



Children's
Cancer and
Leukaemia
Group

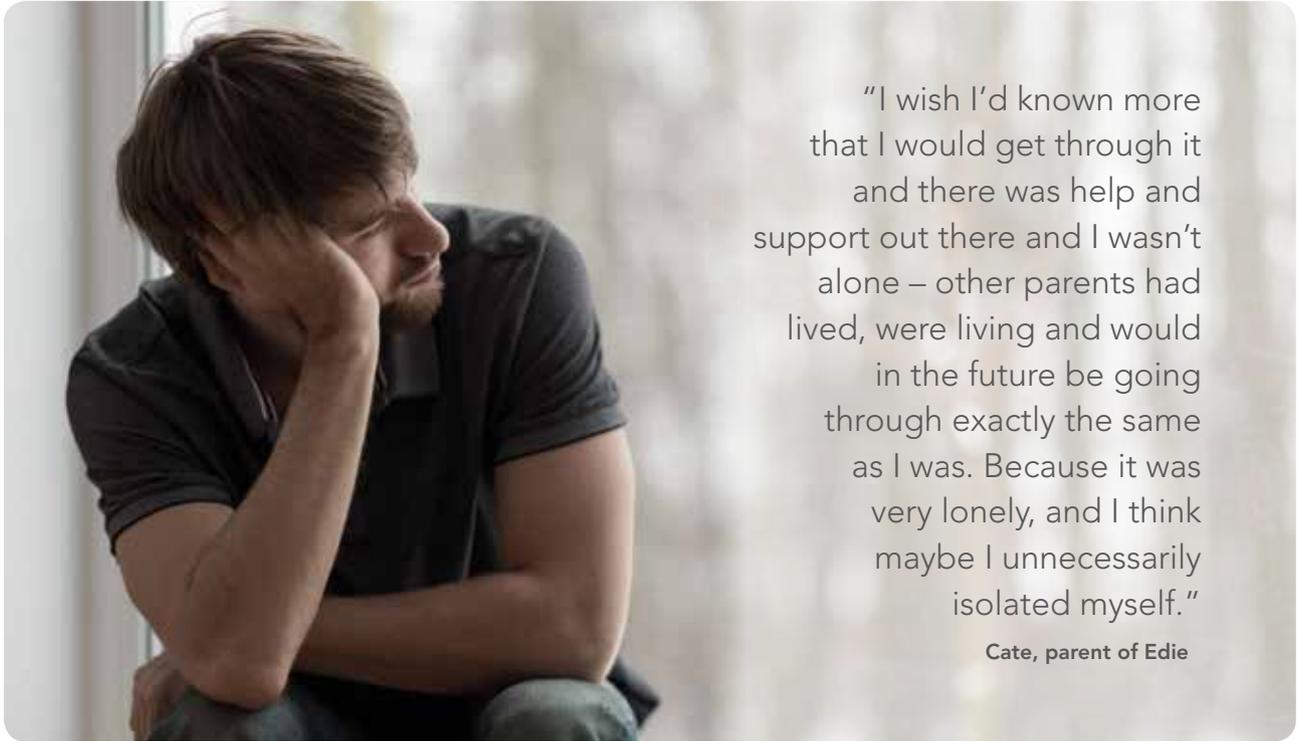
My child has a brain or spinal tumour

A guide for parents and carers



Phoebe with her younger brother

www.cclg.org.uk



“I wish I’d known more that I would get through it and there was help and support out there and I wasn’t alone – other parents had lived, were living and would in the future be going through exactly the same as I was. Because it was very lonely, and I think maybe I unnecessarily isolated myself.”

Cate, parent of Edie

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“The surgeon told me my daughter’s cancer type was nothing that runs in families or anything – it’s just a one in a however many gazillions chance. He said ‘You’ve been exceptionally unlucky, basically.’”

Rachel, parent of Phoebe



Phoebe during treatment

Introduction

Reading this guide, you are likely to be going through one of the hardest things a parent can face – knowing your child may have a brain or spinal tumour. You may be feeling frightened, overwhelmed, bewildered or numb, while at the same time trying to appear strong and calm for your child and other family members.

Be assured you are not alone. Between 400 and 500 children are diagnosed with brain or spinal tumours each year in the UK. That means many families have been through this journey over the years, and there is support out there, from them and from your child's health professionals.

In the meantime, this guide is here to accompany you through this journey. It was written with the help of parents and carers who have been through something similar to you. They told us

what it was like for them, and what they learned along the way, so that we can share it with you. You can find their experiences and tips throughout this booklet.

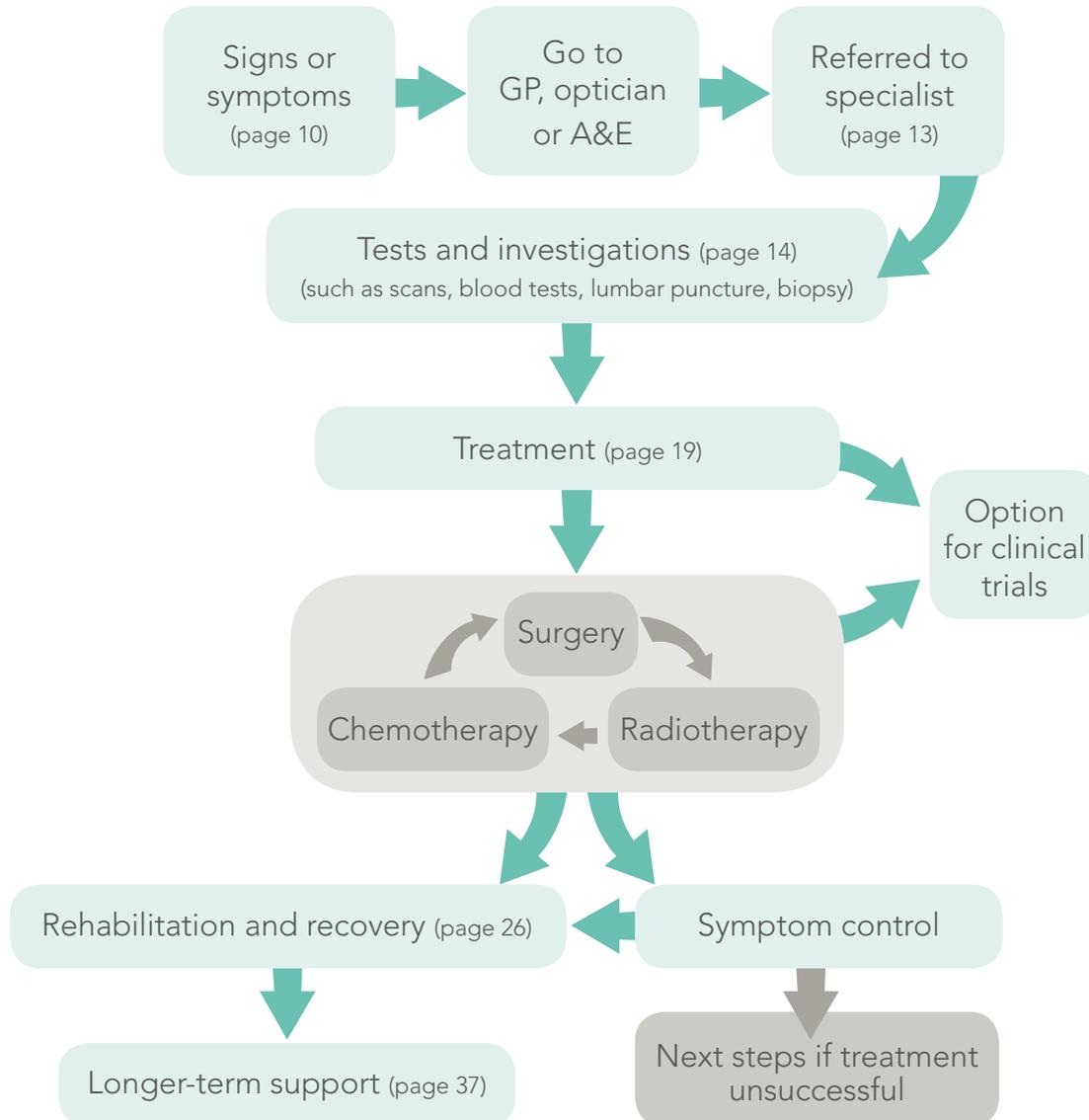
It gives an overview of the conditions, diagnosis, treatment and rehabilitation, as well as how to look after your child, yourself and loved ones. If you would like more detail about anything covered here, please ask your healthcare team.

“You suddenly find yourself in this world where you don't know anything, and there's so much to take in. If I find myself involved in something I'm not too sure about, I want to read up on it. But there wasn't time for any of that, everything moved so fast, so you're there in a sort of passive experience of it. I found it very disorientating and disempowering at first.”

Jane, parent of Amy



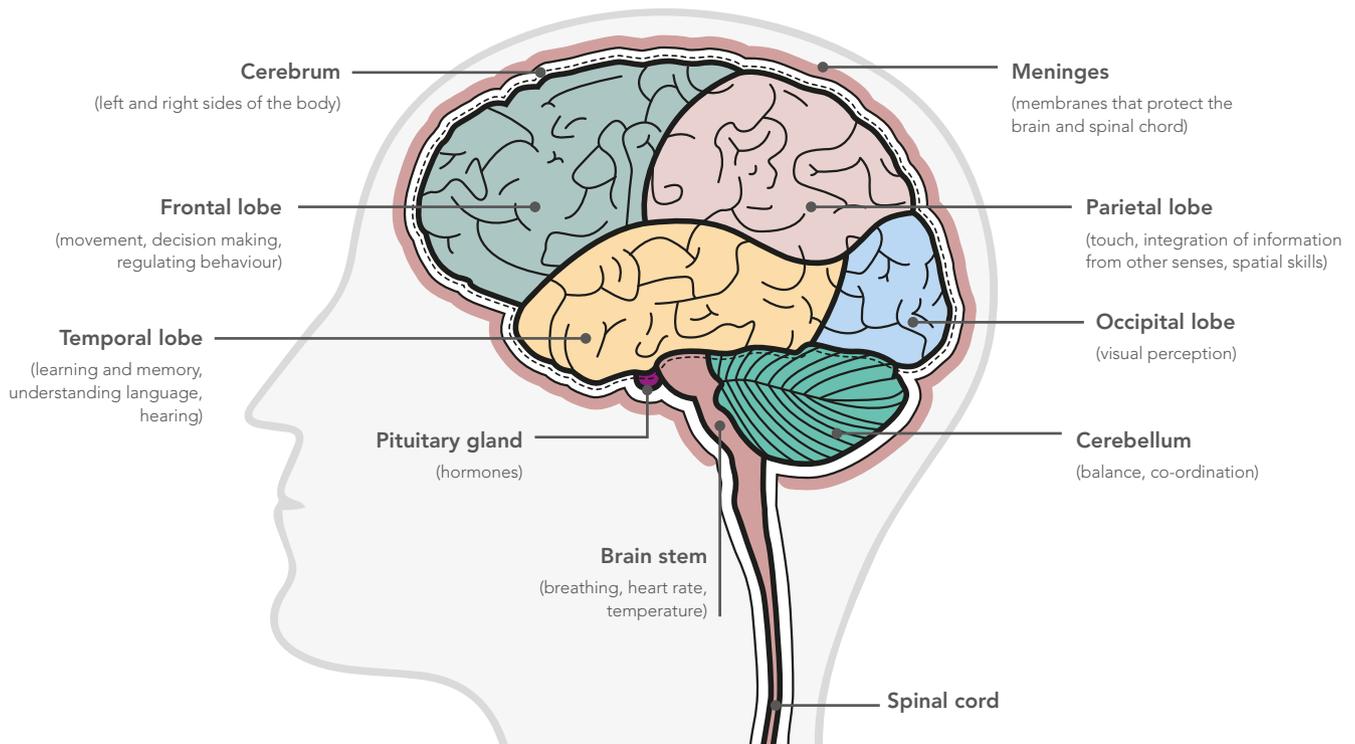
Brain or spinal tumours – your child’s healthcare journey



