

# Children and Young People with Cancer: A Parent's Guide

Children's Cancer and Leukaemia Group



This booklet was revised and edited by Dr Boo Messahel (Consultant Paediatric Oncologist) and colleagues in conjunction with the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

The previous version of the 'Parent's Guide to Children's Cancer' was developed by a collaboration between CCLG and Macmillan Cancer Support.

CCLG makes every effort to ensure that information provided is accurate and up-to-date at time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Thank you to all those whose pictures appear in this booklet.



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# Contents

**About this booklet** ..... 5  
**Initial reactions** ..... 7

**Childhood cancer**  
What is cancer? .....10  
What causes cancer? .....11  
Types of children's cancer .....11  
Cancers of teenagers and young people .....12  
Survival rates .....12  
Principal Treatment Centres .....13

**Diagnosis**  
Tests .....16  
Staging .....19

**Treatment**  
The MDT .....22  
Giving consent to treatment .....22  
Being in hospital .....23  
Hospital staff .....25  
Surgery .....26  
Chemotherapy.....27  
Central lines .....28  
Immunotherapy.....35  
Targeted therapy .....35  
Radiotherapy .....36  
Bone marrow or stem cell transplants .....38  
Maintenance therapy .....39  
Research and clinical trials .....40  
Alternative treatments .....41  
Complementary treatments.....41  
Health and activities during treatment.....41  
After treatment and follow up.....42

**Emotions and feelings**  
Your child's feelings .....45  
Talking to your child .....46  
Dealing with school .....47  
Effects on parents and carers .....50  
Looking after yourself .....52  
Effects on brothers and sisters .....54  
After treatment and follow up .....55

**Drug information and glossary**  
Chemotherapy drugs and their  
possible side effects .....58  
Medical terms explained .....60

**Help and support**  
About CCLG .....64  
Support for children and families .....65  
Useful websites .....68  
Questions you might like to ask your child's  
doctor or nurse ..... 69

# About this booklet

This booklet is for parents and carers of a child who has been diagnosed with cancer. We hope it answers your questions and helps you deal with some of the feelings you may have.

The booklet gives information about children's cancers, the treatments that can be used and their possible side effects. It also discusses how a cancer diagnosis can affect you, your child and the rest of the family.

Although this booklet is for parents of both children and young people, it refers to children's cancer within the text. While this information may answer some of your questions, you'll need to talk in detail with the doctors and nurses looking after your child. They can give you further information about your child's specific type of cancer.

We hope this booklet helps you support your child through their treatment.

We've listed other sources of support and information, which we hope you'll find useful. Turn to pages 64-68 for some useful addresses and websites, and page 69 to write down questions for your child's doctor or nurse.



On pages 60-61 you'll also find a useful glossary, which explains some of the clinical terms doctors and nurses often use.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.





## Initial reactions

Although many children with cancer can be cured, it is still devastating to hear that your child has cancer. Both you and your child will have many different feelings and emotions.

When told the diagnosis, you may feel numb or as if you've been physically hit. Some of the feelings you have may include fear, denial, sadness, guilt and anger. These are normal reactions. It's important to remember that it's not your fault your child has cancer and it's not because of anything you've done or anything you have not done.

When a child is diagnosed with cancer, it obviously has a big impact on the whole family. Your child's routine is likely to change, they may have to stay in hospital for treatment, and they're likely to have regular hospital appointments.

This may feel overwhelming for you, your child and the rest of the family. But there are many healthcare professionals and support organisations who can help you through this difficult time.

For more information about feelings and emotions and supporting your child, see pages 45-55.

# Childhood cancer

Cancer in children and young people is rare. In the UK, only 1 in every 500 children under 15 develops a cancer. So about 1,600 children (up to the age of 15) in the UK are diagnosed with cancer each year. These cancers can be quite different from cancers affecting adults. They tend to occur in different parts of the body to adult cancers. They also look different under the microscope and respond differently to treatment. In the UK, around 2,200 teenagers and young adults (15-24 years old) are diagnosed with cancer every year.

Cure rates for children are much higher than for most adult cancers. The survival rate for children's cancer has more than doubled since the 1960s. On average, 82% (over 8 in 10) of all children can now be completely cured. For some types of children's cancer, the cure rate is much higher.

There is a network of specialist centres, known as Principal Treatment Centres, for diagnosing and treating children's and teenage/young adult cancers. See the map on page 13 to find out where your nearest centre is.

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Normally, cells divide in an orderly and controlled way. But if for some reason the process gets out of control, the cells carry on dividing. In many cases these cells develop into a lump called a tumour. Tumours are either benign (non-cancerous) or malignant (cancerous). Doctors can tell if a tumour is benign or malignant by removing a piece of tissue (biopsy) and examining a small sample of cells under a microscope.

In a benign tumour, the cells do not spread to other parts of the body and so are not cancerous. However, they may carry on growing at the original site, and may cause a problem by pressing on surrounding organs.

In a malignant tumour, the cancer cells have the ability to spread beyond the original area of the body. If the tumour is left untreated, it may spread into surrounding tissue.

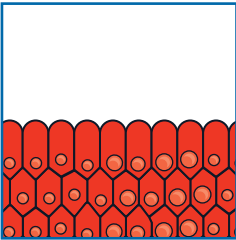
Cancer can occur in different parts of the body – there are more than 200 different types of cancer, each with its own name and treatment. Cancer can occur in organs of the body such as the kidney or the brain. These are sometimes called solid tumours.

Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system. When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a secondary cancer or a metastasis.

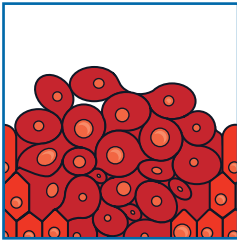
Cancer can also occur in the blood cells in the bone marrow (leukaemia) or in the lymphatic system (lymphoma).

See pages 11-12 for more information about different types of children's cancer.

**i** We have factsheets about all the different types of children's cancer and these are available online from CCLG or Macmillan Cancer Support.



Normal Cells



Cells forming a tumour

Illustrations on this page reproduced with permission from Macmillan Cancer Support

What causes cancer?

It is still unknown as to what causes childhood cancer and research is being done to find out more. Parents often worry that something they did or didn't do may have caused their child's cancer. This is not the case, so you shouldn't feel guilty or that you're to blame for your child's illness.

It's very rare for another child in a family to develop cancer, as most cancers aren't caused by an inherited faulty gene and so it is usually not necessary to investigate siblings.

Cancer is not infectious and can't be passed on to anyone who comes into contact with your child.

Cancer clusters

Sometimes, two or three children in the same school or local area develop cancer. This can make people worry that something in the local area is causing the cancer. Several cases of cancer in a small area are known as a cancer cluster.

Cancer clusters are carefully investigated, but are usually found to be a coincidence rather than being caused by a particular chemical or environmental change.

Types of children's cancer

Leukaemia

Leukaemia is a cancer of the bone marrow. This is the spongy material in the middle of our bones where blood cells are made. When someone has leukaemia, their body produces too many abnormal white blood cells. The cells don't usually form a lump (tumour), but travel around the body in the blood.

Leukaemia is the most common cancer in children. The main types found in children are acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML).

Each type of leukaemia can be divided into different sub-types. Blood and bone marrow samples will be tested to find out which type of cell has become leukaemic and at what stage of its development this happened. The cells may be tested to see if they have certain proteins on their surface. This is known as immunophenotyping which aids the diagnosis.

Almost all of the cells in our body contain chromosomes. Chromosomes are made up of genes, which control the activity of the cell. There are often changes in the structure of the chromosomes in leukaemia cells. Testing the cells for these changes is known as cytogenetics. Knowing the exact type of leukaemia your child has helps the doctors plan the most effective treatment.

Other childhood cancers

Other types of cancer that occur in children include brain tumours, sarcomas, embryonal tumours, and lymphomas.

Sarcomas (including soft tissue sarcomas and osteosarcomas) develop from tissue such as bone or muscle, and can occur in any part of the body.

Embryonal tumours develop from tissue that is normally only seen in the developing embryo. They can also occur in different parts of the body.

Lymphoma is cancer of the lymphatic system and can occur in any lymphatic tissue in the body. There are two main types of lymphoma: Hodgkin lymphoma (HL) (sometimes called Hodgkin’s disease) and non-Hodgkin lymphoma (NHL).

Cancers of teenagers and young people

Teenagers and young people tend to get different types of cancers to children and adults with the most common ones being lymphomas and carcinomas, germ cell (ovarian and testicular) and brain and central nervous system (CNS) tumours.

Survival rates

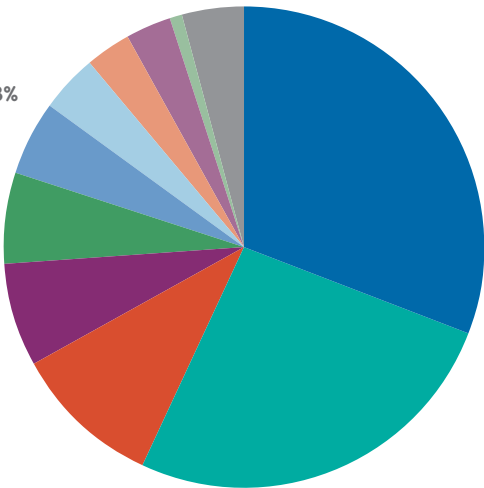
More children than ever before are surviving cancer. There have been huge improvements in cancer treatment for children in the past 50 years. Over 8 in 10 (82%) of children with cancer are now cured, compared with fewer than 3 in 10 (less than 30%) between 1962–1971. Research is continuing to improve treatments and reduce side effects.

