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FIGHTING CHILDHOOD CANCER

Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

A parent's guide to neuroblastoma

Information and support for when your child is diagnosed with a type of cancer called neuroblastoma

www.cclg.org.uk

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About this guide

This guide has been written with the help of experts and parents whose children have had neuroblastoma. 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 provides a reference to the information you have already been given, or will be given in the future, and will act as a helpful reminder for any discussions you have with your child's treatment team.

This guide is a general overview of neuroblastoma. 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 hope it helps answer your questions so that you understand more about neuroblastoma and its treatment.

We strongly recommend this guide is read in conjunction with our main resource entitled '**A parent's guide to cancer**' which is designed to accompany you through every step of the cancer experience.

Contents

Beginning the journey

When you are told that your child has neuroblastoma, it can feel as if your life has turned upside down overnight.

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. All of these feelings are completely normal and many parents say that they felt the same.

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.

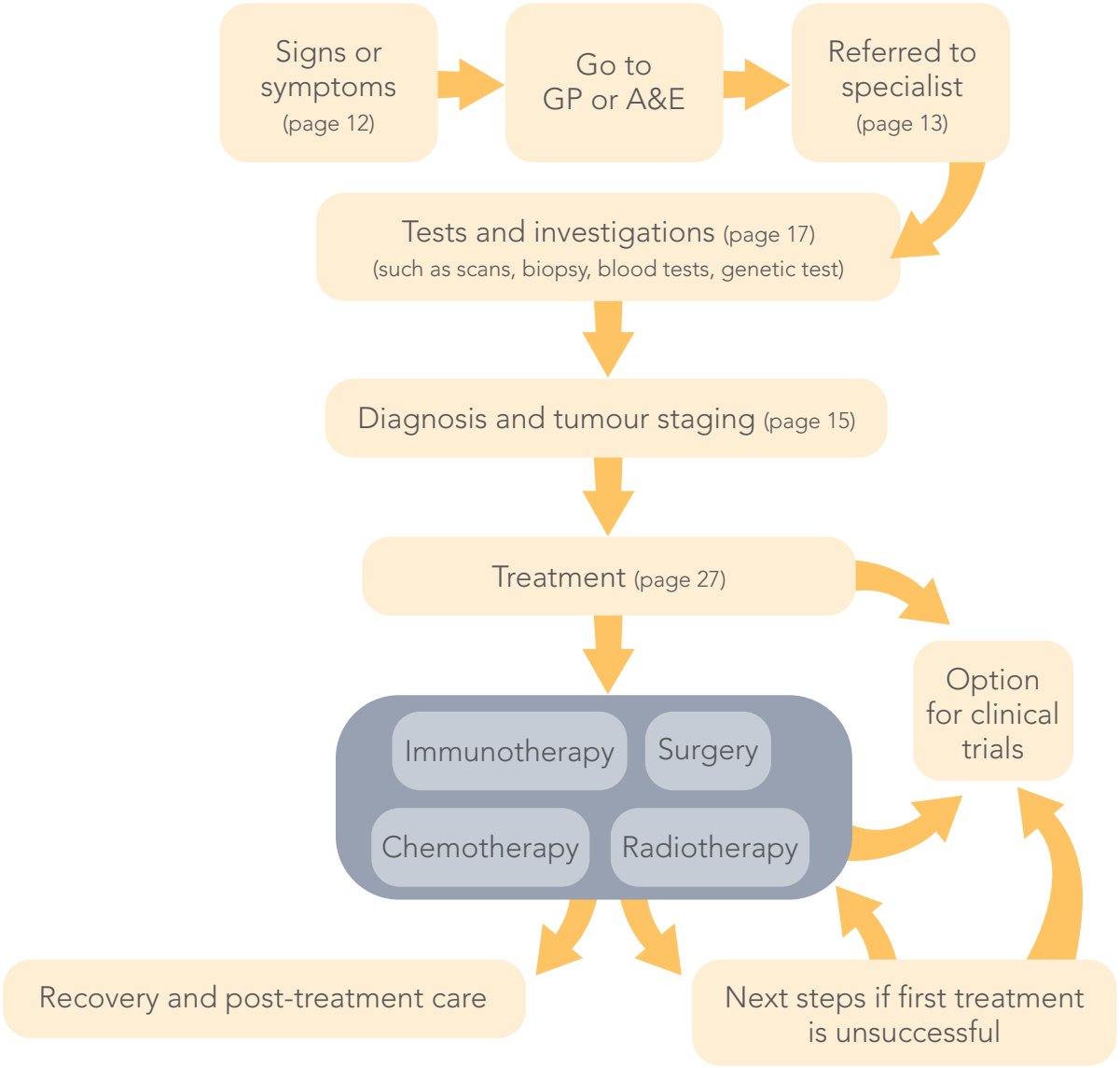
Many parents cannot think of any questions to ask during a hospital consultation but think of all sorts of things as soon as they get home. It is a good idea to write down questions as soon as you think of them so that you can discuss them at the next opportunity.

When a 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.

TOP TIP

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

Neuroblastoma – your child's healthcare journey



About neuroblastoma

Neuroblastoma is a cancer that is almost always found in children. Childhood cancers are usually different from cancers affecting adults. They tend to happen in different parts of the body to adult cancers and behave differently. Cancers in children also respond differently to treatment.

What is neuroblastoma?

It is the second most common solid tumour in children after brain tumours.

Around 100 children in the UK are diagnosed each year with neuroblastoma, making up about 6% of the total number of childhood cancer diagnoses.