The brain and spine

The brain and spinal cord are two complex organs that form the central nervous system. They work together to interpret the messages from our senses and tell our bodies how to respond. There are many different parts within the central nervous system: it is important to know which part is affected by the tumour as this can help us to understand some of the symptoms. For example, certain parts control movement whilst others store memories. The main parts of the brain include:

- **Cerebrum** This is the largest part of the brain and is what most people think of when they imagine a brain. It has many wrinkles over its surface. It is responsible for feeling, movements, memories and thinking. The cerebrum is divided into halves (the right and left). Each half is called a hemisphere and can be divided into four different parts called lobes (frontal, temporal, parietal, occipital).
- **Brainstem** This sits at the bottom of the brain and connects the cerebrum to the spinal cord and controls breathing and the heart.
- **Cerebellum** This sits at the back of the brain behind the brain stem and helps with balance and co-ordination.
- **Pituitary gland** This is a gland that sits underneath the brain and releases hormones into the blood that control lots of different parts of the body.



Introducing brain and spinal tumours

When your child is diagnosed with a brain or spinal tumour, you will be overwhelmed with a whole range of new information, while you try to cope emotionally. Parents have told us it can help to have basic information to understand what is happening inside their child's body.

This section explains what we mean by brain and spinal tumours, what we know about their causes, and some of the most common types.

What are brain and spinal tumours?

'Tumour' is a general term for a range of conditions where a group of cells (the tiny building blocks of our bodies) keep multiplying in an uncontrolled way and form a lump or mass.

They can be cancerous (malignant) or non-cancerous (benign). Brain and spinal tumours can be especially complicated because the brain and spinal cord control so many functions of the body and mind – from physical movements to senses such as vision and hearing, memory and emotion. The tumour itself can interfere with these functions, and so can the treatment.

What causes them?

In most cases, we do not know what causes these types of tumour and there is nothing that could have been done to avoid them developing.

People with some genetic conditions may be at higher risk of developing a brain tumour. If this is a possibility for your child, your doctor will discuss this with you. But you can always talk to your healthcare team if you want to know more about this. Brain tumours are rare, so it is very unlikely that another family member will develop one.

“If I saw somebody now with a child in the state my daughter was in, I would want to say to them ‘I know it doesn't feel like this now, and you can't probably see any light but things can not only change, things can transform completely. They can and you have to live in hope they will for you.”

Jane, parent of Amy

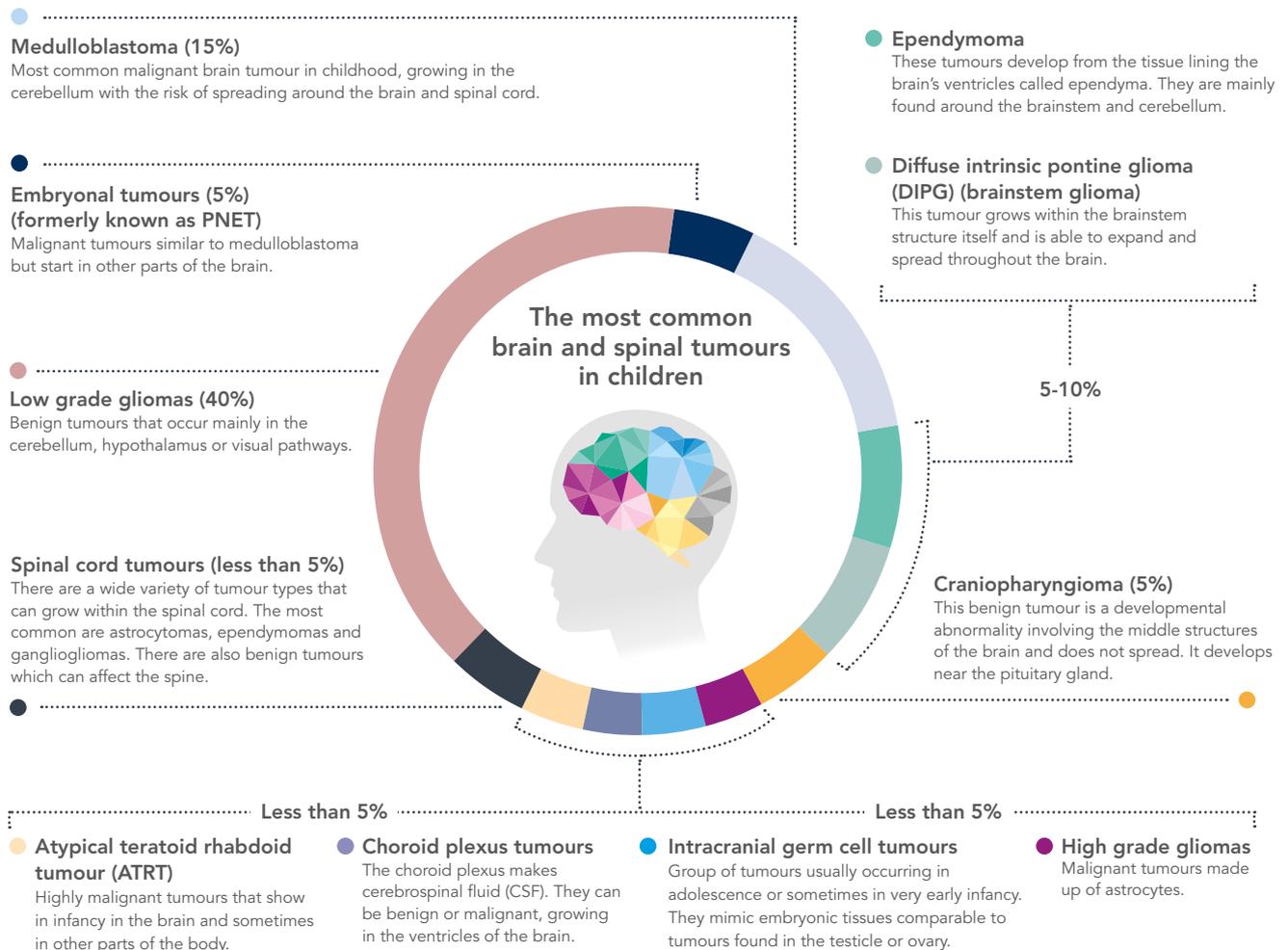


As the brain and spinal cord have so much control over how we function – from walking to talking and organising our thoughts – tumours in these areas can affect a child in many different ways.

Types of tumour

There are many different types of brain and spinal tumour. Some are cancers that can spread beyond the initial area of disease (high grade). In general terms, high grade tumours grow faster and are more likely to spread whereas low grade tumours grow more slowly and are less likely to spread. However, unlike tumours in other areas of the body, even a benign brain tumour can cause significant effects. Many brain tumours, whether cancerous or benign, require radiotherapy or chemotherapy as well as surgery to treat them.

If your child has one of the types of cancer listed below, you can find out more by downloading a free factsheet at www.cclg.org.uk. Doctors and other publications may use different terms. We have used 'glioma', an overarching term for a group of tumours including astrocytoma and oligodendroglioma. You may also hear DIPG referred to as diffuse midline glioma.



My child has a brain or spinal tumour

Signs and symptoms

As the brain and spinal cord control so many functions, there are many different symptoms that might indicate that a child could have a tumour. They may include:

Repeated headaches or being sick

Problems with eye movements or vision, including squint, double vision or visual disturbances

One-sided weakness of legs, arms or face

Clumsiness or poor coordination (including difficulties with balance)

Changes in consciousness

Problems with speech or swallowing

Memory problems

Hormonal changes

Changes in behaviour or character or emotional outbursts

Tremors

Seizures

Symptoms of spinal cord compression, which may indicate a spinal tumour include:

back pain, loss of sensation or disturbance of feeling, problems with bladder or bowel, new limp or leg weakness

The difficulty for parents – and for doctors – is that many of these symptoms, such as headaches or nausea, can seem very general. This can mean that it takes a while for parents to take their child to a doctor, and it may take a while for the symptoms to be recognised as a possible tumour.

Visit www.headsmart.org.uk for more information on symptoms.

“My son has a rare type of tumour that spread around his central nervous system. It’s benign and very slow growing, but it’s been causing blockages and drainage problems in his brain. We feel lucky – not that most people would envy us. That word ‘benign’ really does help. But we don’t want to look too far ahead. We’ll just appreciate what we have while we have it.”

Julie, parent of George



George

Survival

A cancer diagnosis is a serious condition that can be life threatening, but there is much cause for hope. We are finding out more every year about how the brain works and the different types of tumour. The outcomes for children with these conditions are improving all the time.

Statistics are difficult because they cannot tell you what will happen to your individual child. There are many factors which vary from tumour to tumour, stage, extent of resection (surgery to remove the tumour) during surgery and also the biology of the tumour. There are UK statistics for some types of brain tumours in children aged 1 to 14. Survival rates have more than doubled between the 1960s and the early 2000s.

“When it first happens, you feel like all the old happy times have just been obliterated by this bomb that’s dropped on them. But actually you find that you can still be happy even though this terrible thing has happened. You do find moments of humour and moments of happiness. It is possible to still be happy.”

Jane, parent of Amy



Managing family life

Through the coming weeks and months, you and your child will be attending a huge number of meetings and appointments with healthcare professionals. (For details of the team, see page 18).

Try these tips to get the best out of your healthcare:

- Before an appointment, spend a moment noting down any questions you have and what you would like to achieve from the meeting.
- Always bring a pen and notepad to an appointment.
- Check how you can contact the person you are seeing if you have any questions afterwards, and what days you can reach them. You should have a keyworker, and some other team members may provide mobile phone numbers or email addresses.
- Bring plenty of activities and refreshments for your child and yourself in case things are running late.



“I was so weak before this. I used to cry over stupid things, like if I had a blood test coming up. Or if my daughter had a runny nose, I’d react as if she was seriously ill. But when you’re thrown in at the deep end and it’s ‘sink or swim’, then you’ve got to swim. And in this situation, I did swim.”