To compare the results of treatments, doctors often use five- or 10-year survival rates. It is estimated that there are at least 35,000 people in the UK alive having been diagnosed with a childhood cancer and survived more than five years. Every child is different and the doctors will discuss your child’s illness and the likely success of treatment with you.

Incidence rates

Types of cancer in children

- Leukaemias **31%**
- Brain and spinal tumours **26%**
- Lymphomas **10%**
- Soft tissue sarcomas **7%**
- Neuroblastoma **6%**
- Kidney tumours **5%**
- Bone tumours **4%**
- Germ cell tumours **3%**
- Retinoblastoma **3%**
- Liver tumours **2%**
- Other **4%**



Principal Treatment Centres

Find out more at [www.cclg.org.uk](http://www.cclg.org.uk)

- 1

**Aberdeen**  
Royal Aberdeen Children’s Hospital
- 2

**Edinburgh**  
Royal Hospital for Sick Children
- 3

**Glasgow**  
Royal Hospital for Sick Children
- 4

**Newcastle-upon-Tyne**  
Royal Victoria Hospital
- 5

**Leeds**  
Leeds General Infirmary
- 6

**Sheffield**  
Sheffield Children’s Hospital
- 7

**Nottingham/Leicester**  
East Midlands Integrated Service at Queens Medical Centre 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 General Hospital
- 13

**Bristol**  
Bristol Hospital for Sick Children
- 14

**Cardiff**  
Children’s Hospital of Wales
- 15

**Oxford**  
John Radcliffe Hospital
- 16

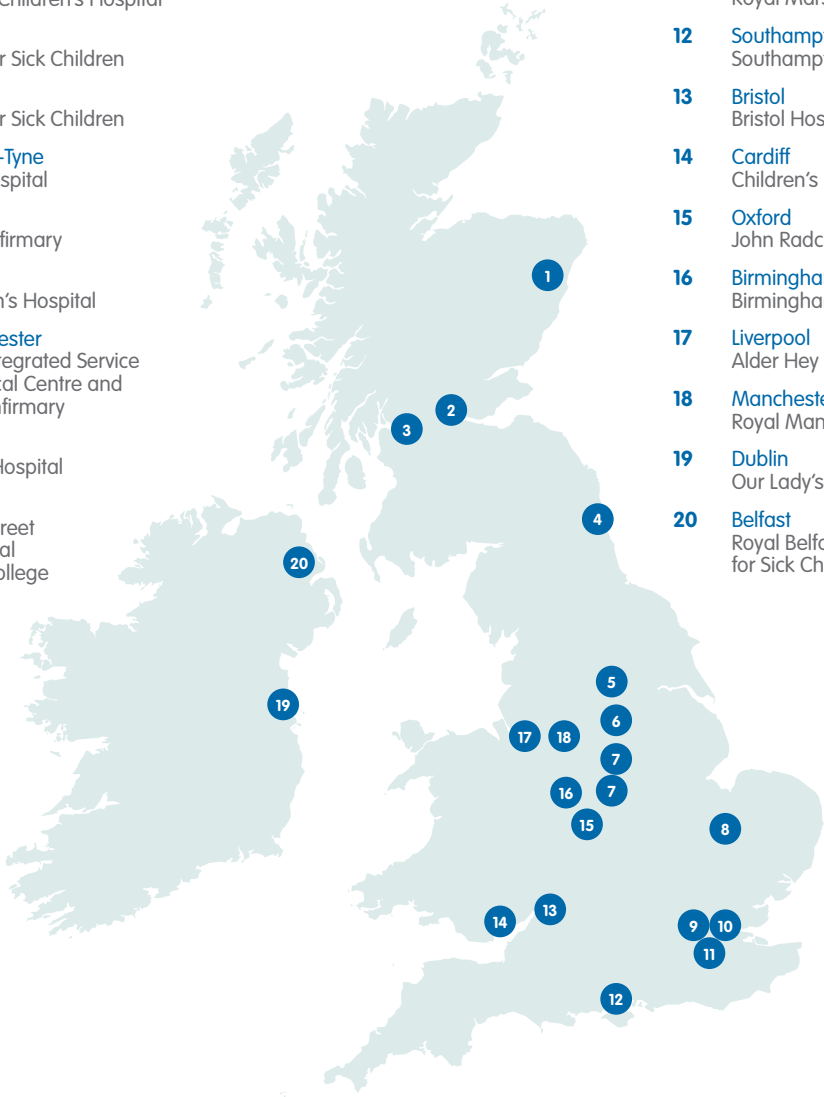
**Birmingham**  
Birmingham Children’s Hospital
- 17

**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







# Diagnosis

**This means finding out if your child has cancer and, if so, what type of cancer they have. Doctors will do this by assessing your child and their symptoms, and by doing tests (see pages 16-19).**

When a child has symptoms that could be caused by cancer, they will be referred by their GP or local hospital to one of the following specialists:

- a paediatrician, who specialises in treating children
- a paediatric oncologist, who specialises in treating children with cancer
- a paediatric haematologist, who specialises in treating blood disorders

Most children with cancer will be treated in a Principal Treatment Centre within a hospital (see page 13). Teenagers may be treated in a unit specially designed for teenagers and young adults with cancer (see page 24).



Tests

Various tests will be done to diagnose your child's illness. Tests are carried out for the following reasons:

- so that the cancer or leukaemia can be diagnosed accurately. Sometimes it's hard to tell the difference between specific types of cancer. Your child's doctor may talk to other doctors to ask their opinion and advice about the diagnosis. They will have the support of other cancer experts around the UK and overseas.
- to see where the cancer is in the body and whether or not it has spread.
- to assess your child's general health, as this may affect the treatment that's given.

Further tests may be needed before treatment begins. This may mean that treatment doesn't start for a few days. Generally, cancer develops slowly, so delaying the start of treatment for a short time won't make it less effective. It is important to know the type of cancer your child has and whether it has spread in the body. This information will help your doctor to choose the most effective treatment.

With some types of cancer it is important to start treatment straight away. Your child's doctor will discuss this with you.

Some of the more common tests are described here. Several of these may be carried out again during the course of treatment to see how well the treatment is working. Some tests can also be used to check for any side effects of treatment.

Biopsy

If your doctor thinks that a tumour may be cancerous, a surgeon may remove part of it to examine under a microscope. There are two types of biopsy:

- Needle biopsy – A needle is put into the tumour through the skin to remove a small part of it. This test can be done under a local anaesthetic.
- Open biopsy – A piece of the tumour is taken during a small operation using a general anaesthetic. The surgeon may sometimes be able to remove the entire tumour rather than just take a sample.

The sample of cells is sent to a laboratory to be examined by a pathologist (a doctor who studies body tissues). They can tell if the sample is cancerous or not and, if it is, what type of cancer it is. It usually takes several days to get the results of a biopsy.

Blood tests

There are lots of different types of blood test. Blood tests may be done when your child is diagnosed, during treatment, and afterwards at follow-up appointments. The following tests may be done on your child's blood:

- Full blood count (FBC). This test measures the number of different types of blood cells in the blood (red blood cells, white blood cells and platelets (see pages 60-61). This is one of the main ways to monitor the side effects of treatment.
- Blood chemistry. This test measures the levels of certain salts and proteins in the blood. It gives information about how well the body's organs, such as the liver and kidneys, are working.
- Blood group and cross-match. Blood samples can be used to find blood from a donor that matches your child's blood. Cross-matching is done in case a blood transfusion is needed during your child's treatment.

- Blood culture. This is when microbiologists (people who study types of infection) check the blood to see if there's any infection in it.
- Blood clotting. The blood may be looked at to see how quickly it clots and if there's a risk of bleeding. Clotting may be affected by a cancer or cancer treatment.
- Other tests. Blood may also be taken to see if your child has had any viruses in the past such as measles, hepatitis, German measles (rubella), cytomegalovirus (CMV) or chickenpox (herpes zoster).

Bone marrow test (bone marrow aspirate)

Some cancers can affect the bone marrow. This is the spongy material in the middle of some of our bones. It produces cells called stem cells, which develop into the three different types of blood cells:

- red blood cells, which carry oxygen around the body
- white blood cells, which are part of the immune system and essential for fighting infection
- platelets, which help the blood to clot and control bleeding

To take a bone marrow sample, a needle is gently put into the hip bone and some of the marrow is drawn out with a syringe. This is then sent to a laboratory to be looked at.

This test is usually done under a general anaesthetic or sedation to make sure your child feels as little discomfort as possible. Older children may prefer to have a local anaesthetic.

The bone where the sample is taken from might feel sore for a few days after the test.

A bone marrow test may be done when your child is diagnosed or at times during treatment.

Lumbar puncture

In some conditions, such as leukaemia or lymphoma, cancer cells can pass into the fluid that surrounds the brain and spinal cord (cerebrospinal fluid or CSF). To see whether this has happened or not, a few drops of the CSF are removed. This is done by inserting a fine needle into the CSF between two spinal (vertebral) bones in the lower part of the spine. This is called a lumbar puncture and is usually done under a general anaesthetic. The sample of CSF is then examined to see if any cancer cells are present.

Sometimes, as part of the cancer treatment, drugs are injected into the CSF. This is known as intrathecal chemotherapy.

X-rays

A tumour often looks different from healthy tissue when seen on an x-ray. An x-ray can show if there's a tumour in the chest, tummy (abdomen) or bones.