It primarily affects younger children and is the most regularly found solid tumour in infants under the age of one, making up around a fifth (22%) of all cancers diagnosed at this age. It is rare for children to be diagnosed with neuroblastoma over the age of five. Only 2% of neuroblastomas are diagnosed in children over the age of 10 years and 0.5% in those over 15 years old.[1]

Neuroblastoma is classified as an **embryonal tumour**, a type of cancer that develops from the cells left behind from a baby's development in the womb. The cells from which it develops from are specific cells in the nervous system called neuroblasts, giving neuroblastoma its name:

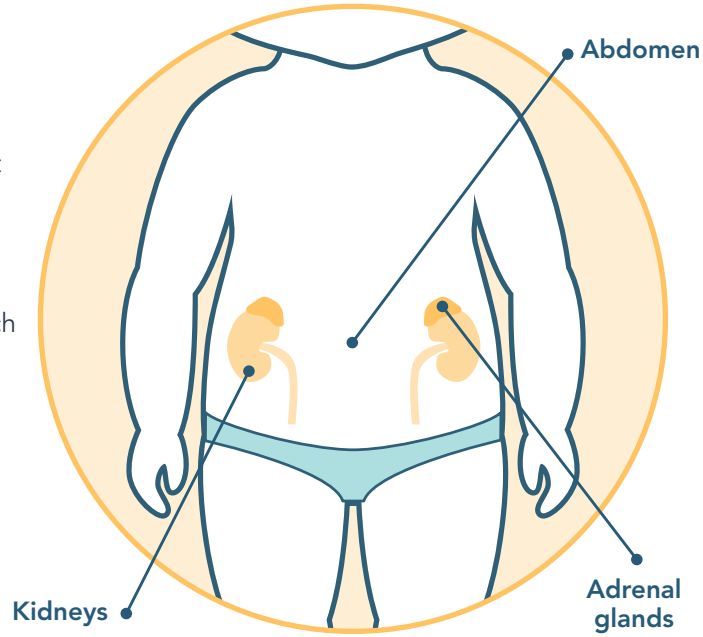
- 'neuro' means nerve
- 'blast' means cells in an early stage of development
- 'oma' means a group of cells, or a tumour

[1] Cancer Research UK. (2014). Children's cancer incidence statistics. [ONLINE] Available at: www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers/incidence#heading-Ten. Last accessed 01/04/2019.

Neuroblastoma can happen anywhere in the body. The most common place for the 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 and skin.



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.

Around 1% of neuroblastoma cases are hereditary, 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 patients who are younger than 18 months old, with more than one primary tumour. In the situation where two or more family members have neuroblastoma, screening of other family members with genetic testing for the above genes, urine testing and ultrasound examination is recommended and will be discussed with you, together with referral to a clinical geneticist.

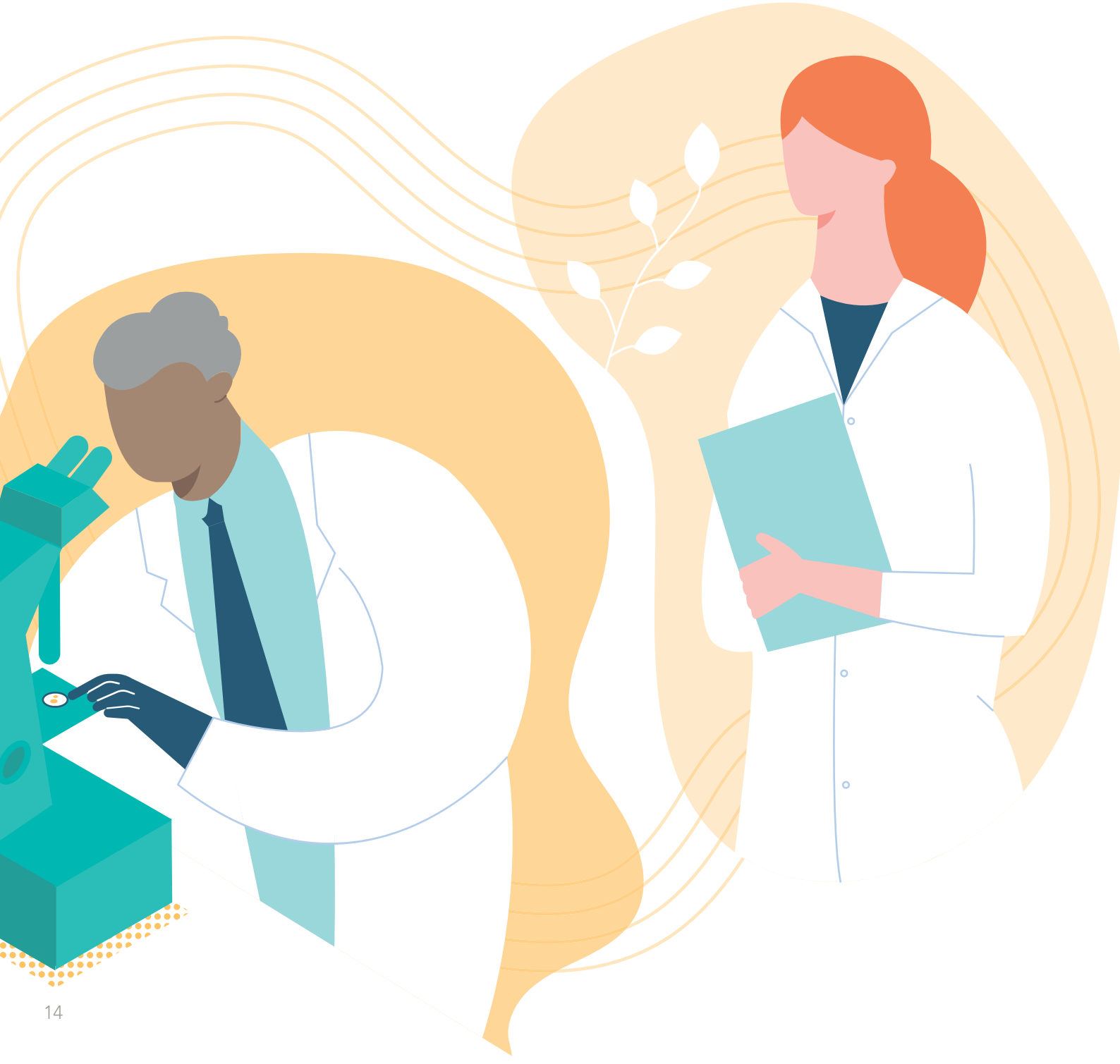
What are the signs and symptoms?