Debbie, parent of Darcyana



Darcyana

Diagnosis

One of the hardest things about coping with a tumour is adjusting to the unexpected new reality of your situation, so the period of diagnosis can be especially demanding. This section explains the tests and procedures that your child will have. This will tell the team whether your child has a brain or spinal tumour, and if so, what type. We also look at some of the practical steps you can take to cope during this time.

Being referred

The first stage of diagnosis will probably involve you taking your child to the GP or A&E because of some symptom or behaviour you are concerned about. (For symptoms, see page 10). If they feel these symptoms could indicate a tumour, they will refer you on to the brain and spinal tumour team (the neuro-oncology team).

If your child's symptoms are not specific, or have gradually built up over time, it may have taken you a long time to reach this point.

“We went into A&E one night and the following morning she was scanned and they found the tumour – the next day she had surgery. You're suddenly thrown into this world you never knew existed. I'm still trying to get my head round the fact it's happened really.”

Rachel, parent of Phoebe



My child has a brain or spinal tumour

Assessments and scans

The doctor will thoroughly examine your child and take a careful history to assess all the signs and symptoms that may indicate a tumour. Your child will then be scanned in the hospital. Younger children may be given a general anaesthetic to help them lie still. Sometimes, patients have an injection to highlight the tumour on the scan.

The different types of scan:

- **CT scan (computerised tomography)**
This scan uses x-rays to see structures and fluids within the brain. It is best used for looking at swellings, fluid problems or bleeding. The scan can be arranged relatively quickly and the scan may only take a few minutes.
- **MRI scan (magnetic resonance imaging)**
This is the most common scan for diagnosing brain tumours. It uses a strong magnet to create very detailed pictures of the brain and spinal cord. It is painless but very noisy, so your child may be given headphones to wear. It may take up to an hour.
- **Advanced MRI (functional imaging)**
There have been many advances in MRI which can show more information on tumour type, how aggressive it is and whether it is close to important nerves. This can give even more detailed information about the tumour and how to treat it.
- **Positron-emission tomography (PET) scan**
This scan mainly looks at metabolism (or the chemical processes of living cells) through the brain and spinal cord, as well as through the tumour. PET scans are not part of routine clinical practice but are used in some research studies.

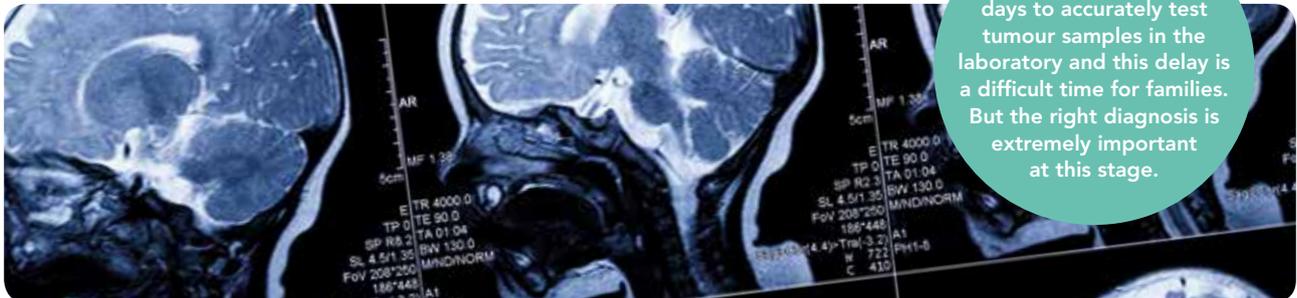
Tests and investigations

Once the team knows where the tumour is and how it is behaving, they often recommend immediate surgery, or they may do some more tests to confirm what type of tumour it is and whether it has spread to the fluid surrounding the brain. These tests will help show what type of tumour your child has and how far it has progressed. This will enable the team to ensure the best form of treatment is offered to your child. The team may also carry out baseline tests to measure your child's progress over time. These include tests on hearing, kidneys, height, weight and heart.

The following tests may be used:

- **Biopsy** If the tumour cannot be removed safely, or if diagnosis is needed before surgery is considered, the team will remove part of the tumour for analysis – known as a biopsy. Sometimes the tumour is biopsied and removed at the same time (see also surgery).
- **Lumbar puncture** This involves inserting a fine needle into the spine to remove some fluid, which can be analysed. This is usually done under general anaesthetic.
- **Blood tests** Blood tests can be used to detect chemicals released by certain tumours. These are known as tumour markers.
- **Eye tests (ophthalmology)** If the tumour is in an area that may affect the eyesight, a full visual examination will take place.
- **Cognitive assessment** Your child may undertake an assessment of intellectual function to check if your child has any difficulties relating to learning now, and to compare against after treatment.

It does take a few days to accurately test tumour samples in the laboratory and this delay is a difficult time for families. But the right diagnosis is extremely important at this stage.



Receiving the diagnosis

If the team tell you that your child does have a tumour, this will be an extremely difficult period for you. You may have very little time for the news to sink in, as your child could begin treatment immediately, and you can experience a lot of changes very quickly.

Try to have someone with you who can give you the support you need. Use this guide to help you think through what you need to put in place – both practical and emotional – to cope during this period.

What will the diagnosis mean for my child?

Physically, tumours affect each child in a different way. Some have a short period of illness and a near-full recovery. Others are left with lasting effects, especially if part of the brain is damaged. It is a sad fact that some children do not survive, but an increasing number of brain and spinal tumours are being cured. As research continues we are finding out more all the time, so there is cause for optimism.

Your doctor will talk to you about your child's possible prognosis (outcome). However, it is important to realise even prognosis is an average 'best guess'. It is different for each child.

“Some parents prefer to say their child has a ‘brain tumour’ than ‘brain cancer’ because they feel it’s safer. Then at some point it kind of dawns on you ‘No, my child has cancer’.”

Cate, parent of Edie

“I remember sitting with the consultant and saying ‘Is she going to die?’ and he said ‘I don’t know – I can’t tell you that for at least a week’. I was like ‘Just tell me she’s not going to die,’ and crying and crying and crying. It’s got easier now because she’s in a lot less critical stage in her journey, but that was hard.”

Debbie, parent of Darciana

Sources of information and support

If you need someone to talk to, turn to page 43 for details of confidential helplines offering telephone or email support.





Talking to your child

Take your time to think about how to explain the situation to your child. Children often see things differently to adults, as they live more in the moment, so a few simple facts may be enough. How much information you offer will depend on your child's age and maturity, and what questions they have been asking.

You will have your own way of communicating with your child. Some parents find it helpful to answer any questions as they arise, giving one piece of information at a time. You can help your child by focusing on the positives and encouraging them to take life one day at a time.

The Brain Tumour Charity has a range of online animation films entitled **'Meet Jake, Charlie and Lily'** to help explain brain tumours and their treatment to children (www.thebraintumourcharity.org.uk)

CLIC Sargent publishes a storybook for young children **'Mary has a brain tumour'** (www.clicsargent.org.uk).

If you are worried about what to say, or concerned about your child's emotional wellbeing, talk to your healthcare team.

Sharing the diagnosis with others

You will also need to tell other people, including family, close friends, school and your work. You might like to tell people yourself, and might even find it therapeutic to talk through what is happening. If not, you could ask a friend or family member to act as a point of contact or post updates on social media. Those involved in your child's care may be able to provide further information and help you to communicate with teachers and children at your child's school. Your keyworker or nurse specialist may also support you by contacting your employer and school.

“ My in-laws were great. They came over a lot and lived with us for a bit, picked the kids up from school and things. On days when they couldn't, or when they needed a break, there was a big network of friends who would step in. I was kind of a bit cut off from it. People just arranged all this for me, really.”

Jane, parent of Amy

“ Some people set up a Facebook page with updates. I'm on Facebook but I don't share my son's journey there. If I want to pass a message to family and friends, I'll cut and paste it into emails. Then my side of the family will pass it on like that.”

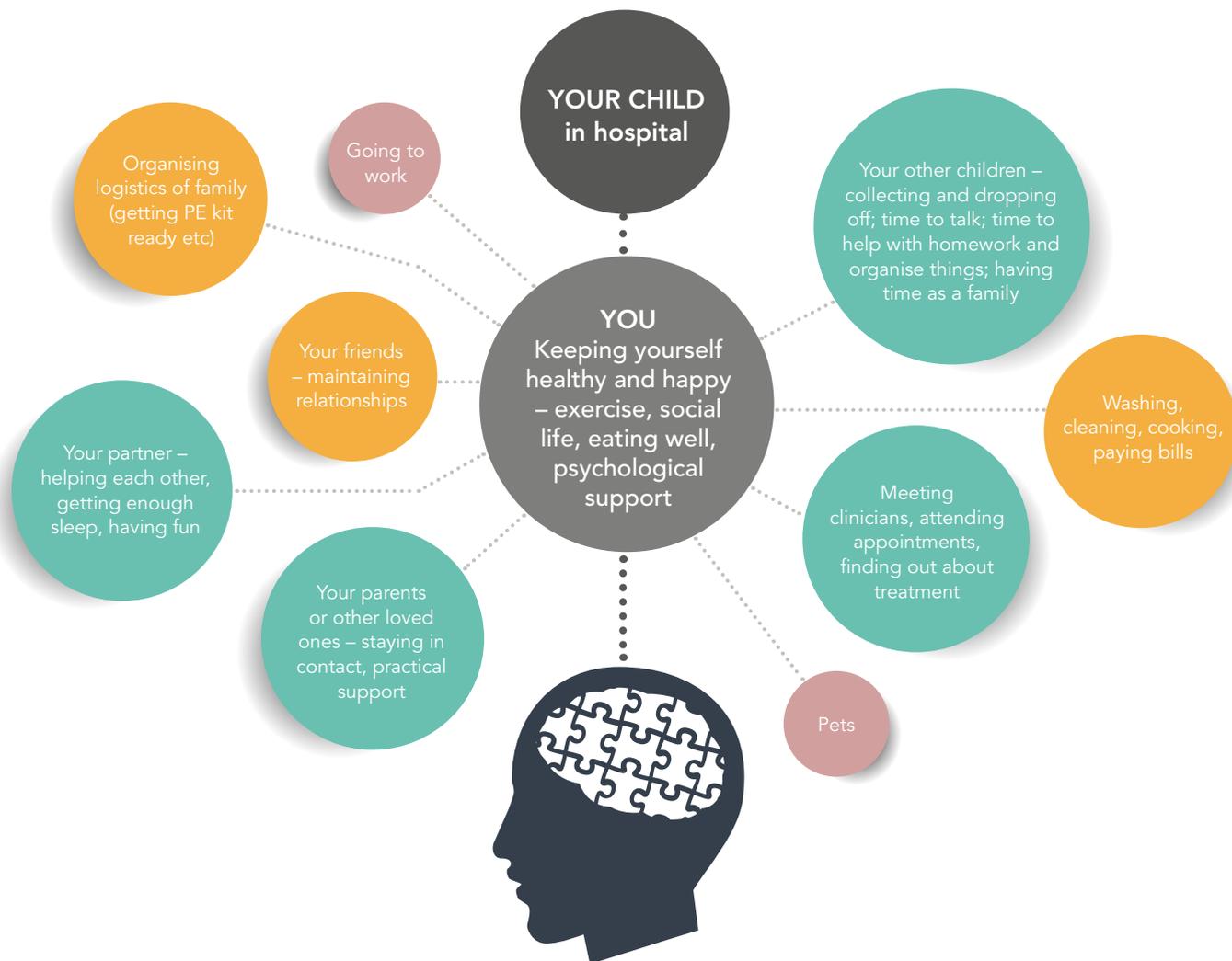
Julie, parent of George

“ My two year old knows she's got a thing called Timmy tumour in her head and he makes her poorly, so she goes to hospital for chemo, which is magic medicine. Now when they put a needle in the port she actually helps them. She cleans it for them and passes it to them. I feel she deals with it a lot easier because she's aware something is making her poorly and she has to have medicine, rather than not knowing what they're going to do.”