Ultrasound scan

This test uses sound waves to build up a picture of the inside of the body. A gel will be spread on to the part of your child's body being scanned. A small device like a microphone, which produces sound waves, is passed over the area. The sound waves are then converted into a picture by a computer.

Ultrasound scans are completely safe and are mainly used to look at the tummy (abdomen) and heart.

### CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. It takes 10–30 minutes and is painless, but your child may be given a sedative or general anaesthetic to make sure they lie still. Sometimes, special dyes are injected into a vein to make certain parts of the body show up better on the CT scan.

### MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of the body. The scan is painless, but the machine is very noisy. It can look frightening, as your child may have to lie in a narrow tunnel. You'll need to sign a consent form to confirm that your child doesn't have any metal objects – such as dental braces – in their body, as the scanner uses strong magnetism. They may be given a sedative or general anaesthetic to make sure they lie still. They will also be given earplugs or headphones to wear. In some hospitals, children can watch videos while having an MRI scan. It may be possible for you to stay in the room with your child while they have the scan.

### Bone scan

If your child has a bone tumour or a tumour that may have spread to the bones, this scan will show how much bone is affected. A small dose of a radioactive substance is injected into a vein, usually in the arm. The substance is absorbed by the bone. Abnormal areas of bone absorb more of the substance than healthy bone and are highlighted on the scanner as 'hot spots'. The radiation dose is very low and not harmful.



### PET (positron emission tomography) scan

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. A very small amount of a mildly radioactive substance is injected into a vein, usually in the arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and show up on the scan. The radiation dose is very low and not harmful.

### GFR (glomerular filtration rate) test

This test shows how well the kidneys are working and excreting drugs. It is done before some types of chemotherapy and may be repeated during treatment. It involves having an injection of a radioactive dye into a vein. Blood tests are taken two, three and four hours later. Local anaesthetic cream may be used before the injection and the blood tests to make them less painful. The radiation dose is very low and not harmful.

### Audiogram

Some cancer treatments may affect your child's hearing. Because of this, your child may have an audiogram (hearing test) before and during treatment. This detailed hearing test is done in a quiet room in the hospital. Your child will be asked to listen to sounds at different frequencies through headphones or speakers.

### Optthalmology

For some children, their sight may be harmed by the position of a tumour. The aim is to treat tumours before too much harm has been caused, and so prevent your child's vision getting worse. Regular monitoring of vision is carried out in those children who are at an increased risk of their vision becoming impaired.

## Staging

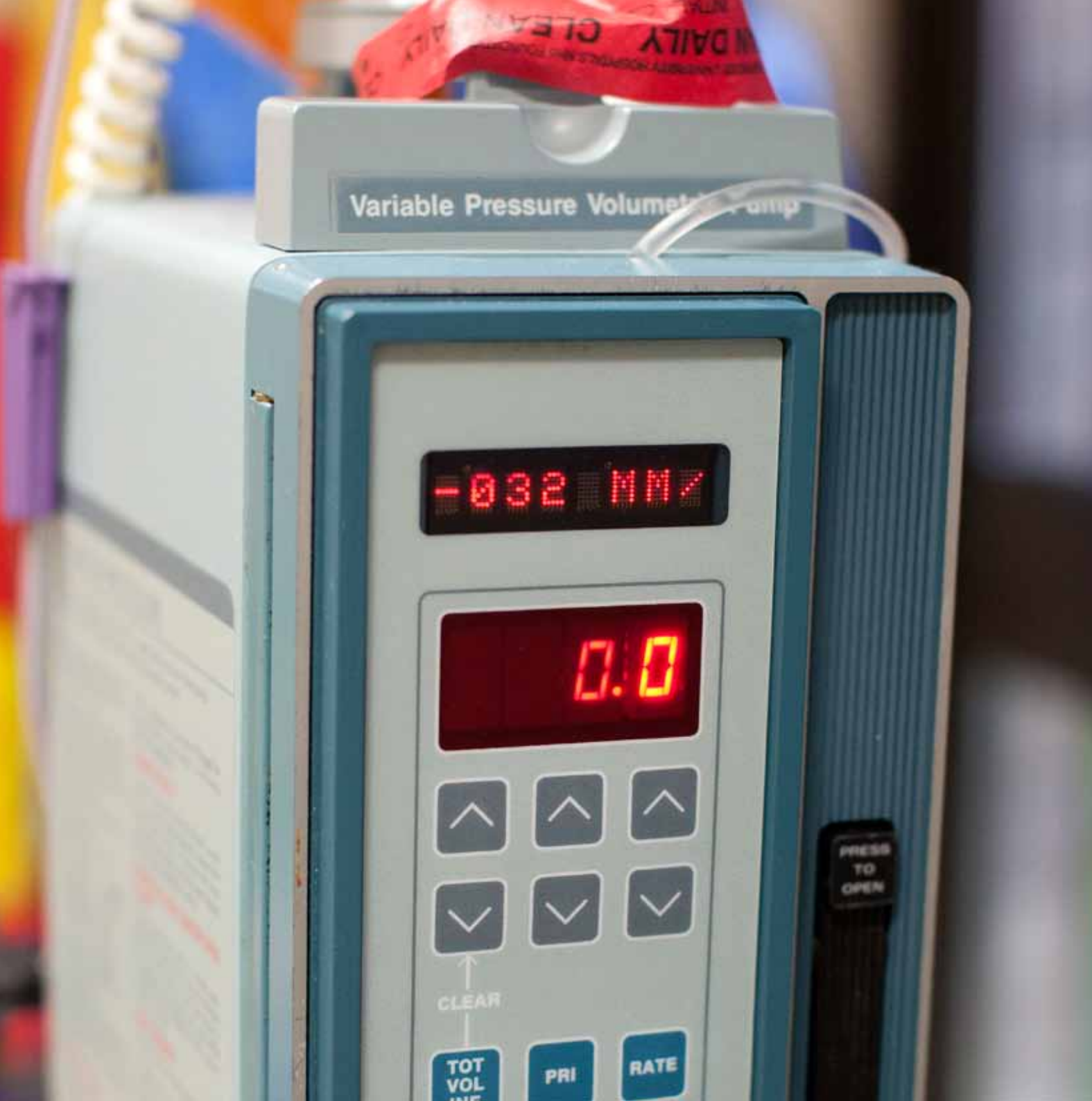
The stage of a cancer means the size of the tumour and whether or not it has spread beyond where it started in the body. Knowing the extent of the cancer helps doctors decide on the best treatment for your child. Staging applies to nearly all cancers apart from leukaemia.

Generally, cancer is divided into four stages:

- Stage 1 – The cancer is small and only in one place in the body
- Stage 2 or 3 – The cancer has spread into parts of the body close to where it started
- Stage 4 – The cancer is large or may have spread to other parts of the body

Different cancers have specific staging systems. The doctors will talk to you about your child's situation and explain what it means.

If the cancer has spread to distant parts of the body it's known as secondary or metastatic cancer.



# Treatment

**The treatment your child has will depend on the type of cancer they have. There are a number of different treatments available. The most common are:**

- surgery, which aims to remove the tumour during an operation (see page 26)
- chemotherapy, which uses anti-cancer (cytotoxic) drugs to destroy cancer cells (see page 27)
- radiotherapy, which uses radiation to destroy cancer cells (see pages 36-37)
- stem cell and bone marrow transplants, which involve having high doses of chemotherapy drugs followed by an infusion of blood stem cells (see page 38)
- immunotherapy, which involves having specific drugs that target particular cancer cells (see page 35)
- targeted therapy, which involves special drugs that target proteins and genes in cancer cells (see page 35)





## The multidisciplinary team (MDT)

In most hospitals, a team of specialists will plan the treatment they feel is best for your child's situation. This multidisciplinary team (MDT) is led by a consultant oncologist/haematologist who specialises in the treatment of cancer or leukaemia.

The MDT may include:

- a paediatric oncologist (cancer specialist)
- a paediatric haematologist (specialist in blood disorders)
- a clinical oncologist (radiotherapy and chemotherapy specialist)
- a paediatric surgeon
- a nurse specialist
- a pharmacist
- a dietitian

It may also include other healthcare professionals, such as a psychologist, occupational therapist, physiotherapist or social worker.

The MDT meets on a regular basis to discuss newly-diagnosed children, treatment options, clinical trials and any situation where people may be having problems or need extra support. These healthcare professionals use their expertise to work together to provide treatment and support for children and young people with cancer.

The doctor will explain to you which treatment, or combination of treatments, is appropriate for your child.

## Giving consent to treatment

Before your child has any treatment, the doctor will explain its aims. They will ask you or your child to sign a form to give permission (consent) for the hospital staff to give the treatment. Once a child reaches the age of 16, they can usually consent to their own treatment. The law about children consenting to treatment is very complicated, so make sure you discuss any concerns you have with your child's doctor.

Before you or your child is asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available

If you don't understand what you've been told, let the staff know so they can explain again. Some cancer treatments are complex, so it's not unusual for people to need repeated explanations.

Many children are offered cancer treatment that is part of a clinical trial. Trials can be done for a number of reasons. Remember, any treatment suggested for your child will be the best treatment for them. If a trial is suggested, you'll be given information about it and what it involves. You will have to consent to the trial as well as to the treatment itself.

**i** You can read more about clinical trials on page 40 or order CCLG's booklet entitled 'A Guide to Clinical Trials'.

It's a good idea to have your partner, a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your child's appointment (you can use page 69 for this).

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect your child. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when the treatment is first explained. In emergencies, decisions may have to be made quickly, but otherwise it's usually possible to have more time to think things over.