Many children with neuroblastoma have little in the way of symptoms. Perhaps they have seemed unwell for a little while or have not been eating much, complaining of vague aches and pains or unexplained sweating. Unless a parent or doctor feels a lump while bathing, dressing or examining the child, a diagnosis of neuroblastoma may not be initially considered.

It is possible that many of the symptoms your child has are similar to those of more common, less serious childhood illnesses. Many parents wonder if they or a doctor should have noticed something sooner, but because this is such an uncommon disease, neuroblastoma is rarely suspected if only fairly vague symptoms are present. Neuroblastoma, particularly 'high-risk' neuroblastoma, often shows itself at a late stage when it has spread around the body.

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.



Diagnosis

If cancer is suspected, your child will be referred by your GP or A&E staff to your nearest children's hospital which has a specialist children's cancer (called paediatric oncology) centre. These centres are located in a network of 20 hospitals in the UK and Ireland with expertise in managing and treating all childhood cancers, including neuroblastoma.

1 **Aberdeen:**
Royal Aberdeen Children's Hospital

2 **Edinburgh:**
Royal Hospital for Sick Children

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 Queens Medical Centre, Nottingham and Leicester Royal Infirmary

8 **Cambridge:**
Addenbrooke's Hospital

9/10 **London:**
Great Ormond Street Children's Hospital and University College London Hospital

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 undergo many different tests in order to confirm whether your child has cancer, what type 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.

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; this procedure is known as a 'needle biopsy'.

The tumour sample is then sent to a laboratory to find out if the tumour is made up of neuroblastoma cells and to look at the biology of the neuroblastoma by looking 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 also acts as a good way of monitoring the side effects of treatment.

Blood tests are common throughout cancer treatment and the clinical team can apply local anaesthetic cream to the skin to make the needle less painful.

Urine tests

A simple specialised test in the diagnosis of neuroblastoma measures 'vanillylmandelic acid' (VMA) in your child's urine. You may hear this test referred to as either the 'VMA' or 'urine catecholamine' test. VMA is a chemical found in the urine in raised amounts when a child has neuroblastoma, and this is a good indicator of diagnosis. Sometimes a similar marker called 'homovanillic acid' (HVA) is also measured. These urinary markers are raised in nine out of 10 cases of children with neuroblastoma. As these VMA/HVA chemicals are produced by the tumour, as well as being useful to help with diagnosis, they can be used to measure tumour activity during treatment, so are sometimes referred to as tumour markers.

Scans and x-rays

Your child will have a number of x-rays and specialist scans to confirm the diagnosis of neuroblastoma. The scans will show where the main neuroblastoma ('primary tumour') is in their body, 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' during some CT scans, or the injection of radioactive liquid for a bone scan or mIBG scan, none of these investigations are painful to your child. However, it is appreciated that they may feel unsettled or frightened. Some of the scans require that your child remains still for quite some time and to assist in this a general anaesthetic (where your child would be asleep) may be needed to have some of the tests. These will be discussed with you prior to any scans being done.

X-rays

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 the body.

Ultrasound scans

The ultrasound scan will be a familiar procedure to all mothers who had this performed during their pregnancy. The sound waves produced by the scanner bounce from solid organs inside the body and are recorded on a screen. The doctors can see the outlines or shadows of normal organs and tumour inside the body.

mIBG scans

This type of scan looks for abnormal cell growth within in the body. It involves injecting a type of isotope called meta-iodobenzylguanidine (mIBG) into your child's veins which then travels around your child's body and is naturally absorbed by neuroblastoma cells. mIBG contains a harmless level of radioactive material so when mIBG builds up in the neuroblastoma cells, a scanner called a gamma camera can detect them as 'hot spots'. 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

This type of scan will show how much the cancer has spread to the bones. It involves injecting a small dose of radioactive liquid 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) uses magnetic fields and radio waves to build up a detailed picture of a part of the body, and 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 sometimes be used to assess how your child may be responding to treatment. FDG stands for 'fluorodeoxyglucose' and PET stands for 'positron emission tomography'.

Bones and bone marrow

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 (see above).

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

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).

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. Most genetic tests are carried out at a specialist laboratory called the National Neuroblastoma Genetics Reference Centre.

There is a small chance that some genetic tests will reveal that your child had an increased hereditary risk of getting neuroblastoma. This information will be shared with you when it is in the best interests of your child and will involve referral to a genetics specialist.

