CCLG The Children & Young People's Cancer Association

A guide to neuroblastoma

Information and support for parents and carers of children and young people with neuroblastoma

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About this guide

This guide has been written with the help of experts and parents. It aims to help parents and carers following their child's diagnosis and gives specific information about neuroblastoma, its treatment and possible side effects.

If your child has only just been diagnosed, there may be information in this booklet that has not yet been discussed with you by the medical team looking after your child. This guide gives a general overview of neuroblastoma and will act as a helpful reminder for any discussions you have with your child's treatment team.

There is a lot of information in this guide and it may be helpful to read it in small sections. Much of this will be new and may feel overwhelming. We hope this guide will help answer some of your questions so that you understand more about neuroblastoma and its treatment. Don't be afraid to talk to your team about anything that you don't understand or would like to discuss in more detail. It is important to remember that every child is an individual and your child's specific diagnosis must always be discussed with the treatment team caring for them.

We strongly recommend this guide is read in conjunction with our main resource called **'A parent's guide to children and young people with cancer'** which is designed to accompany you through every step of the cancer experience. Available **FREE** of charge from your child's hospital or from our website: **www.cclg.org.uk/publications**

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> “Hearing the words cancer and neuroblastoma in the same sentence as your child is a huge shock. Often parents can feel isolated and alone. A childhood cancer diagnosis introduces you to a whole new world of care and support. I found connecting with other families who were a little further on in treatment really helpful.”

Beginning the journey

When you are told that your child has neuroblastoma, it can feel as if your life has turned upside down overnight. These feelings are completely normal and many parents say that they feel the same.

You will probably be feeling numb, scared, not believing that any of this is really happening, angry as to why this is happening to your child, and maybe feeling guilty that your child's cancer is because of something you have or haven't done, even though this isn't true. You may feel relieved, especially if a diagnosis has taken a while.

Since your child's diagnosis, you may have met many new people, heard a lot of unfamiliar medical terms and your child may have undergone a series of tests. This can feel very overwhelming and daunting as a parent. Don't worry, hospital staff fully understand that it takes time for you to digest what is happening and what the next steps might be. They are there to help you through this difficult time with information and reassurance.

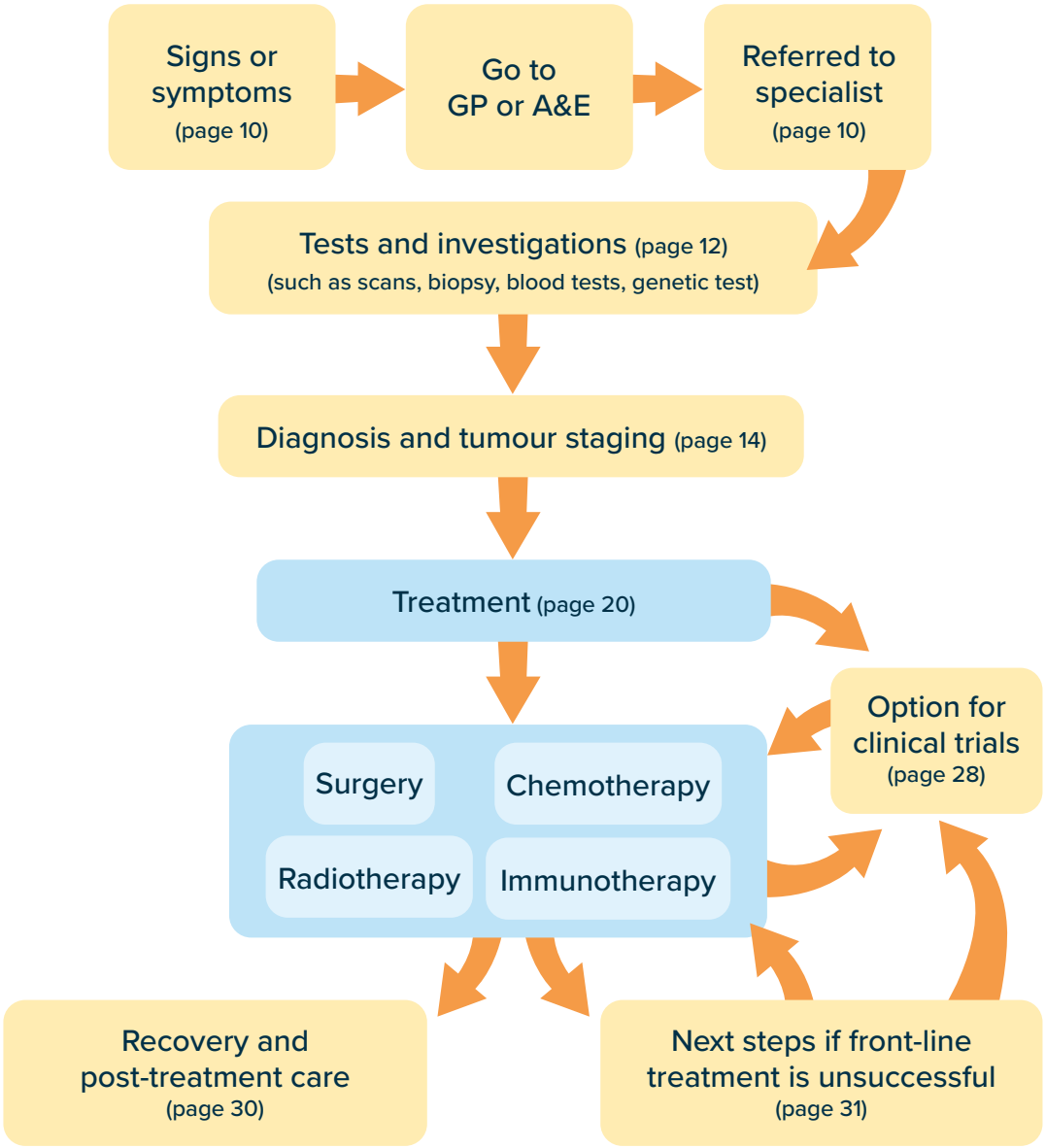
Many parents cannot think of any questions to ask during a hospital consultation but think of all sorts of things as soon as they get home. It is a good idea to write down questions as soon as you think of them so that you can discuss them at the next opportunity.

When your child is diagnosed with cancer, it has a huge impact on your whole family. Your child's routine is likely to change with hospital stays and regular appointments and this can feel overwhelming for you, your child and the rest of your family. There are many support organisations who can help you through this time and some of these organisations are listed at the end of this guide, but you should also discuss your feelings with the team looking after your child.

Write down your questions at the back of this guide or on your phone and fill in the answers during your clinic appointments.

> "You soon find a cancer family - people who 'get it' – who completely understand the earth shattering diagnosis."

Neuroblastoma – your child's healthcare journey



About neuroblastoma

Neuroblastoma is a cancer that is almost always found in children. Childhood cancers are not the same as adult cancers as they behave differently. They tend to appear in different parts of the body to adults, and respond differently to treatment.

What is neuroblastoma?

Neuroblastoma is the most common solid tumour in children outside the brain. Around 100 children in the UK are diagnosed each year, making up about 6% of the total number of all childhood cancer diagnoses.

Neuroblastoma primarily affects younger children. Around 80%[1] (eight out of ten) of neuroblastoma cases are found in children aged 0-4 years. It is less common in children over the age of five and only a small percentage of cases occur in teenagers and young adults.

1. Public Health England. Children, teenagers and young adults UK cancer statistics report 2021. Published February 2021.

Neuroblastoma is an embryonal tumour, that develops from the cells left over during a baby's development in the womb. The cells in the nervous system from which it develops are called neuroblasts, giving neuroblastoma its name:

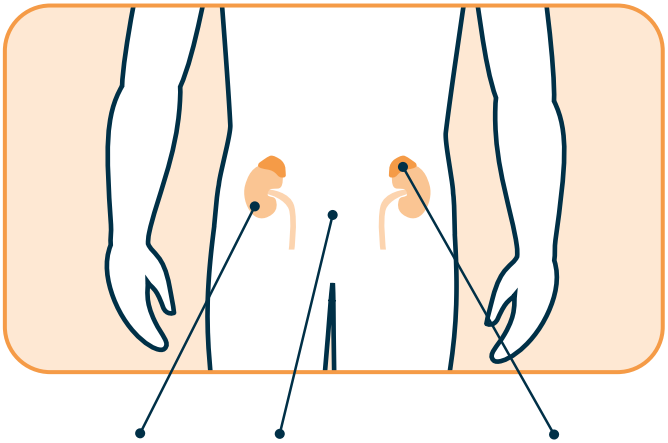
- 'neuro' means nerve
- 'blast' means cells in an early stage of development
- 'oma' means a group of cells, or a tumour

> "You may find yourself re-telling the events leading up to your child's diagnosis. I found this really helped me in those early days of shock to process what was happening."