## Being in hospital

Your child will probably need to spend some time in hospital during their treatment. There are 20 Principal Treatment Centres in the UK and the Republic of Ireland (see page 13). These are specialist centres for diagnosing and treating children's cancers. If the doctors at your local hospital think that your child has cancer, they are likely to send them to one of these centres.

Often, some of the treatment can be given at your local hospital under the guidance of the nearest specialist centre. This is called shared care and the 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 Principal Treatment Centre.





Children's wards are relaxed and friendly places that aim to give you and your child as positive an experience as possible. You're likely to get to know the staff well.

Almost all children's wards have facilities where parents can stay overnight. Brothers and sisters may be able to stay too. Most children, especially younger ones, want their family to spend as much time with them as possible. Your child may seem upset when you arrive or leave, and this can be difficult for both of you. Whenever you have to leave, make sure you say goodbye and tell your child and the ward staff when you'll be back.

Being in the same surroundings all day where everyone is worried and frightened can be a great strain, so it's often helpful to try to leave the ward for at least one short break during the day. The nursing staff will understand this and encourage you to take regular breaks.

You can usually visit your child in hospital whenever you want – the ward staff will be able to tell you if there are any restrictions. Visits from the wider family and school friends can be good for your child. But remember, it can also be tiring for them if there are too many people

visiting at once. It's also important that anyone who wants to visit is well and doesn't show any signs of infection.

It's okay to talk about your feelings or worries with the nurses or social worker. They are experienced in caring for children with cancer and are there to help and support you. Many wards have teachers and play specialists. Children who are feeling well enough can attend the hospital school.

Many people will be involved in looking after your child, both at home and while they are in hospital. Some of these people and their roles are described on the next page.

More and more hospitals now have specially designed wards or units for teenagers with cancer. Organisations such as Teenager and Young Adults with Cancer (TYAC) and the Teenage Cancer Trust (TCT) work to improve cancer services for teenagers (see page 67). Teenagers can meet people of their own age which, along with the surroundings and experienced staff, can help them get the support they need.

## Hospital staff

Many different hospital staff will be involved in your child's care and at first meeting all the staff may seem overwhelming:

**Paediatric oncologists** are doctors who treat children with cancer. They are specialists in planning and giving cancer treatments such as chemotherapy and radiotherapy.

**Haematologists** are doctors who specialise in blood disorders including leukaemia. They look after patients on the ward and examine blood samples in the laboratory.

**Clinical oncologists** (also known as **radiotherapists**) are doctors who specialise in using radiotherapy and chemotherapy to treat cancer.

**Surgeons** perform operations. They may take a biopsy (remove a piece of tissue from the tumour for examination under a microscope) and/or remove the whole tumour. They also put in central lines and implantable ports (see pages 28–29).

**Paediatric anaesthetist** a doctor who will anaesthetise and monitor your child throughout surgery or a procedure requiring an anaesthetic.

**Junior ward doctors** These doctors are at different stages of their training and specialise in looking after children with cancer.

**Clinical nurse specialists** There may be a clinical nurse specialist, or specialist nurse, based at the Principal Treatment Centre where your child has their treatment. They may act as your child's key worker. This means that they coordinate your child's care and liaise with the Paediatric Oncology Shared Care Units, which have specialist or community nurses who work with children who have cancer.

**Nurses** The sister, ward manager or charge nurse is in charge of the ward. Staff nurses, student nurses and healthcare assistants work under the sister/ward manager/charge

nurse's direction. All nurses will be specialised in working with children with cancer.

**Pharmacists** are responsible for preparing and dispensing medicines. They're based in the hospital pharmacy and may also visit the ward.

**Physiotherapists** and **occupational therapists** help children with moving around and carrying out daily activities.

**Pathologists** analyse tissues samples (for example, biopsies) under the microscope to diagnose illness or see how an illness is being affected by treatment.

**Psychologists** can help children who have difficulties with behaviour or learning during their treatment and also support the child's family.

**Radiographers** take x-rays and give radiotherapy treatment.

**Radiologists** interpret x-rays and scans to help diagnose the cancer and plan your child's treatment.

**Dietitians** make sure that your child has the best food to keep them as healthy as possible during their treatment. If your child isn't able to eat for a while, the dietitian can advise on other ways of giving them the nutrients they need.

**Play specialists** use play to help children cope with the experience of being ill.

**Social workers** can help with any practical, emotional and financial problems you may have. CLIC Sargent (see page 66) provides social workers who specifically support children with cancer, and their families.

**Teachers** Each children's hospital has a school that provides education for children when they're in hospital. The hospital school will contact your child's school, and together they will plan an education programme for your child.



## Surgery

Surgery is an important part of cancer treatment. Depending on the size and position of the tumour in the body, an operation to remove it may be the first part of treatment.

A biopsy (see page 60) of the tumour is often taken first to make the diagnosis. This involves taking a piece of tissue from the tumour so it can be looked at in the laboratory by the pathologist. They will then identify the type of cancer (see pages 11-12).

Sometimes, an operation may be dangerous or cause too much damage because of the size and position of the tumour. In this situation, chemotherapy or radiotherapy may be given before the operation to shrink the tumour and make surgery easier.

## Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. Children usually have a combination of chemotherapy drugs. The number of drugs they have will depend on the type of cancer or leukaemia they have. The doctors will explain to you which drugs are being used and when they'll be given. The drugs are carried in the blood and can reach cancer cells all over the body.

Chemotherapy drugs affect dividing cells. This includes some normal cells, such as those in the lining of the mouth, the bone marrow, the hair follicles and the digestive system. Healthy cells can repair the damage caused by chemotherapy but cancer cells can't, so they eventually die.

Chemotherapy can be given in different ways – either as tablets, capsules or liquids that are swallowed, or by injection. There are many technical terms used to describe how the drugs are given. You will see these on your child's drug chart and on treatment plans (protocols). Common terms are:

- intravenous or IV – injection into a vein
- oral, PO, O or by mouth – tablets, capsules or a liquid that is swallowed
- intramuscular or IM – injection into muscle
- subcutaneous or SC – injection under the skin
- intrathecal or IT – by lumbar puncture (see page 17)

Whichever way chemotherapy drugs are given, they are absorbed into the bloodstream and carried around the body so they can reach and destroy cancer cells. This makes chemotherapy especially useful in treating cancers that are likely to spread, or have spread, to other parts of the body.

### Planning treatment

Chemotherapy has to be planned carefully. It's usually given as a series of sessions of treatment. Each session destroys some of the cancer cells and will cause some damage to healthy cells. After each treatment, there's usually a rest period to allow the healthy cells to recover before the next dose. A session of chemotherapy and the rest period is known as a cycle of treatment. A series of cycles make up a course of treatment.

There are many different ways of giving chemotherapy. Sometimes, high doses of the drugs are given intensively over a short period of time, or they may be given as lower doses over a longer period.

### Intravenous chemotherapy

Intravenous (IV) chemotherapy is the most common way of giving chemotherapy. It may be given into a vein either through a central line (see page 28), implantable port (see page 28) or PICC line (see page 29). These are all tubes that are inserted into a vein and can stay in place for some months or, in some cases, years. They can be used for taking blood as well as giving treatment and other medicines. These devices avoid repeated cannula insertions in children when treatment is needed.

Usually the doctors will suggest which type of line your child should have, although you may be offered a choice. The chemotherapy drugs are usually diluted into a bag of liquid such as salt water (saline) and given as a drip (infusion) through the line.

Sometimes, treatment is given through a thin tube, which is inserted into a vein and then taped firmly to your child's arm. This is called a cannula. A cannula only stays in place for a few days.

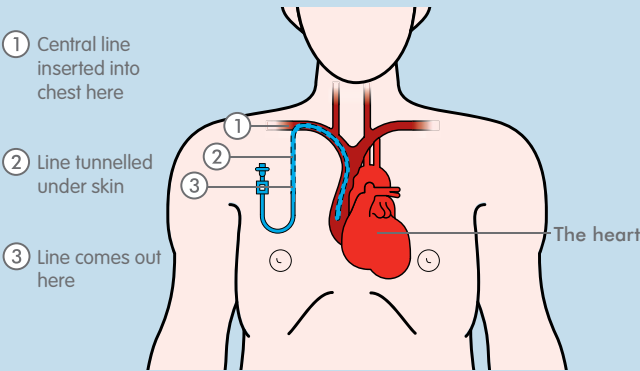
Central lines, implantable ports and PICC lines

Central line

A central line (central venous catheter) is a thin, flexible, plastic tube, that's inserted into a vein usually near the collarbone. A central line is often called a Hickman line, after the person who developed it. It's put in under a general anaesthetic. The surgeon makes a small cut into a vein near the collarbone and feeds the tube down until the tip is in one of the large veins near the heart.

The other end of the tube is then tunnelled under the skin and comes out on the front of the chest. A removable bung is attached to the end of the line, which allows samples of blood to be taken or medicines to be injected. It can also be used to give blood or platelet transfusions.

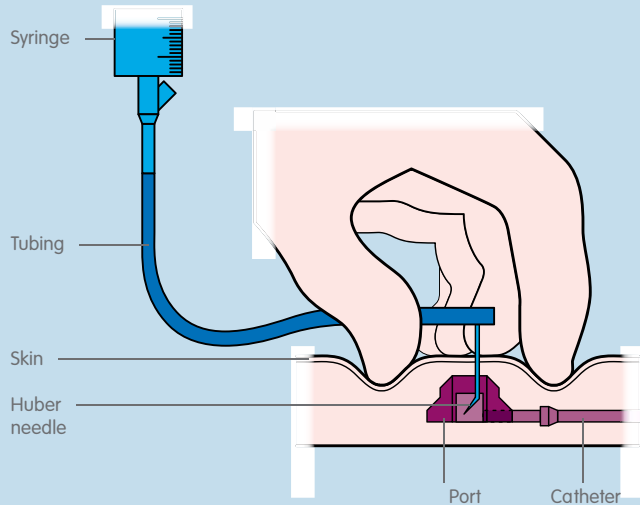
A central line needs to be kept dry while showering or bathing – a plastic dressing can be used for this. The central lines have clamps on them which should be closed when the line is not being used.