It can take several days for any tests to be completed and the results analysed. Undergoing these tests and waiting for results is an extremely anxious and stressful time for families. However, exact assessment of the extent of your child's tumour before beginning treatment is very important. The results found will allow your child's doctor to select the right type and length of treatment for your individual child.

Tumour 'staging'

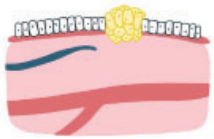
When your child is diagnosed, you will also be told what stage the cancer is at. This considers the size of the tumour and whether it has spread beyond the part of the body where it started.

Doctors recognise several categories of neuroblastoma that are grouped into different 'stages' and 'risk groups'. The treatment your child has for their neuroblastoma depends on their tumour 'stage' and 'risk group'. Knowing the stage of your child's cancer helps doctors make sure your child is in the correct risk group so that they can give the right treatment and care.

Doctors use imaging tests 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 neuroblastoma 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.

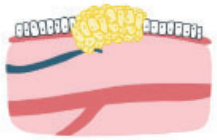
The **International Neuroblastoma Risk Group (INRG) Staging System** is used to assess the tumours of individual children to match the right treatment with the biology of their tumour taking into account risk factors and possible side effects.

The INRG stages:



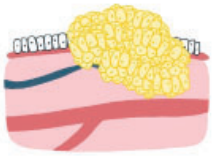
INRG stage L1 (INSS stage 1)

This means that the tumour is in one area (L = localised) and has not spread anywhere else in the body, so is able to be removed completely by an operation. This type of tumour is usually curable by surgery alone.



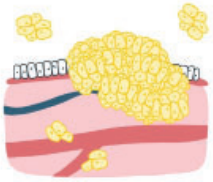
INRG stage L1 (INSS stage 2)

As with stage 1, the tumour is restricted to one area and has not spread anywhere else in the body. However, it may be larger than a stage 1 neuroblastoma and it may be more difficult to remove completely during an operation. Sometimes, a lymph node or some glands nearby may also be affected by the tumour. Stage 2 neuroblastoma is usually treated by surgery alone but depending on the site and results of certain genetic tests such as MYCN amplification, additional treatment like chemotherapy may be needed.



INRG stage L2 (INSS stage 3)

This stage of tumour is also confined to the primary location and has not spread to other parts of the body. The tumour may be large and said to have crossed the 'mid-line' of the body. This means that the tumour has grown right across the child's stomach or chest from the original side where it began to the other. This type of tumour would usually be difficult to safely remove with surgery alone. In other cases, the tumour may be wrapped around blood vessels that make it unable to be removed even though it is localised. Chemotherapy may initially be recommended to try to shrink the tumour before an operation, depending on the child's age and the biology of the tumour. After the operation, radiotherapy and an oral medication called 13-cis-retinoic acid may also be recommended in some cases.



INRG stage M (INSS stage 4)

This means that the primary tumour may be any size, but some neuroblastoma cells have broken away and spread to other parts of the body, most commonly to the bones, bone marrow or liver. Depending on age, children with stage 4 neuroblastoma will likely require more intensive treatment. 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 is a type of neuroblastoma most often found in very young babies, under one year old. The tumour cells may have spread beyond the primary location to other parts of the body, but the cells usually behave in a less aggressive way than in an older child. The areas of the body affected by stage MS neuroblastoma, in addition to a small primary tumour (which is often in one of the adrenal glands), are most typically the liver (which on occasions can become extremely large), skin, distant lymph nodes and sometimes the bone marrow but not bone, lung or the brain.

Note: The older INSS classification of neuroblastoma stages is also included seen here in brackets. This is because some research study results that used INSS to determine a child's risk group have not been published yet, and this information is needed to help decide on treatment options. For this reason, we have included them here as you might hear about both.

Ganglioneuroblastoma

Ganglioneuroblastoma is another type of tumour which 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.

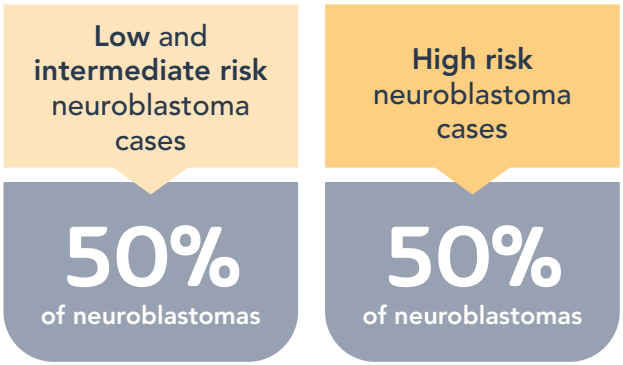
There are two types of ganglioneuroblastoma – intermixed and nodular. An intermixed ganglioneurobastoma is a benign (non-harmful) tumour which is either INRG L1 or L2 and, if it cannot safely be removed by an operation, it can often simply be observed.

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.

Knowing your child's neuroblastoma 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-** and **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-risk neuroblastoma

This group includes:

- infants aged 18 months or under at diagnosis with localised (L1)
- 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

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

Children with low-risk localised neuroblastoma who have symptoms which 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 removing the tumour by surgery later.

In some cases, children with low-risk localised neuroblastoma that is not causing any symptoms and whose tumour shows favourable biology (such as lack of MYCN amplification and no segmental chromosomal abnormalities) may not require any definitive treatment. Instead, they can be closely observed to monitor changes within their tumour which can naturally decrease in size.