Debbie, parent of Darcyna

Managing family life at diagnosis

As your child starts undergoing investigations, it may feel that life is put on hold. Depending on how long your child is in hospital, you may need to rely on friends, neighbours and families to keep everything going at home. As the shock of diagnosis wears off and treatment begins, start to think carefully about the different responsibilities in your life and what you need. Use the diagram below to help you plan what you need to put in place. In the diagram, you are at the centre, right under your child. This is because although your child's needs are – rightly – at the top of everyone's agendas, it's very important your own needs are met too so that you can cope throughout this challenging time. We talk more about this in 'Looking after yourself', page 31.





Amy and her family

“When someone says they’re in hospital with somebody, you imagine them sitting in a chair by the bed, don’t you? But most paediatric units have a system of self-caring where as much as possible they get the parent to take over the care of their child to learn what to do. It’s right I think, and most parents want to do that, but I was exhausted. I was doing her tube feeds and everything – so basically I was a very active carer in hospital.”

Jane, parent of Amy

Getting the support you need

Your child’s cancer team will be familiar with some of the difficulties you might face and how these may affect you and your family. They can help and support you throughout your child’s illness. You should be given a key worker or main person who you can contact with any questions. Ask for their phone number and email address. Don’t forget, there are also helplines and support outside the hospital (see page 43).

Treatment

The start of cancer treatment can feel like a whirlwind. Suddenly, you are thrown into the world of cancer care, with unfamiliar language and treatments. This section explains who will look after your child, the main types of treatment (surgery, chemotherapy and radiotherapy), clinical trials and some of the practicalities you need to think about.

Your child's health and care team

Your child will be looked after by a team of professionals (known as a multidisciplinary team or MDT) who will work together to help with your child's physical and psychological recovery. Each person has their own role, but they work closely together to plan how to meet the needs of your child and your family. Who is in this team will depend on where your child is treated and what your child needs, but it will include some of the people described in the box below.

Who's who in my child's care?

Consultants are the lead doctors in your child's care. These include oncologists (**paediatric oncologists** who are responsible for leading your child's care and supervision of chemotherapy and **clinical oncologists** who are radiotherapy specialists), **neurosurgeons** (brain surgeons), **neuropathologists** (who make the diagnosis from the biopsy) and other specialists such as **ophthalmologists** (eye doctors), **endocrinologists** (hormone doctors), **radiologists** (experts in reading x-rays and more complex scans) and **anaesthetists**.

Other doctors work under the supervision of the consultant.

Dietitians provide advice and support to meet your child's nutritional needs during treatment and recovery.

Nurses may include clinical nurse specialists, Macmillan nurses and CLIC Sargent nurses. Hospital care and ongoing care at home are provided by two separate nursing teams. You should have a key worker who acts as a link between all the different teams involved in your child's care.

Play therapists help make sure children's emotional and physical needs are met through play and prepare them for unfamiliar procedures, such as lying still for radiotherapy.

Diagnostic radiographers take x-rays and scans.

Therapeutic radiographers are in charge of the radiotherapy. Many radiotherapy centres have specialist **paediatric radiographers** who help in the radiotherapy department and work closely with clinical oncologists.

Physiotherapists work with your child to restore any movement and function affected by the brain tumour or its treatment.

Occupational therapists support children to take part in everyday life activities and enable them to regain their independence.

Clinical psychologists and **neuropsychologists** identify difficulties with learning and emotional or behavioural issues and provide support.

Social workers provide you and your child with practical, emotional and financial support throughout your child's treatment and rehabilitation.

Speech and language therapists help with any speech, language and communication difficulty as well as problems with swallowing or eating and drinking.

My child has a brain or spinal tumour

Treatments available

After a definite diagnosis has been made, your doctor will discuss with you which treatment is best for your child. It is likely to involve one or more of the following:

- **Surgery**
- **Radiotherapy**
- **Chemotherapy**

Each of these is described below.

Surgery

The neurosurgical team will often be the first set of doctors that you meet, especially if your child is quite unwell when the tumour is identified. They will discuss surgery and other potential treatments with the rest of the MDT. Your child may receive surgery:

- **To diagnose the tumour** - Modern scans give us lots of information about a brain tumour but we can still not be sure about exactly what type of tumour it is and how quickly it is growing until at least some of it is removed and studied by the neuropathology team. Getting good quality tumour samples, either as a biopsy operation or as part of a bigger operation to remove the tumour, is a very important part of surgery. Detailed scans are usually used now as a form of 'sat-nav' during the operation and this is known as 'image-guidance' or image-guided surgery.
- **To remove the tumour** - Surgery is sometimes used to physically remove the tumour. In some cases, completely removing the tumour if that is safely possible greatly improves the chances of survival. Surgery may even be the only treatment that is needed for certain tumours. In other cases, leaving some of the tumour behind and using other treatments for this may be better to reduce potential damage from an operation. Your child's surgeon will be able to tell you afterwards how much of the tumour they have removed and will usually do a scan after surgery within a day or two to confirm this as part of making post-operative plans.
- **To relieve pressure related to excess fluid in the brain** - Some tumours can block the normal flow of fluid around the brain. If this results in a build-up of fluid in the brain it can increase pressure in the head which causes headaches and drowsiness. This is called hydrocephalus. This may need to be relieved by inserting a plastic shunt tube usually down to the abdominal cavity, or having a procedure called a third ventriculostomy, which creates a new internal channel in the brain through which the fluid can drain away.

What are the risks and side effects?

The challenge for brain surgery is to remove as much tumour as safely as possible but avoid damaging important parts of the brain or nerves that could affect the way a child functions in the longer term. Brain surgery can also cause temporary effects that will settle over days to weeks especially if there is bruising after the operation or swelling of the surrounding areas of the brain. Hydrocephalus (build up of brain fluid) can sometimes develop after surgery, even if it was not there before and so can seizures or 'fits'. However, many children will get over their surgery surprisingly quickly and will be up and about within a few days.

Posterior fossa syndrome (PFS) is a name given to a collection of symptoms which may occur together following surgery to the back of the brain. For further information, please read the CCLG factsheet entitled '**Posterior fossa syndrome: Information for parents of a child with PFS**'.

“While they are in surgery, the wait feels like the longest day of your life. We ventured out to Starbucks, which is right next to the hospital, because if you're sat on a corridor sort of waiting for eight hours it would drive you crazy. Obviously they've got your details if they need to call you. There were moments where it was awful then there were moments where we were just laughing and chatting about the stupidest of things because you have to lighten the tone a bit at some point just to survive.”

Rachel, parent of Phoebe



“Surgery was a success, they removed all of the tumour, and the following week they told us that she was eligible for proton therapy and we would in fact be moving to Florida for ten weeks.”

Cate, parent of Edie

Radiotherapy

Radiotherapy is a treatment that uses high-energy radiation to treat tumours. Treatment is like 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 chemotherapy.

It is important for children to keep very still during treatments. The team will make a special mask to keep their head still. 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 clinical 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 a number of types of radiotherapy. X-rays are most commonly used, often using a special technique known as IMRT (intensity modulated radiotherapy). This enables very accurate sculpting of the dose around the tumour while minimising the dose to the surrounding organs.

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 yet available in the UK, but the NHS funds the Proton Overseas Programme for certain types of tumour that are most likely to benefit from this option. Your doctor 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 delays in radiotherapy. Ask your doctor if you'd like to find out more.

What are the risks and side effects?

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, these can include tiredness, nausea and loss of appetite and skin soreness. These get worse towards the end of the treatment course, and often peak a few weeks after treatment ends, before fading away. The radiographers will give advice about what to expect and will answer any queries that arise during radiotherapy. Your child will also be reviewed by their clinical oncologist on a regular basis during radiotherapy. Generally, children tolerate radiotherapy very well in the short term and you may be encouraged to send your child to school during radiotherapy to maintain some normality if they are well enough.

“The first couple of radiotherapy sessions were hard because you can't stay in the room. But we all got into a routine of it and it just became a fun, social thing. My daughter had a sticker chart and she got a sticker for every time, so she could see how she was working through the 31 sessions. It didn't particularly make her feel poorly or anything, so she would go to radiotherapy and then go off to school and be fine really.”

Rachel, parent of Phoebe



Phoebe undergoing radiotherapy

My child has a brain or spinal tumour

While radiotherapy is a very effective part of treatment, it can result in permanent side effects. These depend on the amount and location of the treatment and the age of the child. Younger children are more sensitive to the long term effects of radiotherapy and the greater the volume of tissue exposed to radiotherapy (such as the whole of the brain and spine), the side effects can be more severe.

Long term side effects can affect your child's growth and may cause an increase in the risk of developing new tumours later in life. Side effects of brain radiotherapy include the potential to affect learning and hormone deficiencies (which can be treated very effectively).

Modern radiotherapy treatments are designed to limit the side effects as far as possible while maximising control of the tumour. Hair loss can also happen and this is usually temporary. However, in a few cases, it may unfortunately be permanent and the hair may not grow back or may be patchy and wispy. If this happens, your child's team will help and support you and advise on the options available such as wigs and headscarves.

It's important that you talk with your doctor about these side effects and how they may affect your individual child, as they can be very variable.

Chemotherapy

This treatment uses drugs (called cytotoxic drugs) that interfere with the cells' ability to divide and reproduce. It affects all dividing cells, including some normal cells – but while normal cells can repair the damage, cancer cells cannot. So, they become damaged and eventually die.

Chemotherapy can be given as a medicine, a tablet, into a vein (usually through a drip), or as a spinal injection. Because the drugs are absorbed into the blood (except for the spinal injections, which are absorbed into the brain and spinal cord), they are carried around the body so they can reach all the cancer cells. This makes chemotherapy particularly useful when cancers have spread to different areas of the body.