Implantable ports

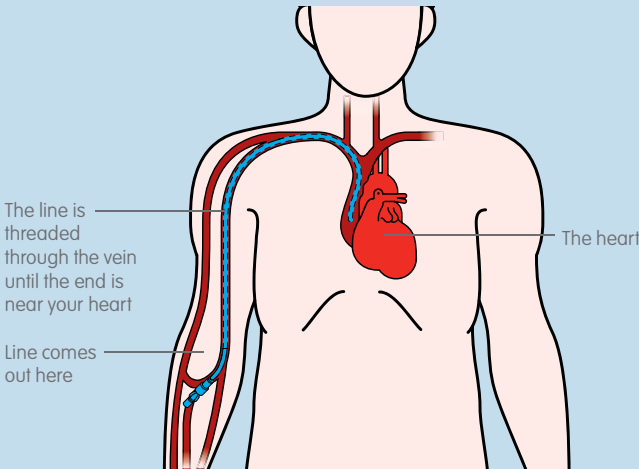
Some tubes don't come out through the skin. Instead, they end in a reservoir or port that is under the skin below the collarbone, so they aren't clearly visible.

These are known as implantable ports or portacaths. Implantable ports are put in under a general anaesthetic. A small needle is pushed through the skin into the port to give chemotherapy or take blood. The skin over the port can be numbed beforehand with an anaesthetic cream (such as Ametop® or Emla® cream) or spray (such as Cryogesic®). The needle can stay in place for up to seven days and is secured in place by a dressing.



PICC lines

Occasionally, your doctor may suggest that your child has a long, thin tube put into a vein in the crook of their arm. This is called a peripherally inserted central venous catheter (PICC). It's put in under local or general anaesthetic. Once in place, the PICC line is taped firmly to your child's arm to prevent it being pulled out of the vein. It can stay in the vein for many months. A PICC line needs to be kept dry while showering or bathing – a plastic dressing can be used for this.



Looking after a line or implantable port

Before your child goes home, the nurses will show you how to care for the central line, PICC line or implantable port. Make sure you feel confident with this and don't be afraid to ask any questions. If you have any problems with the line when you're at home, contact the hospital staff.



Advantages and possible problems with lines and implantable ports

Central lines, implantable ports and PICC lines can stay in place for many months and are a very good way of avoiding the discomfort of repeated injections. However, there are four potential problems that can happen with them: blockage, infection, falling out and splitting.

Blockage

Occasionally, lines or ports may become blocked. This can happen if the tip of the line lies at an odd angle against the wall of the vein. Sometimes the line gets clogged up, even if it has been flushed with liquid regularly. If this happens, drugs can be put into the tube to dissolve the blockage so the line can be used again. Your child may also have a linogram (a special x-ray) to show the position of the tube.

Infection

Despite being carefully looked after, some lines or ports become infected. If infection occurs, antibiotics are given. But if these don't clear the infection, the line may need to be removed and, if necessary, replaced.



Falling out

Rarely, a central line or PICC line may fall out or move because a child pulls on the tube by accident when they are playing or sleeping. Fortunately, if a tube does fall out, the blood clots quickly and seals up the wall of the vein. Some blood may ooze down the tunnel under the skin where the line was. However, the blood usually clots and seals off the tunnel very quickly. The hospital staff will tell you what to do if this happens.


Splitting

Rarely some central lines can split or puncture during flushing. If this does happen then a clamp is usually put on straight away to avoid blood leaking and infection. Sometimes split lines can be fixed with a simple puncture repair kit. Other times the central line may need to be replaced.

Side effects of chemotherapy

Chemotherapy drugs can cause unpleasant side effects. However, these are mostly temporary and there are often ways of controlling or reducing them. The main areas of the body that are affected are those where normal cells rapidly divide and grow. These include cells in the mouth, the lining of the digestive system, the skin, hair follicles and the bone marrow.

Some common short-term side effects and ways of dealing with them are described on the next few pages. Different children will be affected by chemotherapy in different ways. Your child will not have all of the side effects described here, but may have some of them. Your child's doctor or nurse will tell you more about the side effects that are likely to occur during your child's treatment, and ways of managing them.

 A table listing some specific chemotherapy drugs and their side effects is on pages 58–59.



Effects on the bone marrow

Low resistance to infection (neutropenia)

Many chemotherapy drugs reduce the production of white blood cells by the bone marrow. This lowers your child's immunity and makes them more prone to infection. This effect usually begins about seven days after treatment is given. If the chemotherapy is being given every 3–4 weeks, the number of white blood cells usually reaches its lowest point (nadir) about 7–14 days after treatment. The number of blood cells will then increase steadily and usually return to a safe level before the next course of chemotherapy is due.

When the white blood cell count is low, your child may develop an infection. They will be able to overcome most minor infections themselves, but it's important to contact the hospital straight away if:

- your child's temperature goes above a certain level (staff at the hospital will tell you what this is)
- your child suddenly feels unwell, even with a normal temperature
- your child becomes shivery

They will probably need to be admitted to hospital for intravenous antibiotics until the doctors know what type of infection they have.

Your child will have a blood test before having their chemotherapy to make sure their cells have recovered. If the white blood cell count is still too low, treatment may be delayed until it is at a safe level again.

Some infections that would normally cause little trouble may be more difficult for your child's immune system to cope with. Measles and chickenpox can be particularly serious. If your child is exposed to either of these, or develops these infections, tell the staff at the hospital straight away so that appropriate treatment can be given.





### Effects on the digestive system

#### Tiredness or breathlessness

Some chemotherapy drugs lower the number of red blood cells produced by the bone marrow, so your child may become anaemic. This can make them feel very tired and breathless, and look pale. If the number of blood cells is very low, a blood transfusion can be given.

#### Bruising or bleeding

Some chemotherapy drugs can reduce the production of platelets. These are the cells that help blood to clot. Let the hospital know if your child has any unexplained bruising or bleeding such as nosebleeds, bleeding gums, blood spots or rashes on the skin (petechiae). If the number of platelets is very low, a platelet transfusion can be given.

#### Feeling sick

Chemotherapy drugs may make your child feel sick (nausea) or in some cases, actually be sick (vomit). However, this can usually be controlled with anti-sickness (anti-emetic) medicines. Tell the doctors if your child's sickness persists – changing the anti-sickness medicine usually helps.

#### Loss of appetite

Sometimes your child may not feel like eating and they may temporarily lose weight. Try giving them their favourite foods and don't worry if they keep eating the same thing. Having smaller meals, but eating more often, can also help.

If necessary, they can be fed through a tube passed down their nose into their stomach (nasogastric tube), or through a tube passed through their abdominal wall into the stomach (PEG tube). Sometimes, they may be fed through a central line. Your hospital will tell you more about ways of giving nutrition.

#### Diarrhoea or constipation

Some drugs can change the way the bowel works, so your child may have diarrhoea or constipation. Let the hospital staff know if constipation becomes a problem, as laxatives can be given to relieve it.

Diarrhoea usually gets better without medication. It's important for your child to drink plenty of fluids if they have diarrhoea. 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

Some drugs can cause a sore mouth, which may lead to mouth ulcers. Mouth care is very important – 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. Any effects on the mouth usually start about 5–10 days after the drugs are given and will clear up within 3–4 weeks after treatment ends.

Macmillan has a factsheet about coping with a sore mouth, which includes helpful tips on looking after the mouth during chemotherapy.

#### Taste changes

Chemotherapy can cause taste changes, which may make food taste more salty, bitter or metallic. Your child's taste will return to normal when chemotherapy treatment finishes.

## Effects on skin and hair

### Hair loss

Some drugs cause hair loss. In some children, all the hair may fall out, but in others it may just get thinner. Also, hair loss is not restricted to the head but can also affect eyebrows, eyelashes and other body hair. There are lots of ways to deal with hair loss – often children like to wear baseball caps, bandanas, hats or scarves rather than having a wig. However, it is possible for the hospital staff to arrange a wig for your child or refer your child to a hair loss support service.

Usually, hair grows back within a few months of stopping treatment. However, it can sometimes be a different colour or texture. For example, it might come back curly when it used to be straight.

Hair can be an important part of a child's identity. You may worry about how your child's different appearance will affect their and your relationships with family and friends. Children and young people may feel less confident and withdraw from social relationships or activities.

It is important that your child knows why their hair will fall out by preparing them for hair loss. The hospital team will be able to advise and help you with this. It may also be beneficial for your child to talk to other children undergoing treatment who have lost their hair.



### Skin changes

Some chemotherapy drugs can cause skin rashes or a change in skin colour. The skin may also become more sensitive to chemicals such as chlorine in swimming pools. The hospital staff will tell you whether it's okay for your child to go swimming during their treatment.

Your child's skin may become more sensitive to the sun. It's important to protect your child's skin by getting them to wear a hat, loose clothing and sunglasses. Use sunscreen with a high sun protection factor (SPF) on any exposed areas (the doctor may be able to prescribe this).