Neuroblastoma starts from either the adrenal gland or from nervous tissue that runs along the spinal cord in the neck, chest, abdomen or pelvis. The most common place for a tumour to grow is in the abdomen.

Some tumours grow at the back of the chest and occasionally even higher up towards the neck. About 50% of tumours start in the adrenal glands, which are found above the kidneys. These glands release hormones such as adrenaline, to maintain blood pressure and enable us to respond to stress.

In some cases, neuroblastoma can spread to tissues beyond the place it started, such as the bone marrow, bone, lymph nodes, liver, skin and brain.



What causes neuroblastoma?

As with most childhood cancers, the cause of neuroblastoma is unknown. It is not infectious and cannot be passed on to other people. It is important to remember that nothing you have done has caused your child's cancer.

Around 1% of neuroblastoma cases are hereditary (passed down through family members). This is most commonly due to genetic changes in DNA present in a gene called anaplastic lymphoma kinase (ALK) or a gene called Phox2B. These genetic changes happen in all cells as well as cancer cells and can be passed on through families.

Hereditary neuroblastoma often appears in children younger than 18 months old, with more than one tumour occuring at the same time. Children with cancer in England are now offered a test called Whole Genome Sequencing (WGS) which can identify whether there is a hereditary genetic mutation or reason for the cancer. If a hereditary mutation is found, then other close family members (parents and siblings) may also be offered testing, together with referral to a clinical geneticist.

> "It took time to accept the fact that we had never considered his symptoms could be cancer. It was not our fault."

Signs and symptoms of neuroblastoma

Many children with neuroblastoma have vague and non-specific symptoms. They may be unwell for a while, not eating much, complaining of aches and pains or have unexplained sweating. Many of the symptoms can be similar to other common childhood illnesses. Unless a parent or doctor feels a lump, neuroblastoma may not be initially considered. Many parents wonder if they or a doctor should have noticed something sooner, but because it is so uncommon, neuroblastoma is rarely suspected. Often, neuroblastoma, particularly 'high-risk' neuroblastoma, shows up at a late stage when it has spread around the body.

The symptoms of neuroblastoma vary depending on where your child's tumour is but could include:

High blood pressure	Small blue coloured lumps in the skin
Continuous viral illness and infections	Bruising around the eyes
Weakness in the legs or walking unsteadily, and back pain	Swollen tummy, constipation or difficulty passing urine
Visible lump	Night sweats
Breathlessness and difficulty swallowing	Jerky eye and muscle movements (called 'dancing eyes syndrome')
Vague and non-specific symptoms such as tiredness, pale complexion, loss of appetite, weight loss and general discomfort/pain which can make a child irritable and unhappy	Different pupil sizes, skin redness and/or a 'droopy' eyelid on one side of the face (called 'Horner's syndrome')

Urgent referrals

The National Institute for Health & Clinical Excellence (NICE) Referral Guidelines for Suspected Cancer recommend very urgent referral (for an appointment within 48 hours) for specialist assessment for neuroblastoma in children with a 'palpable abdominal mass' (a lump in their tummy) or an unexplained enlarged abdominal organ. In the process of your child's diagnosis, you may have experienced this urgent referral. When things happen so fast this can be scary and overwhelming. Talk to your medical team if you are unsure about why or how any of this happened, or if you are unsure about anything at all.

Diagnosis

If cancer is suspected, your child will be referred to your nearest hospital which has a specialist children's cancer (paediatric oncology) centre. These Principal Treatment Centres (PTCs) are located in a network of 20 hospitals in the UK and Ireland with expertise in all childhood cancers, including neuroblastoma.

1 **Aberdeen:** Royal Aberdeen Children's Hospital
2 **Edinburgh:** Royal Hospital for Children and Young People
3 **Glasgow:** Royal Hospital for Children
4 **Newcastle-Upon-Tyne:** Great North Children's Hospital, Royal Victoria Infirmary
5 **Leeds:** Leeds Children's Hospital, Leeds General Infirmary
6 **Sheffield:** Sheffield Children's Hospital
7 **Nottingham/Leicester:** East Midlands Integrated Service at Queen's Medical Centre, Nottingham and Leicester Royal Infirmary
8 **Cambridge:** Addenbrooke's Hospital
9/10 **London:** Great Ormond Street Hospital for Children and University College Hospital London
11 **Sutton:** Royal Marsden Hospital
12 **Southampton**: Southampton Children's Hospital, Southampton General Hospital
13 **Bristol:** Bristol Royal Hospital for Children
14 **Cardiff:** Noah's Ark Children's Hospital for Wales
15 **Oxford**: Oxford Children's Hospital, John Radcliffe Hospital
16 **Birmingham:** Birmingham Children's Hospital
17 **Liverpool:** Alder Hey Children's Hospital
18 **Manchester**: Royal Manchester Children's Hospital
19 **Dublin:** Our Lady's Children's Hospital, Crumlin
20 **Belfast:** Royal Belfast Hospital for Sick Children

Your child will have many different tests to confirm whether they have cancer, what type it is and which treatment will be best.

Tests, assessments and scans

Your child's medical team will run a whole range of tests, assessments and scans to get an accurate diagnosis. All of these may seem frightening to both you and your child, but it is important for doctors to see where the cancer is in your child's body, whether it has spread, and to assess the general health of your child. This will then help your child's doctor to decide which treatment will be best.

Scans and X-rays

Your child will have X-rays and specialist scans to confirm the diagnosis of neuroblastoma. The scans will show where the main neuroblastoma ('primary tumour') is and if there are neuroblastoma cells which have spread to other parts of their body ('secondary tumours' or 'metastases').

Apart from the need for an injection of 'contrast' or radioactive liquid for certain scans, none of these investigations are painful for your child.

However, it is normal that they may feel unsettled or frightened. Health play specialists may be available to help your child to understand what is happening and reduce their anxiety. Please talk to your team if you feel your child needs this support. Some of the scans require your child to stay still for quite some time and to help this a general anaesthetic (where your child would be asleep) or sedation may be needed. These will be discussed with you before any scans are done.

X-rays – may be used to see if neuroblastoma has spread to certain bones.

CT scans – the CT scanner takes multiple X-ray images to build up a 3D picture of the inside of the body.

Ultrasound scans – use sound waves (as used in pregnancy). The waves bounce against solid organs in the body and are recorded on a screen. The doctors can see the outlines or shadows of normal organs and tumours inside the body.

mIBG scans – this type of scan looks for abnormal cell growth within the body. It works by injecting a small amount of radioactive substance, called meta-iodobenzylguanidine (mIBG) into your child's veins. This injection takes place a day before the scan. Active neuroblastoma cells naturally absorb mIBG so when the body is scanned with a gamma camera the cells show up as 'hot spots'. To protect the thyroid from radiation, your child will need to have medication for some time before and after the injection and scan. Your team will talk to you about this. This type of scan is a useful tool for diagnosis as it gives a complete picture of where the tumour cells are in the body. mIBG shows up in neuroblastoma cells in around 90% of cases.

Bone scans – show how much the cancer has spread to the bones. A small dose of radioactive liquid is injected into a vein, usually in the hand or arm. The substance is absorbed by the bone, but affected areas will absorb more so they will be highlighted on the scanner as 'hot spots'. Bone scans are only used if mIBG scans are negative.

MRI scans – an MRI (magnetic resonance imaging) scan uses magnetic fields and radio waves to build up a detailed picture of a part of the body. No radiation is used. It takes longer than a CT scan and is quite noisy. Your child may be given a sedative or general anaesthetic to make sure that they lie still.

FDG-PET scans – this is another type of radionuclide scan, like an mIBG scan, which can be useful to see where neuroblastoma has spread to, particularly in cases where the mIBG scan is negative (around 10% of cases). In some children, whose mIBG scan does not detect neuroblastoma tumours, the FDG-PET scan can be used to assess how your child may be responding to treatment. FDG stands for 'fluorodeoxyglucose' and PET stands for 'positron emission tomography'.