Each person's chemotherapy treatment is different. It can be given intensively in high doses over a relatively short period, or in lower doses over a longer period. Each dose destroys some of the cancer cells along with some normal cells and tissues. After each dose there is usually a rest period so that your child's normal cells can recover before the next dose.



Darcyana with her family

“We get up at 7 o'clock on a Friday morning and get to the hospital at 10. We get to the ward and they take my daughter's blood counts, which takes an hour or two. If they are ok, we are sent away for two hours while they prepare the medication. Then she'll have the chemo, which takes about two minutes, and we'll come home. The next day she'll be groggy, moody and constipated. On Sunday she won't have much appetite and she'll sleep for 12-18 hours. By Monday she has a bit more energy. By Tuesday she's fine and starts eating again and we get on with physio and things. Then on Friday it's back to hospital.”

Debbie, parent of Darcyana

What are the risks and side effects?

Some chemotherapy drugs cause unpleasant short-term side effects, such as hair loss, feeling sick or being sick. These are usually temporary, and there are effective ways of making these as manageable as possible. But some treatments can have longer term effects. These may include effects on fertility and the function of the heart. These are not always obvious at the time, so your child will have follow-up appointments to check for these after treatment has finished.

Chemotherapy side effects are most likely to affect areas of the body where normal cells rapidly divide and grow, such as the mouth, digestive system, skin, hair, and bone marrow.

Targeted chemotherapy

Slow-release drug delivery devices can be used to release chemotherapy drugs at affected areas over days or weeks. Once the tumour has been removed, these jelly-like wafers containing the drug can be inserted into the place where the tumour started. A similar approach being trialled involves surgically placing a tube close to the tumour and infusing chemotherapy directly into it.

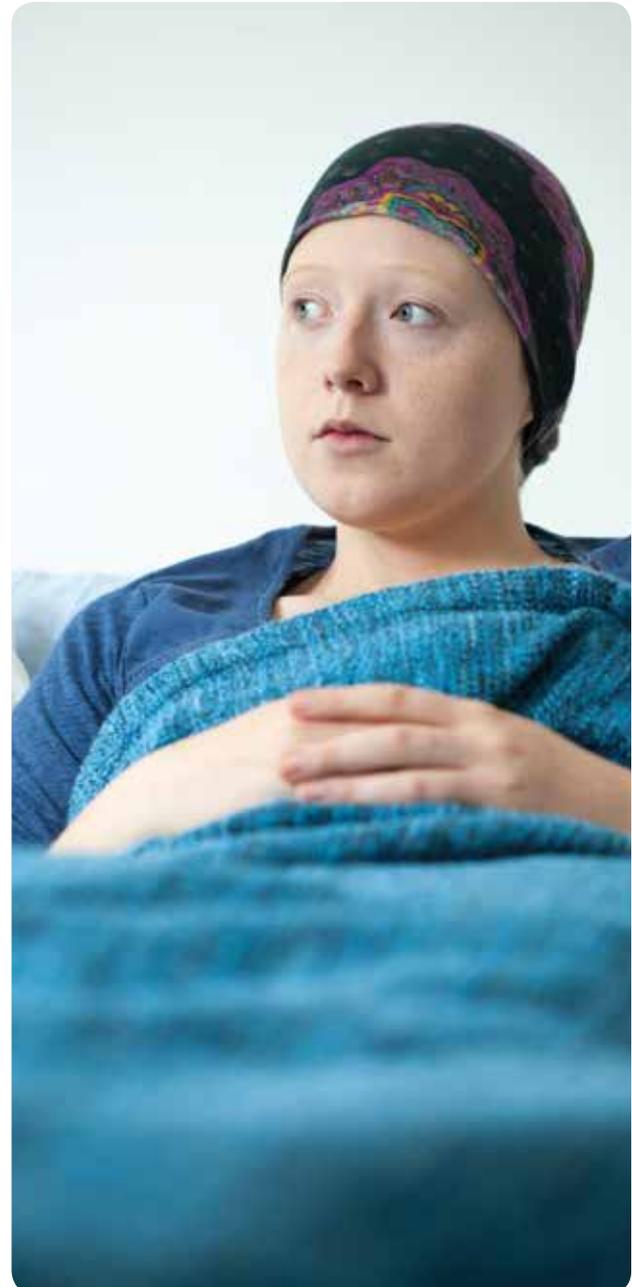
What about clinical trials?

Every cancer treatment in current use began its life in a clinical trial, and new treatments are being developed all the time. Your child may be able to access either new treatments, new combinations of existing treatments, or new ways of using existing treatments, by taking part in a trial. Only drugs that have been successfully tested on adults are tested on children. If you are interested in your child taking part in a trial, talk to your doctor. Your child will be monitored very carefully and will have the opportunity to try groundbreaking treatments while helping research find the cancer cures of the future.

Participants need to be selected at random to ensure that the results of the trial are not accidentally biased. So if you do apply, there is no guarantee that your child will be selected. Ask your team if you would like to know more.

“There are times when you think ‘It’s not fair!’ but we try and look on the positive things of what this journey has given us.”

Julie, parent of George





Having a tumour, and the associated treatment, uses up a lot of the body's energy. It is important your child gets a well-balanced diet so they are best able to respond to treatment, tolerate chemotherapy, fight infection and repair damaged cells from either radiotherapy or surgery. If your child cannot eat or drink, they may be given special high-calorie drinks and milkshakes or tube fed if necessary. Your child's medical team will include a specialist paediatric dietitian who will be able to provide free, personalised nutrition and diet plans for your child.

Managing family life during treatment

Once your child starts treatment, the period of change you experienced during diagnosis becomes a more long-term situation. You may be spending a lot of time in the hospital, so you will need to think about who will manage the rest of family life while you are focusing on your child.

If you are working, you will need to discuss this with your employers. You may be eligible for some financial or practical support during this time. Talk to your hospital CLIC Sargent social worker or contact their welfare advice line to find out about employment rights and benefits. You may be entitled to free transport and carers' benefits.

Think also about what you will need to cope emotionally. If your child has cancer, you will need to look after yourself so that you can cope – not just in the coming days and weeks, but perhaps in the months and years ahead too.

Little pockets of time on your own or with a close friend or partner may help you stay strong for your child.

- Ask relatives such as grandparents or teenage family members to stay for a while to help with the running of the household.
- Ask one friend if they can coordinate a rota among other friends and neighbours so you get the help you need.
- If you have a partner, discuss your schedules in detail and see how you can spread the load.
- Make time for yourself to have some support – if you don't want to leave the hospital, ask a friend to pop over for quick coffee in the hospital cafe.



“It’s a long ride – a marathon, not a sprint – and you don’t need all your help at once. To begin with, we had loads of people offering help and I’d say ‘No, no we’re fine, honestly we’ve got too much help.’ What I should have said was ‘Come back in a month, come back in two months.’ Because when I really need help is on a wet, rainy Tuesday when I’ve got to get my son from school but my daughter’s unwell at home.”

Cate, parent of Edie

“It’s funny because, actually, I think my daughter will look back and have quite fond memories of her time in treatment. She really connected with some of the radiotherapists and it was fun to go there every morning. The play therapists have been brilliant at taking fear of the unknown out of different procedures. That was definitely really helpful.”

Rachel, parent of Phoebe

Moving on

The end of cancer treatment feels like an important milestone, and rightly so. But while it is the end of one journey, it is the start of another one: recovery.

Once your child goes home, life may feel more normal but your child will still need care, and you will need to cope without the safety net of the hospital team.

In this section we talk about ongoing support, rehabilitation, going back to school and timescales for recovery.

“It would have helped me for somebody to have said ‘Don’t think it’s all over once you get home’. Leaving hospital, we were so euphoric, but we got home and that was almost my hardest part of the year because it was much more difficult than I anticipated. My daughter was still quite unwell, on a lot of medication, still being tube fed, so we were responsible for all this stuff that in hospital the nurses are responsible for. I would encourage other families to plan something lovely and exciting for three months after you’ve left hospital, rather than immediately.”

Rachel, parent of Phoebe



Edie

What if my child’s treatment is not successful?

If your child’s treatment was not successful, there are lots of things that can be done. Your doctor will talk to you about alternative trials and treatments. If the team believe your child may not survive, it is very important you receive the right kind of support. The team will discuss with you the options available, and will refer you to receive support where you feel most comfortable, whether in hospital, a hospice or at home.

“My daughter’s cancer is life limiting. We don’t know how long that is, but clearly something related to all this is going to get her in the end. Her prognosis is poor as she has incurable cancer. Now that means today it is incurable – whether it will be in three years’ time, I don’t know.”

Cate, parent of Edie

If your child’s treatment was not successful, you may find some of the information in this section is not relevant for you. Further information resources will be given to you at this point by your child’s team.

Ongoing support

The hospital team will start preparing for your child's discharge home as soon as your child is admitted, as it can take some time to arrange the right support. They will involve you in your child's care so that you learn to meet their needs. The medical and nursing team will work closely with the other professionals (see 'Who's who?', page 19) to assess what support your child needs, both in the short and longer term.

Your child may need ongoing support in one or more of these areas:

- **Medical** If your child is having ongoing treatment, you will receive information on how to care for your child at home, including what to do if your child becomes unwell. The community nursing team will help you with this once your child is discharged. If your child has complex nursing needs that are too much for you to manage, your child may continue ongoing nursing support.
- **Physical** If your child is having physical difficulties, they will be assessed to check how they will cope at home with things like going to the toilet and getting into bed, and the occupational therapy team will order in equipment if it's needed.
- **Psychological and practical** Before your child is discharged from hospital, it's important that you have some emotional and practical support in place so that you don't spend any time unsupported. Some of this help may come from professionals such as outreach nurses, social workers, clinical psychologists and support groups, while family, friends and voluntary agencies may also be able to help you.

“My son sees a physio and has hydrotherapy at hospital. He has orthotics on his splints. Then we see a psychologist to help with his eating, an occupational therapist and a social worker. Then if his levels are low, we have to nip up to hospital mid-week and top up with platelets or haemoglobin. We have huge amounts of appointments, really.”

Julie, parent of George

If your child has ongoing complex needs, it may be useful to be referred to a community paediatrician to oversee their ongoing needs, once their appointments with the hospital team become less frequent. Find out more from your GP.

Rehabilitation

Rehabilitation is the process of regaining and maintaining skills and abilities. The team will already have started working on your child's rehabilitation when they were diagnosed, and this process will continue throughout the treatment and ongoing recovery.

Once your child goes home, their rehabilitation care will be transferred from the hospital team to a community team. Therapists such as physiotherapists, speech and language therapists, play therapists and clinical psychologists will continue to work with your child – either at home or in a local clinic – to help them regain and maintain their skills and abilities.

Therapy with your child

You may need to practice rehabilitation exercises with your child yourself at home. This can be challenging and frustrating at first but the most effective rehabilitation incorporates therapeutic activities or exercises into everyday tasks. This gives your child more opportunities to practice and can be made fun by using games and activities that your child really enjoys. It also helps to get into a routine so that it becomes something you automatically do at certain times of the day.