## Other effects

### Kidney, liver or heart damage

Some drugs cause changes in the way the kidneys, liver or heart works. These effects may be long-term (see chart on pages 58-59). If necessary, your child will have regular tests to check their kidneys, liver and heart are working properly. But many children will not need these tests.

### Behaviour changes

Some drugs can cause feelings of anxiety, restlessness, dizziness, sleeplessness or headaches. Some children may also find it hard to concentrate. Others may have mood swings or feel grumpy and irritable. If your child has any of these side effects, let your doctor know.

## Immunotherapy

Immunotherapy drugs target specific cancer cells. For example, rituximab (Mabthera®) is a treatment used to treat some types of lymphoma. It attaches itself to a particular protein on the cancer cell and triggers the body's own immune system to attack and destroy the cancer cells. Because it targets specific cells, other parts of the body are not affected and the side effects are usually mild. Immunotherapy is only suitable for certain types of cancer. It's usually given with chemotherapy.

## Targeted therapy

There are many new drugs being developed for children's cancer that work differently from the way chemotherapy works. These are often called biological agents or targeted drugs. They work by blocking a specific gene or protein that cancer cells have. Special tests on your child's cancer cells in the laboratory may be done to see whether any of the new targeted drugs may work on your child. Often, as these drugs are new, they are used in clinical trials.

Imatinib (Glivec®) is one such drug that's mostly used to treat a particular form of acute lymphoblastic leukaemia and occasionally some other types of cancer. It works by blocking signals within cancer cells and preventing a series of chemical reactions that cause the cells to grow and divide. Your child's doctor will advise if this type of treatment is suitable for your child.

Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy cancer cells in a particular part of the body, while doing as little harm as possible to normal cells. The treatment is usually given in the hospital radiotherapy department as a series of short daily sessions over a few weeks.

The treatments are usually given from Monday–Friday with a rest at the weekend. Your child’s doctor will discuss the treatment and possible side effects with you. The length of treatment will depend on the type of cancer your child has.

Planning radiotherapy

Radiotherapy has to be planned carefully and this may take a few visits. On your child’s first visit to the radiotherapy department, they may have a CT scan or lie under a machine called a simulator. The CT scanner or simulator takes x-rays of the area to be treated.

The treatment is planned by a cancer specialist (clinical oncologist). Marks may be drawn on your child’s skin to help the radiographer, who gives the treatment, to position them accurately. This makes sure that the treatment is given to the right place each time.

Sometimes a mould or mask is made to keep the affected part of the body still each time the treatment is given. The doctors or specialist nurse will explain more about this if your child needs a mould or mask.

Treatment sessions

At the start of each radiotherapy session, the radiographer will position your child carefully on the couch and make sure they’re comfortable. During the treatment, your child will be left alone in the room, but they will be able to talk to the radiographer who will be watching from the next room. In some hospitals, story tapes can be played or you can read stories over the communication system while your child has their treatment.

Radiotherapy is not painful, but your child has to lie completely still for a few minutes while the treatment is being given. Occasionally, they may need to have a general anaesthetic so the treatment can be given.

Remember, radiotherapy will not make your child radioactive and it is safe for them to be with other people.

Proton therapy

Proton therapy is a specialised type of radiotherapy that can be used to treat some types of cancer. Proton beams are thought to cause fewer side effects, particularly long-term effects.

Currently, there are no high-energy proton machines in the UK. However, if the doctors feel this is the best treatment for your child, it may be possible for you to travel abroad for treatment. Your child’s doctor can tell you more about this treatment.



Side effects of radiotherapy

The immediate side effects of radiotherapy are usually very mild. We discuss some of the general side effects here. Your child might have other side effects depending on the area of the body being treated. Your doctor or nurse will be able to explain these to you.

Tiredness

Your child may feel very tired while they are having radiotherapy and for a few weeks afterwards. Their energy levels may take a few months to return to normal once the treatment is finished.

Effects on the digestive system

You may find that your child loses their appetite. It may help for them to eat small snacks and meals frequently throughout the day, rather than large meals. Some children feel sick (nausea) or may be sick (vomit). Your child’s doctor can prescribe drugs to help with this.

Effects on the bone marrow

Radiotherapy to some parts of the body can sometimes affect the bone marrow, which produces the different types of blood cells. If this is likely to be a problem, your child will have regular blood tests during their treatment to check their blood cell levels. If these become low, they may feel very tired and lethargic. Let your child’s doctor know if this becomes a problem. Some children may need to have a blood transfusion – your child’s doctor can give you more information about this.

Effects on the skin

Some children develop a skin reaction similar to sunburn while having radiotherapy. This can happen after 3–4 weeks of treatment. In children with pale skin, the skin in the treatment area can become red and sore or itchy. In those with dark skin, it becomes darker. The extent of the reaction depends on the area being treated and your child’s skin type. Some children have no skin problems at all. Your child’s radiographers will be looking out for these reactions and will advise you about skin care.

Long-term side effects

Radiotherapy can sometimes cause other long-term side effects, which can develop gradually, months or sometimes years after the treatment. As time goes by, the effect of radiotherapy on any growing tissues may become more noticeable. In particular, radiotherapy to the brain can affect a child’s growth and development. Your doctor will be able to discuss this with you in more detail when planning treatment.



Bone marrow or stem cell transplants (high-dose treatment)

A stem cell transplant (sometimes called a bone marrow transplant) allows your child to have much higher doses of chemotherapy than usual. This can improve the chance of curing their cancer but has more side effects.

Bone marrow and stem cells

Bone marrow is a spongy material that's found inside some of our hollow bones. The bone marrow contains stem cells. These are cells at a very early stage of development that develop into the three different types of blood cell (see page 17). When the cells are fully mature, they are released into the bloodstream.

Stem cell transplant

Before a stem cell transplant, stem cells are collected from either the bone marrow or the blood. Your child will then be given very high doses of chemotherapy, usually over a few days. Sometimes, radiotherapy to the whole body, known as total body irradiation (TBI), is also given. As well as destroying any remaining cancer cells, the high doses of chemotherapy also destroy the stem cells in the bone marrow.

After the chemotherapy, your child is given the stem cells that were collected before the treatment through a drip. They make their way into the bone marrow and start producing mature blood cells again.



Types of transplant

There are two main types of transplant:

- Autologous. This uses your child's own stem cells. The stem cells are collected some time before the high-dose treatment and are stored until needed
- Allogeneic. This uses stem cells from a donor – it's also known as an allograft. An allogeneic transplant is a more complicated procedure than an autologous one and is only carried out in specialist hospitals. Recovery may take several months or longer



CCLG has a number of booklets about transplants, including a storybook for younger children entitled: 'Ben's Stem Cell Transplant' and a booklet aimed at teenagers entitled: 'Stem Cell Transplant'.

Maintenance chemotherapy treatment for acute lymphoblastic leukaemia (ALL)

This is the 18-month (for girls) or 30-month period (for boys) of treatment given to most children with ALL, and to some with non-Hodgkin's lymphoma. The aim of maintenance chemotherapy is to mop up those few leukaemia cells that may be left after the first high-dose intensive part of the treatment. To make sure all these cells are destroyed, maintenance chemotherapy must last a long time.

It consists of drug treatment by mouth (oral drugs) given as an outpatient, in between doses of intravenous (IV) and intrathecal medication (IT). Treatment is monitored by regular full blood counts either once a week or once a fortnight, and the drug doses are increased or decreased depending upon the child's blood count level. The main drugs used are: Mercaptopurine, Methotrexate (MTX), Dexamethasone (steroid), Co-trimoxazole (antibiotic) and Vincristine (VCR).

Reducing infection risk while on treatment

There are various ways you can help to reduce your child's chances of infection:

- Good hand hygiene – always ensure hands are washed and cleaned with soap and water regularly particularly after going to the toilet, before eating or drinking and after handling animals. Alcohol gel is a good way of quickly disinfecting hands that are already clean. This is good advice for the whole family to follow too.

- Avoid anyone who is obviously infectious, i.e. coughing and sneezing excessively such as on public transport, shopping, cinema trips and visitors to your home.
- Drink boiled cooled water which should be replaced every 24 hours. Other drinks such as milk, fizzy pop, fizzy water or cartons of juice are all fine to drink as these drinks have undergone some form of pasteurisation. This precaution is to reduce the risk of contracting a specific stomach bug which can cause diarrhoea and may delay treatment.
- Vaccinations/Immunisations for the whole family – ensure you receive full advice from your child's doctor regarding chicken pox, measles, live vaccines and influenza (flu).





Research and clinical trials

Cancer research trials and studies are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. Clinical trials mean there are now better results for curing children's cancers compared with just a few years ago.

Types of research

- test new treatments, such as new chemotherapy drugs
- look at new combinations of existing treatments, or change the way they're given, to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- look at improving the quality of life and services for children and young people who have been treated for cancer
- look at the biology of cancer and its treatment
- find out which treatments are the most cost-effective

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, radiotherapy or other treatment is better than what's already available.

Taking part in a trial

Many children are offered treatment that's part of a clinical trial, so you're likely to be asked for your consent for your child to take part. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments.

Your child will be carefully monitored during and after the trial. Usually, several hospitals around the UK, and increasingly in other countries, take part in these trials, which are coordinated by UK oncologists and haematologists. If you agree to your child taking part in a trial, you will be asked to sign a consent form.

Randomisation

In trials looking at whether a new treatment is better than the best available standard treatment, a process called randomisation may be used. 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.