Infants who are aged 18 months or under with low-risk L2 neuroblastoma which is not causing many symptoms and with favourable biology (no segmental chromosomal abnormalities) can be closely observed to monitor changes within their tumour, which may 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 possibly surgery regardless of whether they have symptoms.

Stage MS neuroblastoma

This is a type of low-risk neuroblastoma with a particular distribution of secondary tumours which can be to skin, liver, bone marrow, distant lymph nodes but not bone, lung or the brain.

When children are diagnosed with this pattern of neuroblastoma, your child's doctor may feel confident that your child will get better with no or very little treatment, as 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

This group includes:

- infants aged 12 months or under at diagnosis with neuroblastoma that has spread (M) without MYCN amplification
- children aged over 18 months with localised and inoperable neuroblastoma (L2) without MYCN amplification

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

Children with intermediate-risk neuroblastoma are initially treated with a period of chemotherapy. This is followed by careful reassessment of the position and extent of the tumour, including bone marrow examination, CT or MRI, mIBG, CT-PET or bone scan. In some children, it may then be possible to proceed with surgical removal of the tumour, or some children may require 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.

Very rarely, a child has stage L1, MYCN amplified, intermediate-risk neuroblastoma. In these cases, the child will also receive radiotherapy 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. Very occasionally, some children with intermediate-risk neuroblastoma will be discussed at a monthly meeting of the national neuroblastoma advisory panel and high-risk type treatment may be recommended.

High-risk neuroblastoma

This 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)

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

Children with high-risk neuroblastoma require intensive treatment of different types 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 immediately 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 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.

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 for a while so that they can be monitored when starting treatment.

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 just means that it is easier for families as they will need to travel less.

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

A lot of different professional staff will be involved in looking after your child, both at home and while they are in hospital. 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.

What your child's cancer care might look like...

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

- Your child's consultant
- Trained staff with expertise and knowledge about childhood cancer
- Full range of supportive care before, during and after treatment
- Specialist wards, facilities and resources

At home

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

CANCER CARE

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

Surgery

Your child's tumour will be removed during an operation if it is possible and safe to do so. In some children, surgery may be involved at a later stage of treatment. This is often after several cycles of chemotherapy have been given to shrink the tumour so that it can be more easily (and therefore more safely) removed by the surgeon. 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 your child has made a full recovery before surgery takes place. This will be discussed with you.

Chemotherapy

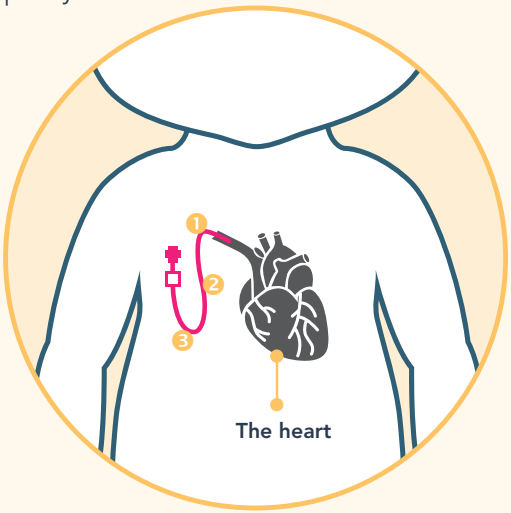
This is the main treatment for intermediate- and high-risk neuroblastoma. Chemotherapy is the use of drugs to destroy cancer cells. They can be given in different ways but the most common way is intravenously – into a vein – whether through injections, cannula, or a line such as a central line, implantable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

Giving chemotherapy to a child

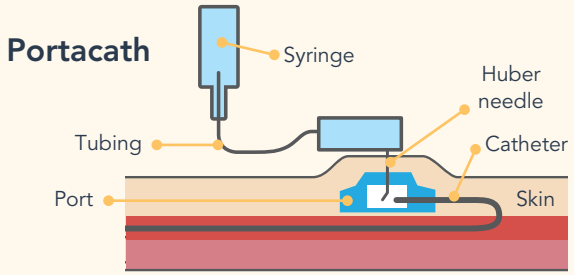
Central lines and ports are similar devices which make it easier to deliver chemotherapeutic drugs to your child and to take blood samples.

A **central line** (sometimes referred to as a wiggly) is a thin, flexible plastic tube that is inserted into a large vein near the collarbone under anaesthetic. This allows drugs to be injected and blood samples taken without having to use a needle.

The line can be seen taped to the child's chest and is normally covered by clothing. It is securely attached, should not fall out and should be kept dry.



1. Central line inserted into chest here
2. Line tunnelled under skin
3. Line comes out here



A **portacath** or **port** is an alternative device which does the same thing and is implanted under the skin usually in the chest. A small needle is pushed through the skin into the port to give drugs or take blood and has no part of it exposed outside of the skin. This has the advantage that swimming and sports are less of a problem.

High-dose chemotherapy

After surgery, children with high-risk neuroblastoma undergo further treatment with 'high-dose chemotherapy', also sometimes called myeloablative therapy. Rarely, high-dose chemotherapy may be given before surgery. The drug(s) used in this type of therapy usually consist of high-dose busulfan 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.

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 found in the bone marrow which makes many different types of blood cells for the body. The bone marrow can become damaged from high-dose chemotherapy so putting healthy stem cells back into the body afterwards can re-populate the child's bone marrow with new blood cells.

What happens?