Your child's therapist will be able to give advice and ideas about how to do this.

Try to be encouraging and positive about the efforts your child makes during therapy. Focus on raising the level of effort rather than the level of achievement, as this may vary depending on their health.

Recovery does not always progress smoothly. At some times, your child may seem to be making extremely encouraging progress, but at others, things may seem to hit a standstill.

During intensive periods of treatment, a child may even seem to regress. This can be very frustrating for both you and your child. It's important to keep going with rehabilitation during these times, to get things back on track as quickly as possible.

My child has a brain or spinal tumour

Your child's community therapy sessions will be less frequent than the sessions they had in the hospital. If you feel that your child has needs that are not being met, discuss this with your keyworker or consultant.

“I found getting my daughter the care and equipment she needed was a real struggle actually, a bit of a fight... I think it's made me quite combative and a bit aggressive sometimes. That's probably not a good thing, but it was necessary and I did get what I wanted in the end.”

Julie, parent of Amy

Going back to school

Going back to school can feel like an important step in getting life back to normal. Your child may breeze through the experience, but depending on their type of tumour and treatment, it may still need careful planning.

If their tumour has affected parts of the brain, they may have developed some difficulties relating to learning, concentration, coordination and fatigue. A cognitive assessment conducted by the clinical psychologist or neuropsychologist can help to identify any specific learning issues and if additional support is likely to be required. Your child may also find school difficult for emotional reasons – they will have been through a lot in the preceding weeks and months, and life may have changed in many ways for them.

Even just being outside of school for a while can affect friendships and confidence. Your child's abilities, appearance or mood may have changed during their illness, and they may feel self-conscious about appearing different from others, or different in some way to before. Going back to school is important for social reasons as children can stay with their friends in a normal school routine.

While in hospital

Your child may have attended the hospital school while staying on the ward depending on their treatment and length of stay

as an in-patient. The hospital school will support them to keep up with their school work as much as possible and can play an important part of your child's rehabilitation. The teachers will keep in close contact with your child's usual school to stay in step with the rest of your child's class. Your child may even be able to sit exams at the hospital school if it is a registered exam centre.



“In some ways when my daughter went back to school she'd become a bit of a celebrity. It's been a very slow, phased return, building the time back up. She's still tired from treatment even all these months afterwards. She still has naps quite often and gets tired more easily than the average six year old.”

Rachel, parent of Phoebe

Getting support in school

Every school has a special educational needs coordinator (SENCO) who is responsible for making sure that every child's needs are met. It's a good idea to involve school in any multidisciplinary team meetings as early as possible, so that they can start to plan to meet your child's needs. Your specialist/ outreach nurse or clinical psychologist should be involved in the planning and your child may be visited at school by community therapists – for example, in occupational therapy or speech and language.

If you and your school work closely together, there is much you can do to encourage your child to feel positive about themselves, reconnect with their friends, and find ways to adapt learning to meet their needs.

Some schools are better at adjusting to children's individual needs than others. If you feel your child is not getting the support and understanding you need, talk to your keyworker or nurse specialist. Part of their role is to help your child integrate back into school and they can help facilitate discussions between yourself and the school.

Your child may receive an education, health and care (EHC) plan which looks at all your child's needs across education, health and

social care to make sure your child receives the right amount of support. An assessment will need to be requested by the school, hospital or parents and is carried out by the local authority.

Whether or not your child has an EHC plan, their progress and level of support should be regularly reviewed.

- The Child Brain Injury Trust offers comprehensive training for teachers, SENCOs and teaching assistants (www.childbraininjurytrust.org.uk)
- Returning to School: A teacher's guide for pupils with brain tumours, during and after treatment. Produced by The Royal Marsden and Cerebra (2015).
- Welcome Back! A guide for teachers helping children and young people returning to school after a diagnosis of cancer. Produced by CCLG (2015).
- Cancer and school life pack. Produced by CLIC Sargent, (2014).
- Education resources for returning to school and college. Produced by The Brain Tumour Charity (2016).



My child has a brain or spinal tumour

Timescales for recovery

All parents want to know how long recovery will take, but unfortunately this is the one thing the team cannot answer for you. They can make an educated guess based on other children with similar conditions. However, circumstances are so different for each child that it is impossible to know how long it will take to regain a skill, or whether some changes may be permanent. Progress also depends on some things that you can't measure, including determination, resilience and self esteem, the level of support available, and individual health and abilities.

This can be very difficult to bear. Many parents cope by not looking too far ahead and taking things one day at a time.

“I would recommend having really low expectations for recovery time. My daughter is several months down the line, and we still live with the consequences of that treatment in terms of her energy levels and her physical frailty. So I think it's important to set parents' expectations.”

Rachel, parent of Phoebe



Managing family life after treatment

Once your child moves home and back into family life, try to avoid having fixed expectations about how things are going to be. This will inevitably be a period of adjustment for all of you. Try to be realistic about how much care your child will need, who will provide it, and whether you will need extra help. Talk to your child about what they would like help with. For example, if they are feeling isolated, your focus might be on inviting friends round. If they are worried about returning to hobbies or regaining skills, you might prioritise that instead. In the meantime, make sure that you have all the benefits, equipment and support you need.

Who can help?

Before your child leaves hospital, ask your specialist nurse or CLIC Sargent social worker for details of support groups and any other agencies that can help. See page 43 for details of charities that can help too.

- If you are caring at home a lot, ask a friend or relative to come over sometimes so you have chance to get out.
- If you are concerned your child seems anxious or low, contact your community team, consultant or GP.
- If you feel you are not getting the support you need from the medical team or at school, do raise your concerns. Bring someone with you to meetings if you find them difficult.
- Try to take each step at a time and remember that just because progress is patchy does not mean things are not improving overall.

“There are things I cared about before that I don't care about any more: what people think about the state of my house or what I'm doing. You've got to live your life. You're grateful you've still got your child and you've come through it. You don't waste time anymore on things that don't matter.”

Jane, parent of Amy

Looking after yourself

Most of this guide focuses on your child's health. But this section is all about looking after your own health and wellbeing. This is as important, as you need to be strong and healthy to cope with the challenges that you are facing during this time.

“I think this is something parents can feel quite guilty about, because obviously everything focuses on your child, and that's all you care about as well. Quite rightly, all the medical professionals care about is getting your child sorted out – and that's the priority for absolutely everybody. But on the sidelines you've got a couple of adults whose lives have imploded, and they are a secondary issue. You are secondary to everything.”

Jane, parent of Amy

“I've written a journal since the day we were rushed into hospital. I don't write it every day, but like this morning I thought 'I'm going to type a little thing,' because it was all in my head. Putting it on paper gets it out, so it's not boiling up in my head. It screws your brain up trying to hold too much in your head, so finding an outlet for how you're feeling is always a really good thing.”

Julie, parent of George



Managing your feelings

It is natural to feel a range of different feelings at different times through your child's journey – from anger or fear to despair. Of course, there will also be times of hope, relief and joy. But it is important to find some way of managing these more difficult feelings.

Some parents find these things helpful:

- Meet up with friends or family who you can talk to openly
- Write a diary or journal
- Talk to other parents going through similar things
- Find an activity or hobby, such as walking, playing an instrument, running or yoga that allows time to reflect or simply relax and focus on something else.

Try to limit the time you talk about your child's illness with your partner or loved ones to, say, a certain time each evening. This will make sure you still have time to talk about things such as your other children, holiday plans or simply to offload about a stressful day at work.

Anxiety and depression

It is normal to feel emotional when your child has a serious illness. But if your emotions are so overwhelming that you are finding it hard to carry on, you may benefit from some help from your healthcare team. The two most common mental health issues are anxiety and low mood or depression.

Both of these conditions are extremely common and most parents will experience some of these symptoms as a normal reaction to difficult circumstances. However, if they do not subside, or you experience other ongoing symptoms such as nightmares or flashbacks, speak to your GP or healthcare team.

Symptoms of anxiety include a constant sense of worry or fear, sometimes with panic attacks

Symptoms of low mood or depression include lack of motivation, feelings of hopelessness and difficulty sleeping or concentrating.

Options available to you could include:

- **Psychological therapy** a talking therapy available on the NHS or privately. Options include psychotherapy, counselling, or cognitive behavioural therapy (CBT) – a short-term talking therapy that helps you recognise thought patterns and break unhelpful habits. Many people benefit from the time and space to process difficult feelings. Talk to your GP or find a therapist at www.counselling.org.uk.
- **Mindfulness** a way of training the brain by focusing on the present and learning to let go of persistent thoughts, available in classes, or books or courses (see below).
- **Medication** a range of medication can help in the short term – for example, anti-depressants can help with depression and anxiety while drugs such as beta-blockers can help reduce high levels of stress.

Talk to your keyworker about mindfulness and relaxation services being run in your local area. You may also want to check out the Mental Health Foundation's free mindfulness course at bemindful.org.uk

Some people find **complementary therapies** such as massage or reflexology relaxing. Some organisations offer these services free of charge to people caring for others with cancer. Your child's hospital may also have more information.

To find out more about these conditions, go to
www.nhs.uk/conditions/stress-anxiety-depression/pages/low-mood-and-depression.aspx

“My husband had to go back to work and I don’t know how he managed that, frankly. I couldn’t have, but he had to. He was fantastic – a very hands-on dad who did his bit in hospital. He was great. I think he felt more of a pressure to hold everything together, whereas I perhaps felt there were times when I felt I could go to bits. He said it actually helped in him the end, because being busy gave him a little respite from thinking about our daughter. He was very calm on the outside and very strong. But he went grey pretty much overnight.”

Jane, parent of Amy



Your relationships with others

An important part of looking after yourself involves maintaining your relationships with other people, including friends, family and partner. You may not feel like seeing people during difficult times in your child’s journey, but the important people in your life can make a big difference so try not to become cut off.

Your partner or spouse

Date nights might not be top of your list when your child becomes ill. But if you have a partner, it’s important to invest some energy into maintaining your relationship. Having a child who is unwell or undergoing difficult treatment can be very challenging, and the worry and stress can put a huge strain on a relationship.

Taking a little time out for yourselves as a couple is not a luxury: it’s an important investment in your whole family. When you are strong as a couple, the atmosphere is happier and everyone in the family benefits.

“We had so little time together, we had to grab little snippets of time where we could. Once a week we had a friend stay at the hospital with Phoebe so that we had one night a week at home together. Sometimes you’d feel torn and think ‘Should I stay?’ but we always made a stand we would have that one night to keep ourselves going for the long run. That was really quite a lifeline to our marriage.”

Rachel, parent of Phoebe

Friends and family

Other relationships need investing in too. Often family and friends want to help out but aren’t sure how, so have a think about what would make the most difference to you (for example, a babysit, a shopping trip, a glass of wine, a school pickup) and let them know.

A friendly ear is just as valuable as practical help, so make time to stay in touch – not only for support but to enjoy time together and take your mind off things. Some people are more

My child has a brain or spinal tumour

comfortable with talking about health problems than others. Try to learn who you can trust to support you in the way you need on a bad day. It doesn't mean that the others aren't important too – just that you may choose not to share your feelings with them when you are feeling vulnerable.