Randomisation is important because if researchers were to decide who should get which treatment, they might be influenced by what they know about their patients. Consciously or unconsciously, they might put patients who they thought were more likely to respond to a new treatment into the new treatment group. This would introduce bias, making the results unreliable. You can ask your child's doctor to explain this to you in more detail if you would like more information.

Blood and tumour samples

Blood samples and bone marrow or tumour biopsies may be taken from your child to help make the right diagnosis. You may be asked for your permission to use some of the left over samples for research into childhood cancer. Your child's name will be removed from the samples so they can't be identified. Some samples may be frozen and stored for future use when new research techniques are available.

The research may be carried out at the hospital where your child is treated or it may be at another one. This type of research takes a long time, so you are unlikely to hear any results. However, the samples will be used to increase knowledge about the causes and treatments of childhood cancer, which will hopefully improve the outlook for children with cancer in the future.

**i** You may find the following CCLG resources helpful: 'A Guide to Clinical Trials' and 'Donating your child's tissue for research'.

Alternative treatments

Alternative treatments are unconventional and unproven therapies that aim to treat cancer. There is often no scientific evidence for their use and some alternative medicines can interact and interfere with conventional treatment. It is important that you speak to your doctor if you want to explore alternative therapies.

'Wonder cures'

From time to time you may see claims for a new 'wonder cure' in the newspapers, on the internet or on television. Occasionally, the reports are about genuine developments in cancer treatment by reputable people, and the doctors at your child's hospital will usually know something about them. However, some reports can be misleading and give false claims for success.

If you have questions about the value of these 'cures', you can discuss them with your child's doctor. Don't worry that they will be offended by your questions. They will take you seriously and give you honest advice.

The doctors working in specialist children's hospitals know about treatments and research going on in other specialist hospitals that aim to cure children's cancers. So if any better treatment becomes available, they will be aware of it and can change a child's treatment to include the new treatment.

There's also close contact with specialist hospitals and healthcare staff in other countries, so all hospitals are kept up-to-date with any progress on new treatments.

Complementary treatments

It is natural to want to try and help your child in any way you can. Many people use complementary treatments to help maintain their health. People with cancer may use them to manage side effects and improve their sense of well-being. If you're interested in your child using a complementary treatment it is important to discuss it with your child (if they're old enough to understand) and with your child's doctor first. Some treatment interacts with standard treatment your child may be receiving and could be harmful.

Health and activities during treatment

While having treatment, your child should be able to continue with many of their usual activities if they feel able to. But it's important to be aware of some basic precautions. The hospital staff will give you guidance on anything your child should or shouldn't do, or anything you need to know related to your child's treatment.

**i** You can order a CCLG booklet entitled: 'Sport and exercise for children and young people with cancer' which gives parents practical advice about sport and exercise for their child, both during and after treatment.

While your child is having cancer treatment, you should avoid giving them any other drugs or medicines without first discussing them with the doctors. This includes any complementary or alternative treatments (see above). While your child is having treatment they should not have any vaccinations or immunisations unless recommended by your principal treatment centre.

## After treatment and follow-up

It is important for you and your child to attend follow-up clinics when treatment is over. The doctors will want to check that everything is well and ensure that your child doesn't have any long-term problems following their cancer treatment. Certain treatments can sometimes affect a child's future development. We discuss some of these effects below.

The doctors will be able to discuss any specific long-term effects your child might have in more detail with you.

### Puberty and fertility

Some treatments may affect your child's puberty and fertility. These include:

- radiotherapy to the brain
- radiotherapy to the lower abdomen or pelvis (that includes the ovaries or testicles)
- total body irradiation (TBI), usually done with a bone marrow transplant
- some chemotherapy drugs
- surgery to the ovaries, womb or testicles

Your child will be checked regularly for signs of puberty. If this appears to be delayed, hormone replacement therapy may be needed so that puberty can occur.



Understandably, it's very distressing to think that your child may not be able to have children in the future. They may also find this difficult to cope with, either now or in the future, as they move towards adulthood.

For children who have already reached puberty, it can be difficult to know whether or not cancer treatment has affected their fertility until they're old enough to have hormone tests. This will be discussed at follow-up clinics.

If fertility is likely to be a problem, older boys may be given the option of storing some sperm before they start treatment. It also may be possible for girls to have ovarian tissue stored. The hospital staff can tell you more about this.

### Growth and development

Radiotherapy can have an effect on a child's growth and development. It may affect growing bones – for example, if radiotherapy is given to the spine, your child may not grow as tall as expected, or if radiotherapy is given to a leg, that leg may be shorter than the other.

The pituitary gland at the base of the brain produces hormones that help to regulate growth and development from childhood to adulthood. Radiotherapy to the brain may affect the production of growth hormone by the pituitary gland. If your child doesn't produce enough of this, they will not grow normally and may need treatment with a man-made growth hormone.

Your child will be regularly weighed and measured at the follow-up clinics. If their growth has been affected, tests will be done to see if replacement growth hormone is needed.

### Effects on the heart and lungs

Certain treatments can affect the heart and lungs. These treatments include some chemotherapy drugs and radiotherapy. The effects may not be seen for some time after treatment finishes. If your child is at risk of these problems, they'll be regularly followed up with echocardiograms (heart ultrasound scans). Sometimes, special tests on the lungs (lung function tests) are also needed.

### Hearing loss

Hearing problems after cancer treatment are uncommon but they may occur with certain drugs and after radiotherapy to the head, in the region of the ear. Cisplatin is the drug most likely to cause hearing impairment (i.e. partial deafness). This causes particular difficulty in hearing high-pitched noises, and can be detected by sensitive hearing tests. It is seldom severe enough to be noticeable by either the patient, their family or friends, since the lower pitched noises used for speech are not usually affected.

### Kidney problems

These can occur after some types of treatment for children's cancer, but fortunately they aren't usually severe. Removal of one kidney as part of treatment doesn't usually cause any problems because the remaining kidney can make up for the one removed.

Some chemotherapy drugs can cause kidney problems. If your child has had these drugs, their doctor will arrange tests, such as GFR (see page 19), to check their kidneys from time to time. Children whose kidneys are working well at the end of treatment shouldn't develop problems in the future.

Intellectual development and education

Following treatment, most children are able to continue with normal education and the development of their ability to think and understand (intellectual development) is not affected. However, some children, especially children treated for brain tumours, may develop learning difficulties and need to have special help at school. The extent of these difficulties will depend on the age of your child when they were treated, and the treatment they had.

Some children will need a statement of special educational needs to provide the necessary help in the school environment (see page 48). You can discuss this with your child's doctor who can give details of treatment and, if necessary, contact the school or education authority.

Second cancer

A very small number of children who are cured of cancer may develop a different cancer later on in life. There are two main reasons for this. Firstly, some families have an inherited risk factor for cancer, although this is very rare. Also, some cancer treatments can themselves increase the risk of developing other cancers. Your child's doctor will be able to discuss any worries you may have about this.

# Emotions and feelings

Your child's feelings

When a child is diagnosed with cancer, it obviously has a big effect on them. They may be very frightened as well as feeling unwell and having side effects of treatment to cope with.

Being away from home, family and friends can also be difficult for a child to cope with. Understandably, this can have an effect on their behaviour. They may become very clingy, argumentative or difficult.

Maintaining normal discipline during this time is reassuring for your child and can help them feel more secure.

Treatment may cause changes in their appearance, such as weight loss or gain, or hair loss. These changes can affect their confidence, especially for older children and teenagers.

## Talking to 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.

Answering questions honestly is best. 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 doctors or nurses for guidance on how to talk to your child. There are also booklets available from CCLG, CLIC Sargent and Macmillan Cancer Support, 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. Older children may be more frightened of pain. It can help to explain that there are good painkillers available to help control any pain they have. Doctors and nurses will be happy to explain more about this and can help you reassure your child.



## Dealing with school

Children with cancer often have gaps in their education. This can be due to going into hospital, the side effects of treatment, or generally not feeling well enough to fully take part in daily school life. Most children's cancer hospitals have education departments that can support your child while they're in hospital. The teaching staff at the hospital will contact your child's teachers to make sure they can continue their schooling whenever they feel well enough. It's even possible for children to take exams in hospital if necessary.

As your child's health improves and if treatment allows, going back to school may be a relief or a challenge. For many children, school is a refuge from the world of hospitals and procedures – a place for fun, friends and learning. Going back to school can be a sign that life is returning to normal.

However, some children, especially teenagers, may dread going back to school. This may be because of temporary or permanent changes in their appearance. Or they may worry that they'll have missed a lot of work, or that being away will have affected their relationships with their friends.

Bullying may be an issue for some children at school, especially more vulnerable children. You can get advice and support from the school and other organisations (see pages 64-68) if you think your child is being bullied.

If treatment has affected your child's ability to learn, this can be a major frustration for them and may affect their confidence and self-esteem. The school can give extra help for children with learning difficulties. Talk to the teachers at school if you think your child may have problems.

### Keeping teachers informed

It's important to let the school know how your child is doing. As soon as your child is diagnosed, contact the head teacher to tell them what's happening. It can help to let the school know about the plans for treatment. The school teachers can then work with the hospital education department to make sure they cover the same work as the rest of the class.

It can help for the teachers at the hospital to let the school know if your child is emotionally or physically fragile. The school teachers can then take this into account.

At any stage of treatment, your child should be involved in letting the teacher know what information they would like to be shared with their classmates.

### Risk of infection at school

For most children on cancer treatment returning to school is recommended, even when their immune system is low. It is important that they carry on with as normal a routine as possible. Most infections that children on cancer treatment pick up are not from other people or children. Chickenpox, measles or shingles can be dangerous to children who have a low immunity due to cancer treatment.