Tumour biopsy

A biopsy involves removing some of the cells from your child's tumour to look at them under a microscope. This is done during an operation where your child is given a general anaesthetic, and a piece of the tumour is taken out through a small cut (or incision) in the skin. Sometimes, a small piece of tumour may be drawn up through a needle, called a 'needle biopsy'.

The tumour sample is then sent to a laboratory to find out if it is made up of neuroblastoma cells and to look at DNA changes and biological markers.

Knowing about your child's tumour biology gives important information that is used in deciding the best treatment for your child.

Blood tests

Blood for testing may be taken from a vein in your child's arm or by a finger prick. This gives important information about your child's current health, blood group, and any infections. It is a good way of monitoring the side effects of treatment.

Urine tests

A specialised test in the diagnosis of neuroblastoma measures 'vanillylmandelic acid' (VMA) and 'homovanillic acid' (HVA) in your child's urine. You may hear this test referred to as a 'urine catecholamine' test. VMA and HVA are chemicals found in the urine in raised amounts in 9 out of 10 cases of children with neuroblastoma, and this is a good indicator of diagnosis. As these VMA/HVA chemicals are produced by the tumour, they can be used to measure tumour activity during treatment, so are sometimes referred to as tumour markers.

Bones and bone marrow tests

The most common places which neuroblastoma cells spread to are the bones and the bone marrow. To detect tumour cells in the bone, your child will undergo either an mIBG, PET-CT or bone scan.

To examine your child's bone marrow (the spongy material in the middle of a bone), a needle is inserted into one of the larger bones (like the hip bone) and a small quantity of bone marrow is drawn out. This is called an aspirate. A trephine (a core of the bone marrow) involves taking a very small piece of bone at the place where the marrow is drawn out.

To make sure that the test is as accurate as possible, aspirates and trephines may be taken from more than one location, usually from the hip bones on either side of the body. Your child will always be given a general anaesthetic before these tests are undertaken.

Genetic tests

Genetic tests are done on the tumour sample to look for biological markers and DNA changes. Most genetic tests are done at a specialist laboratory called the National Neuroblastoma Genetics Reference Centre at the Newcastle Genetics Laboratory.

One important biological marker to test for in neuroblastoma cases is the gene called *MYCN* (pronounced 'mikken'). When additional numbers of copies of this gene are present, this is called *MYCN* amplification and happens in around 25% of

neuroblastoma cases. It is more common in younger children and it indicates that it is a more aggressive cancer that is likely to spread. If your child has *MYCN* amplification then we know that more intensive treatment is needed from the start.

Another genetic test involves looking at the number of each chromosome; a healthy cell should have two copies of 23 chromosomes. In neuroblastoma, there may be gains or losses of all or parts of chromosomes. This test is particularly important for deciding treatment in children with low- and medium-risk neuroblastoma. Children who have changes to whole chromosomes are less likely to require treatment than those with changes to parts of chromosomes (called segmental chromosomal abnormalities).

Currently, in England, all children and young people with cancer are eligible to have a Whole Genome Sequencing (WGS) test. This test is not yet routinely available in Wales, Scotland and Northern Ireland. The test compares the DNA of their tumour to the DNA of their healthy cells (usually a blood sample). This is a more detailed test that looks at all of the genetic changes in the tumour, not just the specific ones which are tested for in the neuroblastoma reference centre.

The results of these genetic tests will help to determine the type of treatment your child has. The *MYCN* test can be done very quickly but other genetic tests looking at all the chromosomes can take slightly longer to do, and the results may take a few weeks to come back to your child's doctor.

Very rarely, genetic tests may show that your child has an increased hereditary risk of neuroblastoma. Your child's doctor will discuss these tests with you and may refer you to a genetics specialist.

It can take some time for tests to be completed and all the results analysed. Having these tests and waiting for results is an extremely anxious and stressful time.

Treatment will often begin before all of these results are received. However, exact assessment of the extent and biology of your child's tumour is very important. The results found will allow your child's doctor to select the right type and length of treatment for your child.

Download or order free of charge 'Whole genome sequencing (WGS) for children' **www.cclg.org.uk/publications**

Tumour 'staging'

When your child is diagnosed, you will also be told what stage the cancer is. This considers the size of the tumour and whether it has spread beyond the part of the body where it started. Doctors recognise several different 'stages' and 'risk groups' of neuroblastoma. The treatment your child has depends on their tumour 'stage' and 'risk group'. Doctors use imaging such as CT or MRI scans to look for particular risk factors for surgery within a child's tumour. These factors can be a sign that the tumour is not suitable for surgery initially and may require chemotherapy to shrink it, or that it could simply be observed. These factors, known as image defined risk factors (IDRF), include whether the tumour is wrapped around an organ or blood vessels and other findings on a CT/MRI scan.

The INRG stages

The International Neuroblastoma Risk Group (INRG) Staging System is used to assess a child's tumour and match the right treatment to it, taking into account risk factors and possible side effects.

INRG stage L1 (INSS stage 1) The tumour is in one area (L = localised) and has not spread anywhere else in the body. It is able to be removed completely by an operation. If genetic features of the tumour make it higher-risk, chemotherapy and radiotherapy may still be required.
INRG stage L1 (INSS stage 2) The tumour is in one area and has not spread anywhere else in the body, but a lymph node or some glands nearby may be affected by the tumour. It may be larger and more difficult to remove completely by an operation. It is usually treated by surgery alone but depending on where it is and certain genetic tests such as MYCN amplification, additional treatment like chemotherapy may be needed.
INRG stage L2 (INSS stage 3) The tumour has not spread to other parts of the body, but is large and may have grown from where it began to the other side of the body (called crossing the 'mid-line'). It is usually difficult to remove with surgery alone. Or it may be wrapped around blood vessels that make it unable to be removed. Chemotherapy may be used to shrink the tumour before an operation. After surgery, radiotherapy and an oral medication called 13-cis-retinoic acid may also be recommended.
INRG stage M (INSS stage 4) The tumour may be any size but it has spread to other parts of the body, most commonly to the bones, bone marrow or liver. Depending on age, more intensive treatment is needed. This will include chemotherapy to kill the tumour cells that have spread to different body parts, and to shrink the primary tumour for possible later removal by an operation.
INRG stage MS (INSS stage 4s) This type of neuroblastoma is most often found in babies under one year old. The tumour cells may have spread to other parts of the body, but they usually behave in a less aggressive way than in an older child. In addition to a primary tumour (which is often in one of the adrenal glands), the liver, skin, lymph nodes and bone marrow may be affected but not the bones, lungs or the brain.

Note: The older INSS classification is also included here as you might hear about both.

> "The first few weeks of diagnosis can be overwhelming – managing your feelings, dealing with well-meaning friends and family, coping with hospital stays and the impact on family life. It may be helpful to have a trusted friend or family member to share updates for you. Your friends and family will want to help. Let them! Make a list – cooking meals, school runs and play dates for siblings are a start."

Ganglioneuroblastoma

Ganglioneuroblastoma is a type of tumour that is closely related to neuroblastoma. It can be seen in any age group, but the cells of this tumour are more 'mature' than those of the ordinary neuroblastoma. When fully mature, they form a ganglioneuroma.

There are two types of ganglioneuroblastoma – intermixed and nodular. An intermixed ganglioneurobastoma is a benign (non-harmful) tumour which is either INRG L1 or L2 and, if it cannot safely be removed by an operation, it can often simply be observed.

A nodular ganglioneuroblastoma can be INRG L1, L2 or M. The nodules of neuroblastoma may break away from the main tumour and in these cases (M disease) will need chemotherapy and the other treatments given to children with high-risk neuroblastoma.

> "There is so much to process and it's difficult to focus. I tried not to think too far ahead and take each day, hour and minute as it came so that I could concentrate on my child. Trying to be present and making the most of times when they were feeling good, helped me to be positive and gave me hope and strength."

Knowing your child's risk group (INRG)

Treatment of neuroblastoma is tailored to each child and is given according to their risk group. Doctors categorise neuroblastoma according to the International Neuroblastoma Risk Group (INRG) classification as low-, intermediate- (medium), or high-risk. This risk takes into account factors such as the child's age at the time of diagnosis, stage of tumour, presence or absence of *MYCN* amplification, specific biological features of your child's tumour, specific genetic abnormalities, or if your child is showing severe clinical symptoms.