Stem cells are collected from your child's blood using a machine. A catheter tube called a vascath is put into your child's vein under general anaesthetic. This catheter allows blood to be sucked into the machine through the vascath. The machine then collects the stem cells and returns the rest of the blood back to your child through a catheter. The collected stem cells are then frozen, stored and given back to your child after the high-dose chemotherapy.

The harvesting procedure takes about 3-4 hours, once a day. Usually two to three days of harvesting are required. This procedure is painless and has few side effects. Harvesting is performed 10 to 14 days after a course of chemotherapy. 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 is started a few days before chemotherapy and is given daily until harvesting is finished. The whole of the harvesting procedure will be discussed in detail with you by your child's treatment team.

Very rarely, as an alternative to stem cell harvest, some children may have stem cells collected straight from the bone marrow in a procedure called a bone marrow harvest. This process is performed under general anaesthetic and is very similar to the bone marrow aspirate described previously. The bone marrow is then stored like stem cells and given back to your child after high-dose chemotherapy.

The CCLG factsheet 'Peripheral blood stem cell (PBSC) harvesting' is available FREE of charge from your child's hospital

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

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 will 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 at the time of surgery. 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 ordinary x-ray. The total radiation dose is spread out over time and often involves treatment every day for 3-5 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.

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

Differentiation therapy/immunotherapy

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 a drug called 13-cis-retinoic acid which 'differentiates' (turns cells from being cancerous to non-cancerous) any remaining tumour cells that may be present. Alongside this, children will receive immunotherapy with a monoclonal antibody called **anti-GD2 antibody**.

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 GD2 on the neuroblastoma cells, the cells die in a different way than after chemotherapy or radiotherapy.

There is evidence that other cells in the immune system may also promote and contribute to destroying neuroblastoma cells. Drugs can be given to increase the number of these immune system cells, but these increased numbers seem responsible for an increase in serious side effects associated with the antibody treatment. Doctors are therefore currently advising that the antibody is given alone.

In the UK, NICE (National Institute for Health and Care Excellence) has recommended the use of the anti-GD2 antibody, dinutuximab beta as maintenance therapy following induction chemotherapy, high-dose chemotherapy and 13-cis-retinoic acid for children with high-risk neuroblastoma whose tumours have responded to initial therapy.

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 these queries with your child's treatment team. You may naturally 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.

It is reassuring to know that your child's treatment will be discussed during the MDT meeting with other oncologists based at the same hospital. Children's cancer, especially in the field of neuroblastoma, is a small and specialised area of medicine and all doctors will know each other and meet regularly. They will be aware of the latest research in the field through being a member of CCLG and its national networks, such as the CCLG Neuroblastoma Special Interest Group. This group has national and international collaborations with

others and has various active projects. Therefore, if a new treatment has been developed anywhere in the world, it is likely that your child's doctor will know of it and be able to discuss it with you.

In some situations, it may be appropriate (with your consent) that your child's case will be discussed with national experts on the national neuroblastoma advisory panel which is held monthly.

Possible 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 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 caused by some drugs may last for several days and most children are affected to some extent but anti-sickness drugs have made this common side effect much less severe. 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. Most children quickly get used to their appearance and parents have often remarked that once their child's hair is lost it does not seem to bother the child at all. Children might like to wear bandanas, hats, scarves or a wig. Your child's cancer team can give you help and advice with this.

The CCLG booklet 'Anna loses her hair' is available FREE of charge from your child's hospital

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

www.cclg.org.uk/publications

Animation for children:
Our short animation, based on the booklet is available to watch online at **cclg.uk/anna-loses-her-hair**

Effects on the blood and bone marrow

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.

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.

Before each round of chemotherapy, your child will have a blood test called a 'full blood count' or 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 such as rapid COJEC, 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. Consequently, 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.

Losing weight

Both neuroblastoma and chemotherapy may cause weight loss and 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. Your child's medical team, which includes a fully qualified dietitian, will talk this through with you if required.

The CCLG booklet 'Helping your child to eat' is available FREE of charge from your child's hospital

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

www.cclg.org.uk/publications

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 the 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.

Effects on the liver

This is called veno-occlusive disease (VOD) and is one of the less common, but still serious, complications which can occur during high-dose chemotherapy and stem cell transplant. VOD is not another 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 have received busulfan, or high-dose melphalan as part of their conditioning treatment before a 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. Therefore, your child will undergo regular hearing tests (audiograms) as well as tests to measure how well the kidneys are working (the 'glomerular filtration rate' (GFR) test). 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.

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.

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.

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 and your child's medical team may discuss this with you. For example, it is known that the drugs cyclophosphamide, busulfan 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. Busulfan and melphalan were found to be superior to another high-dose chemotherapy regimen in the last high-risk neuroblastoma clinical trial (HR-NBL-1) and will be used again in the next clinical trial (HR-NB-2).

Reactions to immunotherapy/antibody treatment

Some children with neuroblastoma will receive treatment with immunotherapy, using a drug called dinutuximab beta. This treatment can commonly cause a reaction whilst your child is receiving the infusion. Some children can notice abdominal (tummy) pain, numbness or tingling, a rash, generalised swelling, dizziness or a sensation of the heart racing. Your child will be very closely monitored throughout antibody treatment and you should alert a member of staff if you have any concerns.

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. 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. This is why improvements are made every year in treating and curing cancer in children.