“My best friends came to see me and were very tolerant of me being completely obsessed. It's only afterwards you realise you were probably a bit of a mad woman at the time! But everybody was very understanding. Being able to talk to people was really good. It is one of the hard things about being stuck in hospital for a long time – being cut off from your friends.”

Jane, parent of Amy



Amy and her sister

If you don't feel much like talking, going for a short walk or a trip to the cinema together can be a way to spend time together.

This may be a time where you make new friends too. Other parents who have been through similar experiences can become invaluable connections. Talk to your treatment centre to find your local group.

“My friends were loyal and supportive in the main – but what you have in common with those people change. It's a bit like when you have children and you lose common ground with friends who don't. What you're interested in, and what keeps you awake at night, isn't what's bothering them. It happens gradually, but you do start hanging round more oncology people. You do adapt and your children adapt – and some of your friends adapt with you, but some don't.”

Cate, parent of Edie

Wider connections may want to help too. Organisations such as school, religious organisations or clubs are often keen to help, and may help organise rotas of support for you – from cooking to school drop offs. It is always worth asking!

Your other children

If you have other children, they may be greatly affected by their sibling's illness which can impact on their feelings and behaviour:

- **Grief and fear** They may be extremely worried about their sibling and missing him or her.
- **Guilt** Sometimes siblings blame themselves and feel it is their fault. They may be tired and jealous of everyone worrying about their sibling all the time. If they experience feelings of jealousy, they may also feel guilty about this.
- **Broken routine** They may have suffered great disruption if other people have been looking after them while you were involved in your child's hospital care and the normal family routines and organisation disturbed.
- **Craving attention** They may need attention themselves – especially if you have had less time or energy to focus on them.
- **World view** Seeing their sibling in a vulnerable state may shake their own sense of security and lead them to feel more fragile, anxious or depressed.

Make a regular time to spend with each child so they feel reassured that you love them even if they are not seeing you as often. They need to know that they are important too.

Help other children to understand what is happening to their sibling and to feel part of things. If they play an active role by helping out, this may give them a sense of being involved and of the valuable part they can play in helping you and your child. Sometimes, siblings may not want to talk to parents about their feelings to protect their parents from further worry. Another family member or friend may be needed for siblings to be open and honest.

“My son has support for young carers because he does so much work with his little brother, even though he’s only eight. He’ll get up and just decide to empty the dishwasher and look in on his brother, or lie with him making sure he doesn’t scratch his stitches out. I’m sometimes sad for him because this is his childhood, and he’s had to do a lot of growing up. But in other ways I think, well, he’s just a lovely boy. It’s made him even more kind and caring than he already was. We always manage it carefully and make sure he’s got people he can talk to, and try and give him lots of normality too.”

Julie, parent of George

Even during difficult times, there are ways to enjoy your time together and still have fun. Cancer may play a part in your family life for months or years to come. It can help to find some sort of a balance so you and your children can focus on other things too. Talk to other parents in similar situations for ideas about managing this tricky balance.

Managing family life at home

Take a moment to think about each person in the family, what their needs are, and how they can be met. That includes parents, siblings, and of course your child with cancer. This can give you some clues about what help you need to put in place.

For example:

- If your child had really enjoyed after-school chess club, can they play against a friend online while they are in hospital?
- If their sibling is eager to keep going to Scouts, can you organise a regular lift?

- If your partner seems very tired and stressed, can you help them find a regular activity that gives them a change of scene?
- If you are struggling to care for your child as well as managing the household tasks, can you talk to a social worker to see if you are entitled to support as a carer?
- Try to notice how you are feeling and notice when things are too much.
- Try to encourage everyone to talk honestly about how they are feeling from time to time – and to think about something completely different too.
- Reassure everyone in your family that no feelings are ‘bad’ – feelings of frustration, jealousy or resentment are natural and talking can help.
- Don’t be afraid or embarrassed to go to your GP if anyone in your family is finding things too much. Sometimes the strongest thing to do is to ask for help.

**Our CCLG’s booklet
‘Managing family life and
cancer’ is available free
of charge from your
child’s hospital**

All CCLG booklets and leaflets
can be downloaded or ordered
from our website.



“Suddenly, my husband and I were at the hospital all day, every day, while our daughter was recovering from the surgery, so our son was being passed around grandparents and friends. He did really well, he was generally quite cheerful, but when it came to saying goodbye to me or his dad he would often be really upset. We marked out Saturday morning as his priority time to play touch rugby so we can see him succeeding and praise him and that’s been a good thing. Now they’re happily squabbling away together again, so things have got back to normal.”

Rachel, parent of Phoebe

“Our daughter is scanned every three months now. We just had the latest results about a week ago and it’s all clear, so we can relax and breathe again – but only for three months. The first five years there’s still high chance of relapse, so we try to get our lives back to some kind of normality, but it’s at the back of my mind all the time – and often at the front of my mind.”

Rachel, parent of Phoebe



Phoebe in hospital

Looking to the future

This final section looks at what a tumour may mean for your child and the rest of your family going forward, and the surprising effects it can have on the lives of everyone in your family.

Children have an amazing ability and desire for recovery. How long this will take, and nature of your child's recovery, will depend on your child's individual circumstances. This can cause an ongoing feeling of uncertainty. This can be unsettling, especially at first – but many parents describe adapting and adjusting over time.

Ongoing care

Once your child finishes therapy, their health will be monitored at the follow-up clinic. At the first visit, the team will fully reassess the area where the tumour was found, along with any other areas that may have been damaged by the tumour or treatment.

The team will monitor your child's condition over time. They do this by checking things like their weight and appetite, blood counts, kidney function, mobility, hearing, vision, hormone levels, and carrying out tests and scans.

They are also there to talk through concerns about rehabilitation, school or employment, so it's a good idea to bring a list of concerns.

Families will usually feel very anxious about follow-up appointments and scans, bringing up memories of treatment and fears of the tumour returning. This is understandable and normal. You may find it helpful to find ways to prepare – especially for your child – and talk these feelings through with the team.

Long-term effects

We have already seen the way that a tumour in the brain and spine can have such wide-ranging effects because of the risk of damage to the brain and spine.

If your child is affected in the longer term, there are some particular areas that they might need help with, depending on their particular situation. Some can be simply addressed with medical treatment, while for others you need to develop strategies and find ways to adapt and adjust.

The key areas where your child may need help include:

- **Growth and hormone levels** A brain tumour and treatment can sometimes affect things like growth, metabolism, puberty and fertility, and response to stress or illness. All hormones are now available in a synthetic form.
- **Hearing/eyesight and other senses** There is a small risk sight and hearing may be affected by the tumour or its treatment, as well as touch, smell and taste. Treatment is designed to keep this risk as low as possible and your child may be tested throughout and beyond treatment to monitor this.
- **Neurological issues** Tumours and treatments can cause symptoms such as weakness down one side, difficulty balancing or a drooping face. These often disappear over time. Some children have problems with fine motor control and find it hard to do up small buttons or complete fiddly tasks.
- **Difficulties with learning** The tumour, its treatment, or post-operative complications can cause difficulties with learning and social skills. Your child may have some challenges with behaviour, language, memory and attention span, and the ability to reason and problem solve. It may take them longer to do things. A neuropsychological assessment can identify any difficulties and also your child's strengths.
- **Independence** Within teenage years and young adulthood, often more complex skills such as learning to go out and about, road safety and managing money can be more difficult and take longer to learn. It is really important your child is able to develop their independence as far as they can; regular practice and gradually reducing the amount of support you give can be helpful. More advice can be given by the multidisciplinary team.
- **Emotions and behaviour** Some children develop emotional difficulties as a result of many factors: for example, change of routine and isolation during treatment, difficulty carrying out tasks, the experiences of treatment, anxiety or overprotectiveness of parents and others around them, long-term effects, and fear of the cancer returning.

“We felt we had to make an effort to get our son out in the fresh air, even though it meant working around the difficulties and adapting things. As his legs get better with the splints he’s wearing, he’s able to do a lot more than we thought he would. He just wants to be a normal boy who plays with his friends without all of these restrictions. We’re trying to keep him as infection free as possible but with the balance of getting him to do things and enjoy his life.”

Julie, parent of George



Emotional or behavioural challenges

Not every child who has had treatment for a brain tumour will be emotionally distressed by the experience. But because they have been through so much, it is important that you and your child talk things through regularly and that they feel they can express their fears. The healthcare team can support you with this, so try not to worry.

If your child’s behaviour becomes more challenging, this could be for several reasons. It could be a sign of anxiety, stress or frustration. Their behaviour may also be affected by neurological changes as a result of the cancer or their treatment, which might affect their impulse control or their ability to regulate their emotions. If you are finding their behaviour difficult to manage, there are strategies that can help you work with your child on their behaviour over time. These are similar to standard parenting strategies, but may need to be more intensive and consistent. Talk to your child’s healthcare team and ask for support.

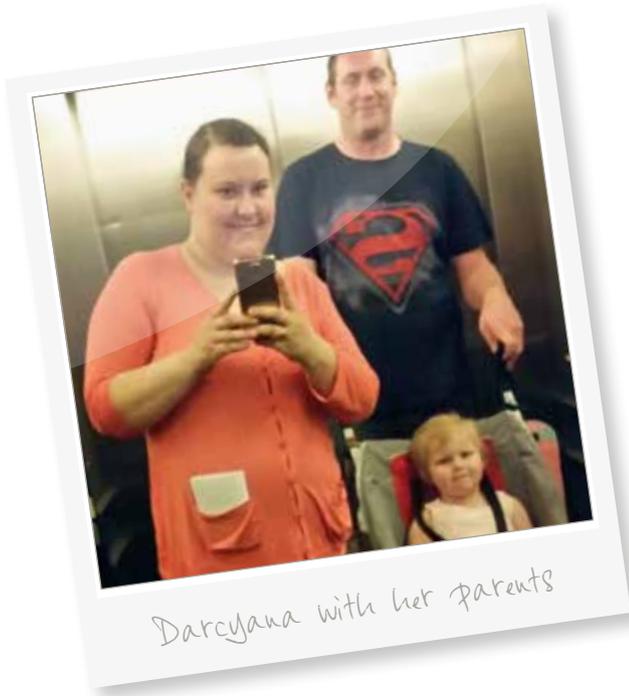
In the meantime, it can help to think of challenging behaviour as your child trying to tell you something, rather than simply ‘behaving badly’. Sometimes it helps to make a note of what was happening before each episode and what happened afterwards. You may be able to identify triggers that are causing distress. It can then be possible to make simple changes to the environment or routine to avoid these situations or to help your child manage these situations differently. It might also help to

take regular breaks and get in the habit of slow breathing or walking away when things get difficult, so you can keep your cool rather than adding to the heat of the situation.