Low- and intermediate- risk neuroblastoma cases

50%
of neuroblastomas

High-risk neuroblastoma cases

50%
of neuroblastomas

Low-risk neuroblastoma

Around 30 children are diagnosed with low-risk neuroblastoma in the UK each year and more than 90% are cured of their disease. This group includes:

- infants aged 18 months or under at diagnosis with localised (L1) neuroblastoma
- infants aged 18 months or under at diagnosis with inoperable neuroblastoma (L2) whose tumours do not have MYCN amplification
- infants under 12 months old with a stage MS pattern of tumour

Children with low-risk localised neuroblastoma who have symptoms that could present a risk to their health, or whose tumours contain certain genetic changes, may require treatment with chemotherapy and possibly subsequent surgery. In these cases, treatment is with chemotherapy followed by re-assessment of the position and extent of the tumour. This may include CT or MRI scan, mIBG scan, urinary catecholamine measurement or FDG-PET scan before consideration of later removal of the tumour.

Children who are aged less than 18 months with low-risk localised L2 neuroblastoma which is not causing many symptoms and has favourable biology (such as lack of *MYCN* amplification and no segmental chromosomal abnormalities) may not require any treatment. Instead, they can be closely observed to monitor changes within their tumour, which can naturally decrease in size or mature to a benign ganglioneuroma.

Infants aged 18 months or under with low-risk L2 neuroblastoma, or infants aged under 12 months with MS neuroblastoma and genetics showing segmental chromosomal abnormalities, require several courses of chemotherapy and possible surgery regardless of whether they have symptoms.

> “Hospital was our second home for such a long time. It was like living with a foot in two totally different worlds at the same time.”

Stage MS neuroblastoma

This is a type of low-risk neuroblastoma with a particular distribution of secondary tumours found in the skin, liver, bone marrow and distant lymph nodes but not in bones, lungs or the brain. With stage MS neuroblastoma, the tumours can shrink and disappear naturally without any treatment.

Sometimes, if the tumour is causing clinical problems or if there are certain genetic changes (presence of segmental chromosomal abnormalities) found in the tumour cells, then low doses of chemotherapy may be given to encourage the tumour to start shrinking. In some children with MS neuroblastoma, removing the primary tumour by surgery will be recommended some months later.

Intermediate-risk neuroblastoma

Around 20 children are diagnosed with intermediate-risk neuroblastoma each year in the UK and over 80% are cured of their disease. This group includes:

- infants aged 12 months or under at diagnosis with neuroblastoma that has spread (M) to bones, lungs or the central nervous system (CNS), without *MYCN* amplification
- children aged over 18 months with localised and inoperable neuroblastoma (L2) without *MYCN* amplification

Children with intermediate-risk neuroblastoma are treated with chemotherapy. This is followed by careful reassessment of the tumour, including bone marrow tests and imaging scans. In some children, it is then possible to have surgery to remove the tumour, or some may need further chemotherapy.

Children over the age of 18 months with localised, unremovable (L2) neuroblastoma, whose tumour biology shows a higher level of cancer activity, will also receive radiotherapy and differentiation therapy, with an oral medication called 13-cis-retinoic acid after chemotherapy and surgery.

Rarely, a child has stage L1, *MYCN* amplified, intermediate-risk neuroblastoma. In these cases, radiotherapy will be given to the site of the primary tumour after surgery, as well as 13-cis-retinoic acid. This will be fully explained to you by your child's doctor. Occasionally, some children with intermediate-risk neuroblastoma will be recommended to have high-risk type treatment. This will usually depend on how the tumour responds to the intermediate-risk treatment.

High-risk neuroblastoma

Around 50% of children with newly-diagnosed neuroblastoma are diagnosed as the INRG high-risk category. In the UK, this is around 50 children per year, approximately 50% of whom will be cured of their disease. This group includes:

- any child with *MYCN* amplification (other than stage L1)
- any child over 12 months old with neuroblastoma that has spread to other areas of the body (stage M)

Children with high-risk neuroblastoma require intensive treatment from the start because their neuroblastoma cells are highly cancerous and therefore likely to behave more aggressively in the body. The majority of children are likely to need a combination of different treatments including surgery, radiotherapy, chemotherapy (including high-dose chemotherapy) and differentiating therapy/immunotherapy.

Children with high-risk neuroblastoma are initially treated with a period of chemotherapy, followed by careful re-assessment of position and extent of tumour locations. This may include bone marrow examination, CT or MRI scans, urinary catecholamine testing, mIBG, bone or FDG CT-PET scan. This initial chemotherapy is referred to as 'induction chemotherapy'.

In some children, it may then be possible to remove the tumour by surgery, or some children may need further chemotherapy. Children treated for high-risk neuroblastoma should then be considered for high-dose chemotherapy, also referred to as 'myeloablative therapy'. Following high-dose chemotherapy, most children will then have treatment with local radiotherapy to the area where the tumour was removed at surgery, followed by differentiation therapy and immunotherapy. Treatment for high-risk neuroblastoma usually takes 12 to 18 months to complete.

> "You may feel overwhelmed, scared, shocked and devastated and all of that is completely normal. Talk to other parents if you can, because it helps to know that there are people you can talk to who will understand your feelings without you needing to explain. You are not alone."

Starting treatment

Once your child has a confirmed diagnosis of neuroblastoma, the medical team will be keen to get your child started on treatment as soon as possible at your nearest specialist Principal Treatment Centre (PTC) for children's cancer.

This means that your child will get highly specialised care and may need to stay in hospital so that they can be monitored when starting treatment. Although your child will not usually be in hospital for the entire duration of treatment, there are likely to be periods of hospital stays.

Over time, your child may also receive some treatment at your local hospital. This is called 'shared care' and allocated local hospitals are known as Paediatric Oncology Shared Care Units (POSCU). If your child has any shared care, the decisions about their treatment will still be made by your child's consultant at the main cancer unit but it means that it is easier for families as they will need to travel less.

A lot of different professional staff will be involved in looking after your child, both at home and while they are in hospital. Hospital staff that may be involved in your child's care include doctors, anaesthetists, surgeons, nurses, health care assistants, pharmacists, pathologists, physiotherapists, occupational therapists, dietitians, radiographers, radiologists, play specialists, social workers and teachers.

A team of specialists called the 'multi-disciplinary team' (MDT) will meet regularly to discuss your child's cancer, treatment options, clinical trials, and any areas in which your child may need support.

Your child's treatment and care will be managed by:

- **Consultant paediatric oncologist** – a doctor who specialises in treating all children with cancer.
- **Consultant clinical oncologist** – a doctor who specialises in using radiotherapy and chemotherapy to treat cancer patients.
- **Clinical nurse specialist** – a nurse who specialises in caring and supporting children with cancer.

> "The play specialists really helped her to understand procedures so that they were less scary. Together we found lots of distractions techniques to help."

What your child's cancer care might look like:

Your child's care

Your local community

- Your GP for your family's health needs
- Local charities
- Community groups for carers
- Hospice support services

Specialist children's cancer centre

- Full team of doctors and nurses specialising in all aspects of cancer treatment
- Supportive care including dietitians, physiotherapists, play specialists, psychologists and occupational therapists
- Specialist wards, facilities and resources

At home

- Outreach nurse services from your hospital to support your child at home
- Local children's community nursing

Shared care unit

- Access to clinical services e.g. blood transfusions, antibiotics, blood tests
- Possible access to chemotherapy services
- Local support and community services

Types of treatment

Once the diagnosis of neuroblastoma is confirmed, the results from the tests will help your child's doctor to decide on the best treatment regimen, often called 'protocol'. The suggested treatment will be discussed fully with you.

Sometimes the order of the treatment that your child is offered will differ to the standard protocol. Your medical team will review how your child's cancer is responding to treatment at every stage and will discuss the next steps with you each time.

Surgery

Your child's tumour will be removed during an operation if it is possible and safe to do so. Surgery often takes place at a later stage of treatment. This will be after several cycles of chemotherapy have been given to shrink the tumour so that it can be more easily (and therefore more safely) removed. The extent of surgery differs for each child, and will depend on factors such as the location of the original tumour and involvement of surrounding organs or structures.

If your child has received chemotherapy before surgery, then it is important to make sure that they have made a full recovery before surgery takes place. This will be discussed with you.

Chemotherapy

This is the main treatment for intermediate- and high-risk neuroblastoma. Chemotherapy is the use of drugs to destroy cancer cells. They can be given in different ways but the most common way is intravenously – into a vein – whether through injections, cannula, or a line such as a central line, implantable port or PICC line. Chemotherapy is usually given as a combination of multiple different drugs.