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, the researchers carry out a process called randomisation. 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

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

After treatment

When treatment finishes, your child will be given a summary of the treatment they have received and an aftercare plan involving regular follow-up checks in hospital over the next few years. This is to make sure there are no signs of the cancer coming back (called 'relapse') and also to 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 affect their heart and lungs, growth hormones, and they may 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.

The CCLG booklet 'My child has finished treatment' is available FREE of charge from your child's hospital

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

www.cclg.org.uk/publications

If neuroblastoma comes back during or after treatment

When high-risk 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 high-risk neuroblastoma does not respond well to the initial treatment – this is called **refractory disease**.

If your child has relapsed or refractory high-risk 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 previously received. Your child's consultant will be able to help you decide which is the most appropriate treatment for your child at this time.

The CCLG factsheet 'Treatment options for relapsed or refractory high risk neuroblastoma' is available FREE of charge from your child's hospital

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

www.cclg.org.uk/publications

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 paediatric oncologist caring for your child. A lot

of factors will need to be considered to reach that decision. Some children might not be eligible for a particular treatment in the UK, for example, a specific form of immunotherapy or vaccine therapy. For other children, going abroad will provide the opportunity to receive unique experimental therapies that are not available in the UK but are available in single centres in other countries. For patients in the UK who have relapsed neuroblastoma, there are a number of treatment options available. These include further second and third line chemotherapy, early phase clinical trials, and targeted radiotherapy. Increasingly, for patients who did not receive immunotherapy in first remission, there is access to immunotherapy treatment.

For patients who have had immunotherapy in first remission, there is an opportunity to have it again as part of a clinical trial.

If treatment doesn't work

For some children, parents are told the devastating news that their child's cancer is not curable. Your child's care will change to focus on giving the best quality of life for your child 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, charities, and organisations.

CCLG has a range of resources to help parents to prepare and plan for the next steps if treatment doesn't work.

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. Other times, talking things through with someone you can trust is all that is needed.

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. By meeting your own needs, you can be there to help everyone else.

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.

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 CLIC Sargent that can help you explain the illness and treatment. Younger 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.

Supporting siblings

Brothers and sisters of a child with cancer may have many or all 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 or showing that you still love them can help to reassure and comfort them.

CCLG has a range of information to help brothers and sisters of children with cancer from a storybook and animation for young children, to a parents and carer resource and a guide for older children and teenagers.

The CCLG booklet 'My brother or sister has cancer' is available FREE of charge from your child's hospital

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

www.cclg.org.uk/publications

Animation for children:
Our short animation, based on the booklet is available to watch online at **cclg.uk/my-brother-or-sister-has-cancer**

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, but 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 keep open the lines of communication. It can help to 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 your child 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 the nursery
- is well enough to attend nursery or pre-school
- has already had chickenpox which can be harmful for children on treatment

It may be useful for you to talk to your specialist nurse or social worker about nursery attendance and the support they can offer to help with this.

The CCLG booklet '**Supporting your pupil after a cancer diagnosis**' is an information guide for teachers but it is useful for parents and carers too.

Supporting grandparents

Being told that their grandchild has cancer will be a huge shock for your parents. They will worry not only about their grandchild but also how you will deal and cope with this news. Most are also concerned about the effects it will have on any other children within your family and, of course, how they will cope themselves.

As parents, you will usually have access to doctors and others who can answer your questions. It is not so easy for your parents to get information first hand and this can lead to feelings of stress and isolation. Keeping them involved and allowing them to help you and your family if they are able to can help them play a valuable role in supporting their family.

The CCLG booklet '**Supporting your grandchild and family**' **is available FREE of charge from your child's hospital**

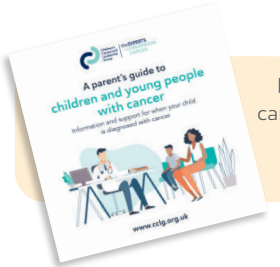
All CCLG booklets and leaflets can be downloaded or ordered from our website: **www.cclg.org.uk/publications**

