nurse. Never be shy about asking questions. It is always better to ask than to worry.

What type of tumour does my child have? Where exactly is it?

What is the tumour called? Is it cancerous?

What tests and investigations does my child need?

What stage is the tumour at? What does this mean?

What treatment choices are there?

Does my child need more than one type of treatment?

Is this the best treatment for my child? Why do you think so?

How long will treatment last?

Will my child be cured and recover?

What are the chances of the treatment working?

How and when will we know if the treatment has been a success?

What side-effects can my child expect in the short term?

Are there any long-term side-effects?

Will treatment affect my child's fertility in the long run?

How can we help our child before and during treatment?

Does my child need to eat special foods?

Can accommodation be arranged for us while our child is in hospital?

Should we tell our child that he/she has a tumour?

What happens if the tumour comes back?

What happens if my child cannot be cured?

Are there any counselling or support services for parents?

Your own questions

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