High-dose chemotherapy

After surgery, children with high-risk neuroblastoma have 'high-dose chemotherapy', also sometimes called myeloablative therapy. The drug(s) used in this type of therapy usually consist of high-dose busulphan and melphalan.

As the treatment is intensive, your child may need to be in hospital for a period of about four to six weeks and be cared for in an isolation cubicle. The treatment will lower your child's blood count for a long period, during which time they will be prone to infections and bleeding. To shorten this period when the blood count is low, children often undergo a procedure known as an autologous stem cell transplant.

High-dose chemotheraphy and autologous stem cell transplant are sometimes called 'consolidation therapy'.

Autologous stem cell transplant

Before high-dose chemotherapy is given, stem cells are collected, or 'harvested', from your child and frozen safely until they can be given back to your child after high-dose chemotherapy so that the bone marrow can recover.

What are stem cells?

Stem cells are cells before they become the different types of blood cells. They are found in the bone marrow. The bone marrow is damaged by high-dose chemotherapy so putting healthy stem cells back into the body afterwards helps the child's bone marrow make new blood cells.

Stem cells are collected from your child's blood using a machine connected to their central line. Sometimes a catheter tube called a vascath is also needed, and will be put into your child's vein under general anaesthetic. Blood is sucked into the machine through the vascath or central line. The machine then collects the stem cells and returns the rest of the blood back to your child. The stem cells are then frozen and stored.

The harvesting procedure takes about three to four hours, once a day. Two to three days of harvesting are usually required. This procedure is painless and has few side effects. To increase the number of stem cells in the blood before harvesting, a drug called 'G-CSF' is given to your child. This drug helps the stem cells to move out of the bone marrow and into the blood ready for harvesting. 'G-CSF' (usually given by injection) is started a few days before the harvest and is given daily until harvesting is finished. This whole process will be discussed with you in detail by your child's team.

Very rarely, as an alternative to stem cell harvest, some children may have stem cells collected straight from the bone marrow, called a bone marrow harvest. This is performed under general anaesthetic and is very similar to a bone marrow aspirate (see p13). The bone marrow is then stored like stem cells.

After high-dose chemotherapy, the harvested stem cells are given back to your child. The cells are defrosted and given intravenously through their line or port.

Download or order free of charge 'Peripheral blood stem cell harvesting' and our children's storybook 'Ruby's stem cell harvest and transplant' **www.cclg.org.uk/publications**

Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy cancer cells in a specific part of the body. Children with high-risk neuroblastoma usually have radiotherapy after their tumour has been removed by surgery and after having high-dose chemotherapy.

Some children with intermediate-risk neuroblastoma will also have radiotherapy after surgery but this decision is taken on an individual basis. Radiotherapy is focused on the area where the primary tumour was removed. It is used to try and kill tumour cells that can sometimes remain after surgery.

Radiotherapy is painless and the machine does not touch your child – it is like having an X-ray. The total radiation dose is spread out over time and often involves treatment every day for three to five weeks, usually excluding weekends. In some situations, the radiotherapy course can be shorter or longer and your child's doctor will discuss this with you. Your child's radiotherapy may take place at a different hospital.

Radiotherapy requires careful preparation and planning to decide where in your child's body to treat and the best way to give the radiotherapy. This can involve several steps. Some children struggle to lie still for radiotherapy so may need general anaesthetic each day. This will be discussed with you by your child's clinical team. The radiotherapy play team will help your child with keeping still and any worries they may have.

Differentiation therapy (13-cis-retinoic acid)/ immunotherapy (anti-GD2 antibody)

For children with high-risk neuroblastoma whose tumours have responded to induction chemotherapy, surgery, high-dose chemotherapy and radiotherapy, additional treatment is recommended. This involves an

oral drug called 13-cis-retinoic acid which 'differentiates' (turns cells from being cancerous to non-cancerous) any remaining tumour cells.

Alongside 13-cis-retinoic acid, children will receive immunotherapy with a monoclonal antibody called anti-GD2 antibody. The anti-GD2 antibody, dinutuximab beta, is given through your child's line or port using a slow release pump, which they are attached to for 10 days. To start with, this treatment is inpatient but once side effects are known and managed, it is possible for this to continue at home.

Immunotherapy treatment for neuroblastoma relies on your child's own immune cells to kill cancer cells. There are different ways to do this and currently antibody therapy is the most commonly used.

The antibody targets a molecule present on nearly all neuroblastoma cells called GD2 (disialoganglioside). When the antibody binds to the GD2, the cells die in a different way than after chemotherapy or radiotherapy.

Differentiation therapy and immunotherapy is usually given for five courses over six months at the end of all other treatment.

Eflornithine (Difluoromethylornithine or DFMO)

Eflornithine (Difluoromethylornithine or DFMO) is an oral drug, which has been investigated for its effects in neuroblastoma. Since this drug was approved in the US for use for patients with high-risk neuroblastoma who have had a response to prior treatment including anti-GD2 immunotherapy, it has been made available to UK patients under a temporary scheme from the pharmaceutical company Norgine, while NHS funding bodies review whether it can be provided by the NHS in the long term. Therefore, the UK Neuroblastoma Clinical Trials Group and CCLG Neuroblastoma Special Interest Group suggest that treatment with DFMO for high-risk neuroblastoma patients is considered and discussed with patients and families who are completing frontline therapy or relapse therapy. More information can be found on our website here **www.cclg.org.uk/Neuroblastoma**

Finding out about other treatments

If you have any queries about new treatments that you may have heard about in the media or from others, we encourage you to discuss them with your child's treatment team. It is natural to feel that you want to explore every avenue for your child and do not want to settle for just one doctor's advice about treatment.

Neuroblastoma is a small and specialised area of medicine and doctors nationally and internationally know each other and meet regularly. Your child's team will be aware of the latest research through being a member of CCLG networks, such as the Neuroblastoma Special Interest Group, as well as international groups, such as SIOPEN (The European neuroblastoma research network).

> "There will be lots of medical jargon to understand which can be difficult. Alongside consent, it is likely that your child's treatment will form part of clinical trials. Write down all the questions you have and speak openly and honestly with your treating team so that they can help you understand."

These groups collaborate nationally and internationally on various projects and research. Therefore, if a new treatment is developed anywhere in the world, it is likely that your child's doctor will know about it and be able to discuss it with you.

It is reassuring to know that your child's treatment will be discussed regularly during MDT meetings. All the staff involved in the MDT are specialists in their field, and work together to ensure a co-ordinated and consistent approach to your child's treatment and care.

In some situations, it may be appropriate (with your consent) for your child's case to be discussed with national experts on the **National Neuroblastoma Advisory Panel (NNAP)** which meets regularly.

Side effects of treatment

Unfortunately, treatment can cause some side effects. Thankfully, these are mostly temporary and there are often ways of controlling or reducing them through supportive care. Your child may be well enough to play, have fun and have a good quality of life during treatment. Your child's cancer team will be able to tell you more about what side effects your child is most likely to have, and how they plan to manage them.

Feeling and being sick

This may happen when chemotherapy drugs are given or after a day or so. The sickness may last for several days and most children are affected to some extent, but anti-sickness drugs can help control this. Babies and very young children seem to have less sickness than older children.

Losing hair

This is the most visible side effect of chemotherapy and it affects all hair – not only on the head but also eyebrows, eyelashes and other body hair. Losing hair begins after starting treatment, most often within two weeks. Hair usually grows back within a few months of stopping treatment.

The idea of hair loss is usually very upsetting to parents and quite a shock to your child. Changes in appearance can affect a child's confidence, especially older children and teenagers. Many children quickly get used to their appearance.

Some children might like to wear bandanas, hats, scarves or a wig. Other children like having no hair. Your child's team can give you help and advice about talking to your child and options available.

See our storybook and animation for young children 'Anna loses her hair' **www.cclg.org.uk/publications**

Low resistance to infection (called neutropenia)

Many chemotherapy drugs reduce the production of white blood cells, which lowers your child's immunity and makes them prone to infection (neutropenic) during treatment. This effect usually begins about seven days after treatment is given. After a few days, the number of blood cells will then increase steadily to return to a safe level before the next chemotherapy drugs are due.

Before each round of chemotherapy, your child will have a blood test called a 'full blood count' (FBC) to make sure that all blood cells such as levels of haemoglobin, number of platelets and the number of neutrophils in the blood have recovered. If levels are still low, then the next course of treatment may be delayed until your child's blood reaches a safe level again.