Seeking information

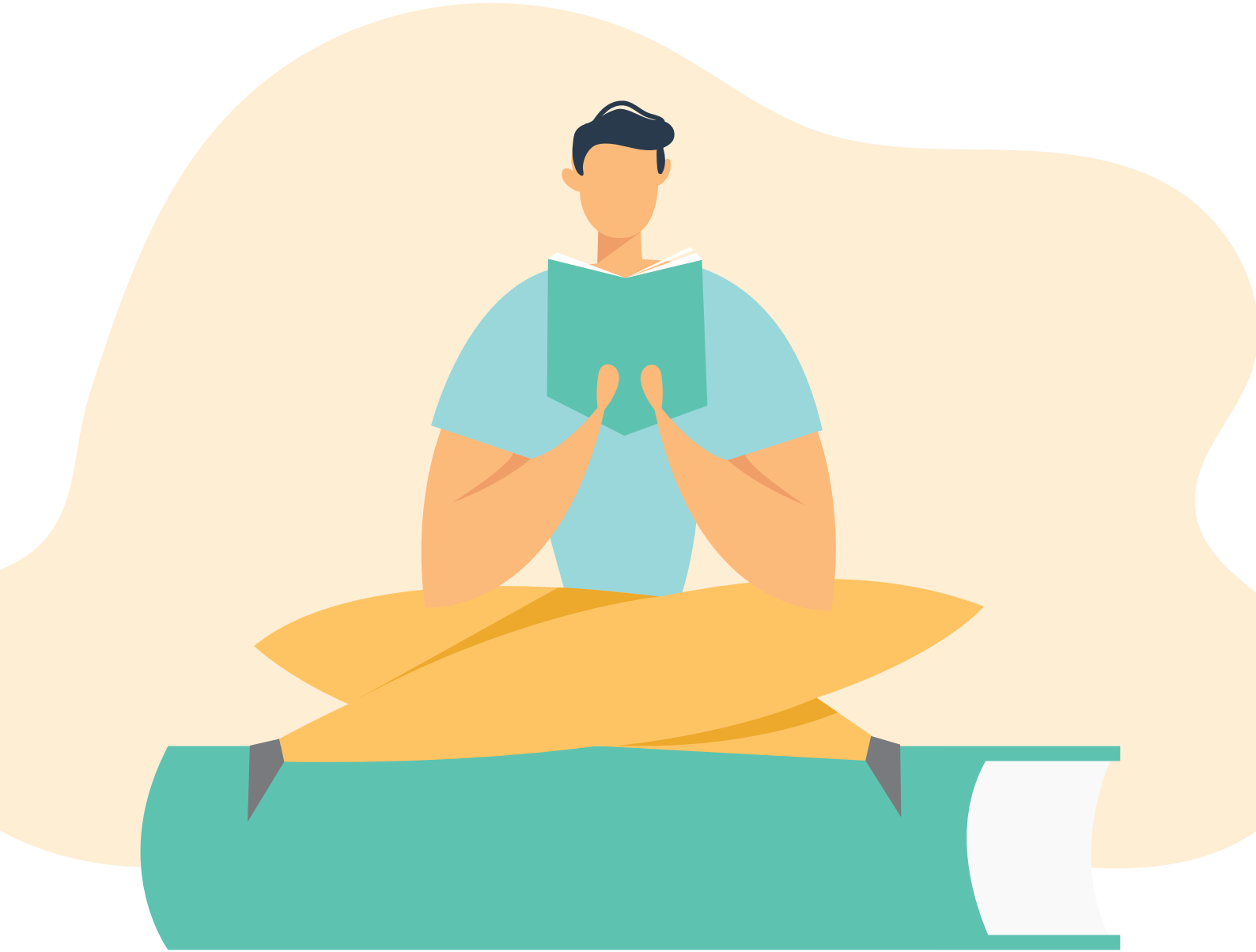
You may want to find out as much as possible about the cancer and its treatment. There is a lot of online information but not all of it is reliable, so talk to the doctors about where to look.

The CCLG leaflet '**Searching for information and support online**' offers advice and tips on searching for cancer information on the internet. **www.cclg.org.uk/publications**

The CCLG childhood cancer information hub brings together reliable information and resources about childhood cancer from a range of organisations into one, easy-to-search place www.cclg.org.uk/infohub



For more detailed information on caring for yourself and others, please read our accompanying booklet '**A parent's guide to cancer**'.



Glossary

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

Anaplastic lymphoma kinase (ALK)
This is 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 of neuroblastoma of all risk groups.

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

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, Port-a-cath)
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 that is a 'close relative' of neuroblastoma.

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

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) in around 25% of children with neuroblastoma. A test for MYCN amplification may be used to determine how aggressive a particular neuroblastoma may be.

Nausea
Feeling sick.

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.

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
A period of good health where there is no longer any visible cancer.

Surgery
An operation.

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.

Help and support

Children's Cancer and Leukaemia Group (CCLG)

www.cclg.org.uk

Information on childhood cancer, funding of research, and a full range of award-winning patient information resources, including Contact magazine.

Join our closed Facebook group just for parents and carers of a child with cancer:

www.facebook.com/groups/cclgparentcarergroup

Cancer Research UK

www.cancerresearchuk.org

Information on all cancer types and a funder of research into cancer.

CLIC Sargent

www.clicsargent.org.uk

FREE helpline: 0300 330 0803

Advice and support for families affected by childhood cancer.

Macmillan Cancer Support

www.macmillan.org.uk

FREE helpline: 0808 808 0000

Practical, financial and emotional support for anyone affected by cancer.

SIOPEN

www.siopen.org

Brings together clinicians from across Europe and beyond to improve the outcomes for patients with neuroblastoma. International collaboration is vital because it ensures there are enough patients to take part in clinical studies. This allows us to learn more about the condition and improve treatments.

Solving Kids' Cancer

www.solvingkidscancer.org.uk

Helps families affected by neuroblastoma by offering family support, access to treatment, research and campaigning on behalf of families.

The Little Princess Trust

www.littleprincesses.org.uk

Provides free real hair wigs to children with hair loss and funds research into childhood cancers.

Notes:

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NEUROBLASTOMA UK
FIGHTING CHILDHOOD CANCER

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

We facilitate communications and collaboration between UK and international researchers, notably through their biennial research symposia, which attracts up to 200 researchers. We also support and fund the UK participation into Europe-wide clinical trials. We work closely with other organisations, such as CCLG, to raise awareness and campaign for better funding and treatment of childhood cancer.

Neuroblastoma UK, 7-14 Great Dover Street, London SE1 4YR
020 3096 7890 | hello@neuroblastoma.org.uk | www.neuroblastoma.org.uk

NeuroblastomaUK

Registered charity number 326385.

Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

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.

Our work is funded by donations. If you would like to help, text '**CCLG**' to **70300** to donate **£5**. You may be charged for one text message at your network's standard or charity rate.

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ChildrensCLG
CCLG_UK
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Registered charity in England and Wales (1182637) and Scotland (SC049948).