A new reality

Finding a new ‘normal’ family life can take time for everyone in the family. Both you and your child may need to process the difficulties, experiences and emotions you have encountered, but might not have been able to think about at the time. Everyone needs time to adjust to things being, or feeling, different from how they were before. Many parents feel extremely protective of their child and constantly look for symptoms of the tumour returning. Some families can feel grief at the loss of aspects of their child or their lives which have been changed by the experience. Depending on your child’s needs, you also may need to reconsider options for school, college or even employment for your child. This means revising your ideas of how you had expected life to be. This can be difficult, but many parents say it gets easier over time.

When a child has a brain or spinal tumour, this can create major life changes in the long term. Of course, there are the practical changes – a new schedule of attending clinics, and getting support and therapy. But it can also change people’s philosophy of life and provide a new world view, with a clearer sense of what really matters in life and a determination to focus on the positives and to make the most of the time we have.



Darcyana with her parents

“I feel really lucky. It’s been a tough time, and we don’t know what the future holds, because he could always have an abnormal scan, but it gives you a lot of clarity. Yes, my job is important, and I love what I do, but actually there are other more important things. It’s brought us closer as a family.”

Julie, parent of George

“It is a transition, like any new world you encounter, or any massive upheaval in your life, it takes time to adapt and to get used to it. I always think the human spirit is quite amazing – how much humans do adapt to their environment. You do adapt, and your children adapt.”

Cate, parent of Edie

“Now she’s coming up to three and us knowing she’s starting nursery, I’m really scared of leaving her with someone else. The health visitor said we can wait until she’s five, but I think she needs that social stimulation and I don’t think she should miss out. I’m looking forward to it because it’s every kid’s normality, I’m looking forward to that little break and to her having a bit of a life – but I’m also absolutely terrified.”

Debbie, parent of Darcyana



Phoebe during treatment

“You realise your happiness actually doesn’t depend on anything other than the people who matter to you. You become sure of that, and that makes you more sure about the decisions you make in life and the reasons you’re making them. That’s a good thing.”

Jane, parent of Amy



“I don’t need to book a holiday to the Maldives to be happy. I can appreciate just even sitting down to breakfast with my boys or taking them out for a day out. And my husband is the same. We sit there and say ‘Isn’t this lovely? We’ve come out to a freezing cold beach – but we got here!’”

Julie, parent of George

“When your child has cancer, you can’t help but realise what matters in life and how much we complain about things that are just mildly inconvenient. It makes you realise how fragile life is and so to make the best of what you have while you have it. I think only the experience of going through something similar to this could give you that. I don’t think anybody could tell you.”

Rachel, parent of Phoebe

“It does change your priorities. I see other people sometimes, getting really stressed out, they’ve got young children and still working full time because they’ve got a massive mortgage. I look at them and I think ‘You’ve got your priorities wrong’. But you can’t say that to somebody and it’s not something you feel until maybe you’ve been through something like this. It does bring everything home to you that the money and the house and the stuff doesn’t matter.”

Julie, parent of George

Glossary

AFP - Alphafetoprotein is a chemical released by certain tumours into the blood. High levels of AFP may be used as a marker to suggest the presence of the tumour.

Arachnoid villi - Tiny channels in the skull that absorb CSF

Astrocytoma - Tumour of the astrocytes (star shaped glial cells), which are one of the supportive cells (glial cells) in the brain. The most common type of glioma.

Ataxia - Jerky, erratic movements probably caused by damage to the cerebellum

Audiometry - A measurement of hearing ability

Benign - Low grade or less aggressive tumours, which rarely spread

beta HCG - Beta human chorionic gonadotrophin is a chemical released by certain tumours into the blood. High levels of this may be used as a marker to suggest the presence of the tumour.

Biopsy - Taking a small sample of the tumour, which can be analysed by a histopathologist to give a diagnosis

Blood brain barrier - A system whereby the composition of the membranes around the CNS protects the brain by not allowing some chemicals to cross it

Brain stem - The brain stem controls the basic functions essential to maintaining life, including blood pressure, breathing, heartbeat and also eye movements and swallowing. It is the bottom part of the brain and connects the cerebral hemispheres to the spinal cord.

Cannula - A fine tube inserted into a vein to give drugs through or take blood

Central venous line - A long, hollow tube used for long-term insertion into a major vein, which can be used for taking blood tests and giving chemotherapy or blood transfusions

Cerebellum - The back part of the brain concerned with balance and coordination

Cerebral cortex - 4 lobes on each side of the upper brain, which process information and maintain our bodily functions

Cerebrospinal fluid (CSF) - The fluid that circulates around the brain and spinal cord

Chemotherapy - Treatment using drugs to interfere with the ability of a cancer cell to divide and reproduce itself

Clinical trials - Research trials on patients to discover new and better treatments

Cognitive assessment - or neuropsychological assessment is an assessment of aspects of your child's intelligence and memory

Craniopharyngioma - A benign tumour that develops from remnants of primitive tissue behind the pituitary gland

CT scan - A computerised tomography scan that uses x-rays to create detailed images of the inside of the body

Ependymoma - Tumour of the ependymal cells, which are one of the supportive cells (glial cells) in the brain. A type of glioma.

Fine motor skills - The small precise movements such as those involved in feeding, dressing and writing

Frontal lobe - Part of the brain responsible for movement and cognitive abilities such as decision-making and influencing behaviour and personality

Gastrostomy tube (PEG tube) - A tube inserted directly into the stomach from an opening made on the outside of the abdomen through which you can be fed

Glioma - Tumour of the glial (supportive cells) of the brain

Hemiparesis - Weakness down one side of the body

High grade tumours - Malignant or aggressive tumours that can spread easily

Histopathologist - The doctor who analyses the tumour under a microscope to give a diagnosis

Hormones - Chemical messengers released from glands eg growth hormone which control growth and development.

Hydrocephalus - Blockage within the brain leading to a build up of CSF and thus raised intracranial pressure

Hypothalamo-pituitaryaxis (HPA) - The hormonal control centre in the centre of the brain

My child has a brain or spinal tumour

Hypothalamus - A small structure located in the centre of the brain that controls the internal body environment (such as temperature, hormone levels) and controls the expressions of emotions such as pleasure, anger etc and the sleep wake cycle

Intracranial - Inside the main part of the brain

Intrathecal - Giving drugs by injection into the spinal fluid

Intravenous - Giving drugs by injection into a vein

Low grade tumours - Benign or less aggressive tumours, which rarely spread

Lumbar puncture - A needle inserted into the spine to remove some of the CSF fluid for analysis

Malignant - A growth with a tendency to invade and destroy nearby tissue and spread to other parts of the body

Medulloblastoma - Tumour arising in the nerve cells in the cerebellum

MRI scan - A magnetic resonance scan that uses strong magnetic fields and radiowaves to create a detailed images of the body. It is particularly useful for imaging the central nervous system (brain and spine).

MRS - A magnetic resonance spectroscopy image is like an MR scan but can give more information about the chemicals in the brain and the workings of the tumour cells

Nasogastric tube (NG tube) - A thin tube that is put down the nose and throat into the stomach and can be used to feed you, usually used for a short time

Neuro-oncology - Specialty concerning the diagnosis and treatment of brain and spinal cord tumours

Neuroscience - Neuroscience is a field that is devoted to the scientific study of the nervous system

Neurosurgery - Surgical treatment of diseases of the brain and spinal cord

Occipital lobe - One lobe of the cerebral cortex where visual understanding and perception are carried out

Occupational therapist, OT - The therapist who helps redevelop the fine motor skills needed to manage the daily activities of living. They also help with practical solutions and strategies to help your child be as independent as possible; from helping with self-care skills, to reduced memory, to handwriting and learning at school.

Oncologist - Doctor who specialises in treating people with cancer

Parietal lobe - Part of the brain responsible for interpreting touch and other senses, spatial awareness and skills

PET scan - A positron-emission tomography scan that mainly looks at the blood flow through the body and can identify active cancer cells, it involves the injection of a small amount of a radioactive material

Physiotherapist (physio) - The therapist who helps with exercise and other physical treatments to regain normal movement

Pituitary - A small bean shaped organ that lies underneath the brain that produces hormones

Posterior fossa - A region at the back of the brain that houses the brain stem and cerebellum

Clinical Psychologist - is trained to support you and your child, provide advice on managing behaviour or strong feelings, and to identify difficulties with learning or memory

Radiotherapy - Treatment using high-energy rays to destroy cancer cells

Raised intracranial pressure - Increased pressure inside the skull due to expansion of the brain caused by excess fluid in the brain or the presence of a tumour

Randomisation - A process in which a computer will randomly allocate patients to have the different treatments in a trial to ensure that no treatment is favoured

Shunt - A device which allows CSF to be diverted from the brain to the abdomen

Spinal cord - The extension of the brain down the spinal column sending out sensory and motor nerves to and from the body

Synapses - Junctions in the nerves

Temporal lobe - Part of the brain involved in learning, memory, understanding language and hearing processing

Tumour - Group of cells that multiply in an uncontrolled way

Ventricle - a fluid filled cavity in the brain (there are 4 – the 2 lateral ventricles and the third and fourth ventricles)

Ventriculostomy - Creation of another drainage route from the ventricles for the CSF fluid

Sources of information and support

Brain and Spine Foundation

Helpline: 0808 808 1000
www.brainandspine.org.uk
Provides support for anyone affected by neurological issues.

The Brain Tumour Charity

Helpline: 0808 800 0004
www.thebraintumourcharity.org.uk
Provides information and support to anyone affected by brain tumours.

Brainbow

Brain tumour rehabilitation service at Addenbrooke's Hospital in Cambridge for children based in the East of England.

Cancer Research UK

www.cancerresearchuk.org
Information and statistics on all cancer types and a funder of research into cancer.

The Child Brain Injury Trust

Helpline: 0303 303 2248
www.childbraininjurytrust.org.uk
Provides information on children's acquired brain injury and offers training and support for professionals including school staff.

Children's Brain Tumour Research Centre

www.cbtrc.org
Leading UK centre committed to improving understanding of childhood brain tumours.

The Children's Trust Brain Injury Hub

www.braininjuryhub.co.uk
Provides information on acquired brain injury. Also provides a discussion forum for parents and families.

Children's Cancer and Leukaemia Group (CCLG)

Tel: 0116 252 5858
www.cclg.org.uk
Provides expert, high quality and award-winning information resources for young patients and their families.

CLIC Sargent

Helpline: 0300 330 0803
www.clicsargent.org.uk
Provides practical support and advice for children and young people affected by cancer and their families and offers accredited information.

The International Brain Tumour Alliance

www.theibta.org
Global network for brain tumour patient and carer groups around the world.

HeadSmart

www.headsmart.org.uk
National awareness campaigns of symptoms of brain tumours in children and young people.

Macmillan Cancer Support

Helpline: 0808 808 2020
www.macmillan.org.uk
Provides practical and emotional support to anyone affected by cancer.



Children's
Cancer and
Leukaemia
Group

Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

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If you have any comments on this booklet, please contact us. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