If your child is receiving an intensive drug regimen, the drugs will usually be given according to the protocol, whatever the blood count. This may mean that your child's blood count is low for much of the treatment. Therefore, your child will need to stay under close observation at all times for signs of infection so they can be quickly treated with antibiotics if needed.

At certain times in your child's treatment they may be given G-CSF (granulocyte-colony stimulating factor), which helps the body to make stem cells and therefore aids recovery. This is given by injection, either intravenously through a line or port, or sub-cutaneously under the skin. How G-CSF is given will depend on the treatment your child is receiving and may differ between treatment centres.

Bruising or bleeding

Other parts of the blood such as platelets and red cells, are also reduced in number by chemotherapy. If the platelets become low, then your child is at risk of bleeding more easily, such as nosebleeds and bleeding gums. For example, if your child has a troublesome and long nosebleed whilst their platelets are low, a platelet transfusion will be given. Your child might also become anaemic because of low numbers of red cells. If this happens, they will receive a blood transfusion.

Constipation or diarrhoea

Some drugs can change the way the bowel works so your child may have diarrhoea or constipation. We encourage you to let hospital staff know if constipation becomes a problem as laxatives can be given to relieve it. Diarrhoea usually gets better without medication and it's important for your child to drink plenty of fluids. Occasionally, anti-diarrhoea medicines may be needed. If your child has persistent diarrhoea, please let your hospital know as it is possible that they may become dehydrated.

Sore mouth (called mucositis)

Some drugs can cause a sore mouth which may lead to mouth ulcers. Mouth care is very important, and the nurses will show you the best way to care for your child's mouth. The doctor may prescribe mouthwashes or other medicines to help.

Losing weight

Both neuroblastoma and chemotherapy may cause weight loss and this is very common. Your child's doctor will consider different ways of making sure your child still receives enough nutrition if this happens. This may be through dietary supplements such as high-calorie milkshakes and powders, or by feeding through a tube passed via the nose into the stomach.

A nasogastric (NG) tube is a thin soft tube that goes down the nose and into the stomach. This is not very pleasant when it is inserted. Sometimes, a gastrostomy tube (PEG) is needed which is surgically placed into your child's stomach. Many families feel upset about feeding tubes. It is not your or your child's fault if a feeding tube is needed and many children have them during treatment. If required, the tube will enable your child to get the nutrition and oral medicines they need. Your child's medical team, which includes a fully qualified dietitian, will talk to you about this.

Download or order free of charge 'Helping your child to eat well during cancer treatment' **www.cclg.org.uk/publications**

Effects on the heart

Some drugs such as doxorubicin can potentially affect the way your child's heart works by causing damage to the heart muscle. Your child will undergo regular tests, such as a heart ultrasound scan (called an echocardiogram), to assess how well their heart is working both during and after completion of their treatment. This can be long-term and care may be needed after treatment is complete.

Effects on the nerves

Some chemotherapy treatments such as vincristine can potentially cause damage to your child's nerves. This can cause your child to have numbness, tingling or painful hands and feet. Some children find it can affect their walking or fine hand movements like picking up small objects. This effect usually recovers after the treatment is stopped.

Emotional/psychological effects

Having cancer and treatment for it is often scary and can be traumatic for children. Being away from home and feeling unwell with side effects can affect behaviour and confidence. Your child may not be themselves and may become clingy, argumentative or emotional. Children may need help to process difficult feelings and help them cope. Play specialists can help with preparing for and coping with procedures. Talk to your team if you feel your child is overwhelmed and needs extra support.

Effects on the liver

This is called veno-occlusive disease (VOD) and is one of the less common, but serious complications that can occur during high-dose chemotherapy and stem cell transplant. VOD is not an illness but a complication that affects the liver. It can range from mild to severe, and occurs in approximately 10-30% of children or young people who receive busulphan or high-dose melphalan as part of their conditioning treatment before stem cell transplant. Although it is serious, it is usually a temporary problem, but it can be more complicated or even cause long-term problems. Your child's consultant will discuss this in more detail with you.

Effects on hearing and the kidneys

Some drugs, such as cisplatin, can affect your child's hearing and potentially damage their kidneys. Your child will undergo regular hearing tests (audiograms) to monitor any effects. A test to measure how well the kidneys are working ('glomerular filtration rate' (GFR) test) will be done. In this test your child receives an injection of radioactive substance (not harmful to your child) into a vein in the hand or arm. Blood samples are then taken at specific intervals over a period of time. These effects can be long-term and care may be needed after treatment is complete.

> "It was hard to accept that there were difficult side effects, some of which could be life-threatening, or long-term. But we knew that the alternative was worse, and that we could support her with whatever she might need in the future if we could get through this now."

Dry skin from 13-cis-retinoic acid

13-cis-retinoic acid is a high concentration vitamin A. A lower dose is often used in the treatment of acne. The medicine can cause the skin to become very dry and sometimes crack. To prevent this, regularly use emollient creams such as vitamin E, particularly on exposed areas like the face, lips and hands. Avoid perfumed creams, soap and body wash.

Future fertility

Parents can also be concerned about the effects of chemotherapy on their child's ability to have children in the future. A long-term outcome of present treatments for neuroblastoma is difficult to predict, but in some cases it is known they are harmful to fertility.

There are some treatments aiming to maintain fertility for children undergoing treatment for neuroblastoma. Your child's medical team may discuss this with you.

It is known that the drugs cyclophosphamide, busulphan and melphalan can be damaging to fertility when given in high doses. However, this side effect has to be weighed against the potential benefit of using these drugs. Busulphan and melphalan were found to be superior to another high-dose chemotherapy regimen in a large clinical trial. These drugs are currently considered to be the best combination and are therefore part of the current high-risk neuroblastoma treatment protocol.

Reactions to immunotherapy treatment

Many children with neuroblastoma will receive immunotherapy treatment, using an anti-GD2 antibody drug called dinutuximab beta. This treatment can often cause a reaction whilst your child is receiving the infusion. Children can notice tummy pain, numbness, tingling, a rash, swelling, dizziness or a sensation of the heart racing.

Usually medication to help with these symptoms, including pain, is given. Your child will be closely monitored throughout this treatment and you should alert a member of staff if you have any concerns.

There are many different medications which can help with side effects and sometimes it is a case of finding the right combination that will work for your child. Medicines may be given via different methods including IV, orally (or via NG tube) or as a skin patch. The method of administration will depend on your particular child and their needs. At times your child may have lots of different medicines to take and this can be difficult to keep on top of. Your team will help you with this.

Taking part in clinical trials

Most children treated for neuroblastoma at one of the specialist children's cancer units in the UK are offered cancer treatment within a clinical trial. These are research studies carried out to try and find new and better treatments for cancer such as a new drug or combination of treatments. These trials usually build on existing knowledge and treatment protocols and ask specific questions aimed at improving neuroblastoma treatments further. By doing this through clinical trials, we can make sure that comparisons are measured consistently and reliably over time to see if one treatment is better than another.

Your child will receive the best possible treatment regardless of whether they are on a trial or not. If a trial is suggested, you will be given information about it and

what is involved. You will need to consent to the trial as well as to the treatment itself. Your child's consultant will be able to discuss potential clinical trials with you.

Giving your consent

Before your child is asked to take part in a clinical trial, your child's medical team will explain what the trial is aiming to achieve and the risks and benefits of taking part. Once you have considered everything you need to know, you will be asked to give your consent for your child to take part and sign a form. There is no pressure to take part and your child will receive the best treatment available, whatever you decide.

When deciding whether to take part in a trial, it can add to the stress of coping with your sick child and the bewildering range of processes associated with treatment. It may seem as though the treatment team is passing over responsibility for deciding what treatment your child should be given. However, in practice, the treatment team will only invite you to join a trial when it is considered in the best interests of your child and where both you and your child are likely to benefit.

Randomisation

For some trials, a process called randomisation is carried out. This means a computer will randomly allocate your child to have a particular treatment in the trial. This is done so that each treatment group has a similar mix of children of different ages, sex and general health. It makes sure that researchers and doctors can't decide who should get which treatment to avoid bias that could skew the findings.

Safety

The safety of children in clinical trials is the top priority. All trials are approved by ethics and regulatory committees, and are reviewed on an ongoing basis.

Download or order free of charge 'Taking part in clinical trials' **www.cclg.org.uk/publications**

Donating to a tissue bank

Your child's hospital team will offer you the opportunity to anonymously donate tissue left over from tests carried out, such as a biopsy or bone marrow test, to the national children's and young people's cancer tissue bank called VIVO Biobank (**www.vivobiobank.org**). This sample of tissue can then be used by scientists to learn more about neuroblastoma and how best to treat it. This is voluntary and you will have plenty of time to decide if you wish to take part.

> "The hardest part about getting involved with clinical trials for us was the burden of decision making. We struggled with the decision ultimately landing with us and how we would feel if our child's health got worse following this. We talked to our consultant, charities offering family support and other parents and it became clear that the only way to deal with it was to base our choice on what we did and didn't know right then, and make peace with the knowledge that it was the right decision for that time."

After treatment

There are now over 45,000 survivors of childhood cancer in the UK who are supported with specialist health care and advice. Many survivors lead a fit, healthy and full life.

When treatment finishes, your child will be given a summary of the treatment they have received and a specialised follow-up plan. They will be seen in clinic over the next few years and the frequency will depend on the needs of your child.

To start with, the focus is to make sure there are no signs of the cancer coming back (called 'relapse'). As time passes, follow-up will also look for and treat any long-term effects that might happen as a result of the cancer and its treatment (called 'late effects').

These possible late effects can include effects on their heart, lungs and growth hormones. They may also be at a higher risk of developing cancer again in the future, so it is important that your child attends their follow-up clinic appointments. You can help your child to reach their full potential by encouraging healthy lifestyle choices. For more information see the 'Living beyond cancer' section on the CCLG website: **www.cclg.org.uk/living-beyond-cancer**

For many parents, reaching the end of treatment can bring mixed emotions. Whilst you may feel happy and relieved that treatment has come to an end, you may also feel anxious, scared and nervous. It can be a very unsettling time. These feelings are normal. Your hospital team will continue to support you once treatment has finished.

Download or order free of charge 'A parent's guide to finishing treatment' **www.cclg.org.uk/publications**

> "Ending treatment feels unreal. Stopping feels wrong after fighting for so long. You're on your constant guard for return of disease and stepping away from this takes a very long time."

If neuroblastoma comes back or doesn't respond to frontline treatment

If your child's neuroblastoma comes back during or after initial treatment, it is called **relapsed disease** and it is often possible to control the disease for years. However, it is usually difficult to achieve a complete cure. Sometimes neuroblastoma does not respond well to the initial treatment – this is called **refractory disease.**

For patients in the UK who have relapsed or refractory neuroblastoma, there are a number of treatment options available. These include chemotherapy, early phase clinical trials, and radiotherapy. For more information, see our factsheet, 'Treatment options for relapsed or refractory neuroblastoma'. **www.cclg.org.uk/publications**

If your child has relapsed or refractory neuroblastoma, choosing which treatment is right for your child will depend on many things. This includes where their disease is and what treatment they have already received. Your child's doctor will be able to help you decide which is the most appropriate treatment for your child at this time.

Being told your child's neuroblastoma has come back or not responded to initial treatment can be a shock. It is common to feel scared, angry and worried about the unknown and the decisions you may need to make. The REDMAPP website has lots of information and support for parents and carers who are having to make treatment decisions for their child. See **www.redmapp.org.uk**

Going for treatment overseas

There has been some media coverage of families who have decided to take their child with neuroblastoma for treatment abroad. The decision to take a child abroad for treatment is always best taken by you and your family and the consultant caring for your child. A lot of factors will need to be considered. The treatment itself (invasiveness, duration, side effects, outcomes) as well as the emotional and financial impact this decision may have on you and your family all have to be thought about carefully. Some children might not be eligible for a particular treatment in the UK. For other children, going abroad will provide the opportunity to receive experimental therapies that are not available in the UK but are available in other countries.

If treatment doesn't work

In some cases, parents are told the devastating news that their child's cancer cannot be cured. Your child's care will change to focus on giving the best quality of life and managing their symptoms. There is a huge amount of practical and emotional support for families at this time, such as from your child's hospital, local hospice and charities.

CCLG has a range of resources to help parents to prepare and plan if treatment doesn't work. These can be found at **www.cclg.org.uk/about-childhood-cancer/my-child-cannot-be-cured**

Caring for yourself and other family members

Your child's diagnosis will have an emotional effect on everyone in your family, as well as many friends and even acquaintances in the wider community. This section addresses your needs because, as a parent, your wellbeing is crucial to your child and the rest of your family.

Looking after yourself

Having a child diagnosed with neuroblastoma has a huge impact on a parent or carer. You will likely have different feelings at different times, with periods of frustration, anger, fear, anguish, panic and grief. At some other times, you may feel quite calm, as you and your child settle into the routine of treatment.

You will probably find that your emotions go up and down a lot during the days and weeks following diagnosis, and that your feelings change over time. When you notice a difficult or uncomfortable emotion, try to calm yourself and notice what you are feeling, rather than pushing it away. Sometimes, your feelings might spur you to take action or make a change At times, even though it may be difficult, talking things through with someone you trust can help.

One of the best things you can do for your family is to take care of your own needs. Eating and sleeping well, getting fresh air outside, addressing any health problems and taking regular breaks are all important. By meeting your own needs, you can be there to help everyone else.

Social

- create boundaries
- use for communication
- ask for help
- seek out positive media

Work

- ask for help from colleagues
- talk to your manager about work options

Hobbies

- make time to chat with friends
- keep up with other interests to help distract and relax you

Physical

- sleep
- stretching
- walking
- healthy eating
- ask for help if struggling to eat or sleep

Emotional

- managing stress
- kindness
- forgiveness
- ask for professional help if feeling overwhelmed
- acceptance

Financial

- saving
- budgeting
- ask social worker for help with grants and benefits
- paying bills

Supporting your child

The effect of a cancer diagnosis and treatment will depend on the age of your child. As well as feeling unwell and coping with side effects, they may be missing home, family and friends, and may struggle with the change in routine. If they are not able to say how they are feeling, they may express this through behaviour such as clinginess, tantrums or tearfulness.

Children may be frightened about being separated from their parents. It's important to reassure them that any separation is only temporary. Doctors and nurses will be happy to explain more about this and can help you reassure your child.

One of the hardest parts of caring for a child with cancer is knowing what to say and how much information to give them. Many families feel that answering questions honestly is best, giving a little information at a time. Some children may not ask questions, but this doesn't mean they don't want to know what's happening. They may be frightened and uncertain of many things. Some children may even wonder if they have done something wrong and that's why they have cancer.

You can ask your child's medical team for guidance on how to talk to your child. There are also booklets for young children available from CCLG and Young Lives vs Cancer that can help you explain the illness and treatment.

Our storybooks for young children are available free of charge from your child's hospital or from our website: **www.cclg.org.uk/publications**

Supporting siblings

Brothers and sisters of a child with cancer may have many or all of the same feelings and emotions that you have. If you need to spend a lot of time in the hospital with your child, your other children may have to be cared for by family members or friends. They may have to spend a lot of time away from you and find their daily routine keeps changing. As well as worrying about their sibling's health, they may also feel resentful of all the attention they're getting. This can make them feel left out and angry. Being there for them and showing that you still love them can help to reassure and comfort them.

Download or order free of charge 'Supporting brothers and sisters' **www.cclg.org.uk/publications**

> "We tried to include her older sister in visiting wherever possible. It helped them both and meant that we still had family time, even if it was in hospital. They both have some good memories from that time, which I am grateful for."

Supporting your child at school

As your child's health improves, they may be able to go back to school. This is important for their educational, psychological and social development. It is also important for the whole family as school routines can help everyone return to a sense of 'normal life'. As soon as your child is diagnosed, contact your nursery or school's head teacher to tell them what's happening and let them know about the plans for treatment.

Many children diagnosed with neuroblastoma are very young and have not yet started school. As a parent, you may have to choose between having your child at nursery throughout treatment or keeping them at home. Keeping your child at home may mean they have less chance for social growth and development, but if they stay at nursery you may feel there is a risk of infection.

There is no right or wrong decision – it's a personal choice for you to make. You may want to think about whether your child:

- is already settled at nursery or pre-school
- has their social needs met by siblings and/or other children outside of nursery
- is well enough to attend nursery or pre-school
- has already had chickenpox, which can be harmful for children on treatment

It may help to talk to your community nurses, specialist nurse or social worker about attending school or nursery and the support they can offer with this. They will often liaise on your behalf.

Download or order free of charge 'A school's guide to supporting a pupil with cancer' **www.cclg.org.uk/publications**

Supporting grandparents

Being told that their grandchild has cancer will be a huge shock for your parents. They will not only worry about their grandchild but also about how you will cope. Most are also concerned about the effects it will have on any other children in your family and, how they will cope themselves. As parents, you will have access to doctors and others who can answer your questions. It is not so easy for grandparents to get information first hand and this can lead to feelings of stress and isolation. Keeping them involved, by allowing them to help you and your family if they are able to, can help them play a valuable role supporting their family.

Download or order free of charge 'Supporting your grandchild and family' **www.cclg.org.uk/publications**

Seeking information

You may want to find out as much as possible about the cancer and its treatment. The internet can be a valuable source of information, but it is important to be aware that there is much that is either incorrect or unhelpful. Always use well-known, reputable sites. Check when information was published and where a site is based. Information from other countries may not always be relevant. Don't worry that your child's doctor will be offended if you turn up with a list of questions about things you have found out online. They will take you seriously and give you honest, balanced advice based on your child's individual situation.

Using social media

Facebook, blogs and other social media outlets offer an easy and instant way of communicating with others. Families can tap into a supportive network of fellow parents from around the world all facing a similar journey. Regardless of what country families live in, the feelings and human experiences of having a child with cancer can be the same. It is easy to be drawn to other cancer stories but it is important to be aware that other people's posts may not be relevant to your child, and may not be factually accurate. Some families have found setting up a closed group on social media is helpful as it allows them to send updates out without having to talk to lots of different people individually.

> "I have found social media incredibly helpful to connect with other parents with similar experiences who can answer some of my questions or point me towards helpful information, but it does come with a health warning. I've had to develop a filter for the posts and replies that are either unhelpful or overwhelming; it's a powerful tool to be used wisely and with care."

Glossary

Adrenal glands
Glands above the kidneys that release hormones to maintain blood pressure and enable us to respond to stress. About 50% of neuroblastomas start here.

Anaplastic lymphoma kinase (ALK)
A protein involved in the normal development of the nervous system. The gene that controls the production of this protein is mutated in around 8-10% of cases.

Anaesthetic
A general anaesthetic makes you unconscious. A local anaesthetic stops feeling in part of the body but you are still awake. Both stop feeling, especially pain.

Biopsy
Removal of a small piece of tumour for testing to establish a diagnosis.

Bone marrow
The substance at the centre of long bones that makes blood cells.

Catheter
Tube that is passed into the body to drain fluid.

Central line (Hickman line, portacath)
Long plastic tube that is inserted into a large vein near the heart under anaesthetic. Central lines are used to take blood samples and give drugs.

Chemotherapy
Treatment using one or more anti-cancer drugs.

CT scans
Multiple X-rays are taken by a CT scanner and converted by a computer to form a 3D view of the part of the body under examination.

Ganglioneuroblastoma
A type of tumour closely related to neuroblastoma.

Genetic
Condition caused by abnormal genes (may be inherited).

Haemoglobin (HB)
The substance in red blood cells that carries oxygen around the body.

Homovanillic acid (HVA)
A substance found in the urine in raised amounts when a child has neuroblastoma.

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

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

Immunotherapy
A form of treatment which relies on cells of the body's own immune system to kill cancer cells.

Immunosuppressive
Lowering the body's ability to fight infection.

Intravenous (IV)
Into a vein, for example, when drugs are given directly through a drip.

Malignant
Cancerous.

Metastases
Cancer that has spread from the place where it started (also known as secondary cancer).

mIBG (meta-iodobenzylguanidine)
A radioactive substance taken up by neuroblastoma cells used in a type of scan that helps to locate neuroblastoma cells in the body.

MYCN
A gene which is amplified (present in many more copies than the normal number of two) in a cell. Found in around 25% of cases. A *MYCN* test is used to determine how aggressive a particular neuroblastoma may be.

Nausea
Feeling sick.

Neutropenia or neutropenic
Low levels of neutrophils.

Neutrophils
A type of white blood cell which fights infection.

Oncologist
A doctor who specialises in the treatment of cancer.

Oncology
The study and treatment of cancer.

Paediatric
To do with children.

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

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

Prognosis
The outlook or expected outcome of a disease and its treatment.

Radiotherapy
The use of radiation to treat cancer.

Refractory
Resistant to treatment.

Relapse
The return of symptoms of a disease after a period of good health; re-occurrence of a tumour after treatment.

Remission
When there is no longer any visible cancer.

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

Therapy
Treatment.

Tumour
An abnormal lump of tissue formed by a collection of cells. It may be benign (non-cancerous) or malignant (cancerous).

Ultrasound scan
The sound waves produced by a scanner bounce from solid organs inside the body and are recorded on a screen. Allows doctors to see the outlines or shadows of normal organs and tumours.

Vanillylmandelic acid (VMA)
A substance found in the urine in raised amounts when a child has neuroblastoma.

White blood cells (WBC)
Blood cells that help fight infection.

Whole genome sequencing (WGS)
Test looking at all genetic changes in a tumour.

Help and support

CCLG: The Children & Young People's Cancer Association
www.cclg.org.uk
Information and guidance, funding of research, and a full range of award-winning patient information resources, including Contact magazine, for families of children with cancer.

Join our closed Facebook group just for parents and carers of a child with cancer: **www.facebook.com/groups/cclgparentcarergroup**

Scan to order or download this booklet or any other CCLG publications FREE of charge **www.cclg.org.uk/publications**

Parent/patient videos
www.cclg.org.uk/neuroblastoma#neuroblastoma-videos
CCLG, in association with the clinical trial HR-NBL2, has created videos to explain treatment for high-risk neuroblastoma and the HR-NBL2 trial.

Redmapp
www.redmapp.org.uk
Website with help and information to support and guide parents through treatment decisions for relapsed and refractory neuroblastoma.

SIOPEN
www.siopen.org
Brings together clinicians from across Europe to improve the outcomes for patients with neuroblastoma. International collaboration is vital to ensure there are enough patients to take part in clinical studies. This allows us to learn more and improve treatments.

Young Lives vs Cancer
www.younglivesvscancer.org.uk
FREE helpline: 0300 303 5220 Provides advice and support for families affected by childhood cancer.

The Little Princess Trust
www.littleprincesses.org.uk
Provides free real hair wigs to children with hair loss and funds research into childhood cancers.

Macmillan Cancer Support
www.macmillan.org.uk
FREE helpline: 0808 808 0000. Practical, financial and emotional support for anyone affected by cancer.

Cancer Research UK
www.cancerresearchuk.org
Cancer information and a funder of cancer research.

Solving Kids' Cancer UK is a dedicated children's cancer charity, with a particular focus on neuroblastoma.

They strive for better outcomes for children affected by cancer both now and in the future under three key pillars of research, support and awareness. SKC are passionate about speeding up pioneering clinical research to save lives and improve outcomes for children. Their Family Support Services provide emotional, practical and financial support to families across the UK. Together with partners, they advocate for greater and better access to treatments that will improve survival and quality of life for children with cancer.

Solving Kids' Cancer UK
support@solvingkidscancer.co.uk
www.solvingkidscancer.org.uk
0207 284 0800

solvingkidscancer365 skc_uk skc365

Registered charity England and Wales (1135601) and Scotland (SC045094)

Neuroblastoma UK is a charity dedicated to funding research into the causes and treatment of neuroblastoma.

It has been dedicated to funding research to improve the understanding of neuroblastoma, and move treatment forwards, for over 40 years. In addition to awarding grants to researchers, it has facilitated communications and collaboration between UK and international researchers through its well-attended biennial research symposia, most recently in 2024. NBUK works closely with other organisations, such as Solving Kids' Cancer and CCLG, to raise awareness and campaign for better funding and treatment of childhood cancer.

Neuroblastoma UK
hello@neuroblastoma.org.uk
www.neuroblastoma.org.uk
020 3096 7890

NeuroblastomaUK Neuroblastoma_UK

Registered charity England and Wales (326385) and Scotland (SC053101)

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We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care, and outcomes.

Our expert information helps children and young people and everyone supporting them to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Our work is funded by donations. If you would like to help, visit **www.cclg.org.uk/donate** or text '**CCLG**' to **70085** to donate **£3.** You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.

We want our information resources to be relevant and useful. Tell us what you think by scanning this code to complete a short survey or contact us at publications@cclg.org.uk