The school can develop a system to let other parents know that they should notify their child's teacher if their child develops chickenpox, measles or shingles, so that appropriate action can be taken.



If your child has been exposed to chickenpox and has not had it before, contact the hospital straight away. It may be necessary to give your child some medicine to prevent chicken pox developing.

It can be difficult to get the balance right between letting your child mix with their friends and worrying that they might pick up an infection.

You can discuss this with both the hospital staff and the teachers at school to make sure you're happy with what your child does.

### Keeping up with schoolwork

It's important for your child to try to keep up with schoolwork whenever they can. Learning can continue outside school. By speaking regularly to the teacher, you'll know which subjects are being covered. Often, the teacher will send assignments and materials home with siblings or arrangements can be made to collect them.

Your child should have an individual education plan in place. This plan can be shared between your child's school and hospital school to ensure there is consistency in what is being taught.

To help your child keep up in school, you may need to ask for a special education statement. This qualifies your child for extra help.



### Helpful tips

- You could ask your child's specialist cancer nurse or social worker to talk to the class about what is happening to your child and how they will look and feel when they come back to school. This could include a question-and-answer session to clear up misunderstandings and reassure the children in the class. Children having cancer treatment should be involved in deciding what information should be given to their classmates.
- You could also send pictures of your child having treatment to the school. Some families have photo albums that can be shared with the classmates
- Encourage classmates to keep in touch by sending cards, phoning, texting and emailing. Social networking sites can be a good way for older children to keep in touch with classmates



### Very young children

Many children diagnosed with cancer 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's 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
- your child's social needs can be met by siblings and/or other children outside of the nursery
- your child is well enough to attend nursery or pre-school
- your child has already had chickenpox

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.



Schoolfriends may find the CCLG leaflet entitled: 'I have a friend who has cancer' useful.

School teachers may find the CCLG booklet 'Welcome back!' helpful when preparing for when a pupil returns to school after cancer treatment. CLIC Sargent has also produced an information pack for schools entitled: 'Cancer and school life'.

Effects on parents and carers

Having a child diagnosed with cancer will affect you as parents or carers, and the people close to you. Understandably, you'll feel worried and stressed as you come to terms with the diagnosis and what it means for your child to go through treatment. You'll worry that your child will suffer and that your family life is going to be completely disrupted. At first, you may worry that your child is going to die.

When you're first told the diagnosis, you may feel numb, confused, or unable to hear or remember information about your child's diagnosis or treatment. You may also feel overwhelmed by painful and powerful emotions. These reactions are normal – remember the doctors and nurses are there to help you at this time. There are also other people and organisations that can offer support (see pages 64-68).

Seeking information

You may want to find out as much as possible about the cancer and its treatment. There's a lot of information on the internet but not all of it is reliable, so talk to the doctors about where to look. The best advice is to use a website by a recognised organisation such as CCLG, Macmillan or Cancer Research UK.

**i** The CCLG can send you a leaflet entitled 'How can the internet help us?'. It gives tips on finding reliable and user-friendly information about cancer care and treatment on the internet.

Everyone is different – you may read about a child in a similar situation to yours, but they may have a very different experience. Remember, too, that statistics are only helpful to a degree. They're based on large numbers of people and can't say what will happen with your child in particular.

You can ask the doctors and nurses questions again if you've been unable to take it all in. It may help to have someone else with you, and to write down your questions beforehand. You can use the form on page 69 to do this.

Feelings and emotions

Some of the feelings and emotions you may have are described briefly below. Your feelings are likely to change over time and you may not experience all the emotions described here.

Shock

This is one of the most common feelings experienced when first faced with a cancer diagnosis. This is a completely normal reaction which can in the short term cause a range of physical and emotional symptoms such as lack of sleep, lack of appetite, nausea and anxiety.

Fear and denial

You may feel scared, anxious and panicky about what's going to happen and what the future holds. Understandably, parents often want to deny that such a terrible thing could happen to their child. Some people may feel tempted to take their child from one doctor to another. At times, you may feel the fear is almost too much to bear, such as when your child is going into the operating theatre and you wave goodbye.

Sadness

It's natural to feel sad or depressed at times. Every parent wants their child to be healthy, happy and carefree. Cancer and its treatment can have a big impact on you and your child's life. At times, you may have feelings of hopelessness. You may find it difficult to eat or sleep, or feel as though you have no energy for the things you need to do each day.

Parents often say that they feel overwhelmed by the enormity of the situation. These painful and unpleasant feelings can't be avoided, and you're likely to have them at various times during your child's illness. It's important to have support to help you through these times.

Guilt

It's very common for a parent to feel guilty if their child has cancer. Some people wonder if it was something they did or didn't do that caused the cancer, or they feel that it's a punishment for something they did in the past. Sometimes, parents blame themselves for not noticing their child's symptoms quickly enough.

Many parents will have strong feelings of guilt, but it's important to remember that you're not responsible for causing your child's cancer.

Anger

It's normal to feel angry at times. You may feel angry with the hospital staff for putting your child through tests and treatment. You may feel angry that you have to cope with such uncertainty, and the unfamiliar world of hospitals, doctors and nurses. Some people even find that they're angry with their child, as it's their illness that is causing so many problems for the family. This can be distressing but it's also normal.

Parents can feel angry at each other, especially if they have different ways of coping with their child's illness. For example, one parent might want to talk about it a lot and the other might just want to get on with normal life as much as possible.

You may also feel angry with family or friends who make thoughtless remarks or are too busy to give you support. Or you might feel frustrated with people who avoid you because they don't know what to say.

## Looking after yourself

It's important to take care of your own needs and to not feel guilty about doing so. For example, eating and sleeping well, exercising if possible, dealing with any health problems and taking regular breaks will help you cope and care for your child.

Parents often find it hard to express their grief and fears to each other, with the result that they bottle up their feelings, become tense and quarrel more than usual.

Different people have different ways of coping with stress and what helps one can irritate another. If you can, try to talk to each other as openly as possible, and be as supportive and patient as you can.



### Socialising

Understandably, when you're feeling unhappy you may want to avoid seeing friends and taking part in social activities. But it can help to keep up with your usual interests as much as possible and if your energy allows. Having a break and being distracted from the cancer and its treatment will do everyone good.

Some of your friends may not know what to say to you, so it may be up to you to bring up the subject of your child's illness. Others may surprise you with their sympathy and understanding.

### Returning to work

It is sometimes very difficult for families to know how to manage work and how and when to return to work. Don't rush into any hasty decisions but tell your employers about the situation and see what flexible working arrangements they can offer you. If you feel unable to work, then it might be a good idea to make an appointment to see your GP.

### Family and friends

Grandparents, aunts, uncles or other close family relatives often have reactions similar to those of parents and may struggle to deal with some of the same emotions. They usually need to be given accurate information about what's happening and, if possible, be asked to give help and support.



### Getting support

There's no right or wrong way to feel. You'll probably find that your emotions go up and down a lot during the days and weeks following the diagnosis, and that your feelings change over time.

There are many people who can help you deal with these difficult feelings and emotions. You might want to talk to someone close to you, such as your partner or other family member. However, some people find it easier to talk to someone they don't know so well such as a healthcare professional or perhaps a colleague at work.

The staff at the hospital, including social workers, specialist nurses and doctors, can listen and talk to you. You can also talk things through with Macmillan's cancer support specialists on 0808 808 00 00. Or you can contact CLIC Sargent on 0300 330 0803 or Leukaemia CARE on 0808 8010 444.

There are many organisations that offer support to parents of a child with cancer (see pages 64-68). Many hospitals treating children have parent groups where you can meet other parents with similar fears and worries.

Looking after an ill child can cause unexpected expenses and difficulties. A CLIC Sargent social worker will be able to give you advice about benefits you may be entitled to and other financial support, such as grants (see page 66).

### Talking to others

One of the worries you may have when you hear that your child has cancer is what to say to friends and relatives. Every family is different, but many parents find it helpful to be open and frank about the situation. It can help to keep family and friends informed over the weeks and months of treatment. It's then easier for them to understand any changes in behaviour and to offer suitable help and support. There may be a family member or close friend who could take on the role of keeping people up-to-date if you don't feel up to doing this yourself.

**i** You may find the following CCLG booklets helpful: 'Family life and cancer' and 'Grandparents'.





### Effects on brothers and sisters

The 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 need to be cared for by family members or friends. They may have a lot of time away from you and find their daily routine keeps changing. As well as worrying about their brother or sister's health, they may also feel resentful of all the attention they're getting. This can make them feel very left out and angry. They may worry that they're also going to get ill.

It can help to plan some time to let your other children be the centre of attention for a while, perhaps by going out for a meal or to see a film. Even 10 minutes at the end of a day can make a big difference. If your child with cancer is having some special attention – for example, having sweet treats or their favourite things to eat – you can do the same for other children in the family so they don't feel left out.

The needs of brothers and sisters can sometimes be overlooked, particularly in the early months when you may spend most of your time caring for your ill child in hospital or at home. Many brothers and sisters keep their feelings bottled up inside to avoid worrying their parents. Often, the place where siblings may show how they feel is at school. They may:

- withdraw and become very quiet
- become disruptive in the classroom
- cry easily
- become frustrated and have outbursts of anger
- fall behind in class work
- get lower marks than usual
- start missing school
- become rebellious towards teachers
- have arguments and fights with friends and other children in their class

It will help to let your children's head teacher(s) know that their brother or sister has been diagnosed with cancer. You can ask for the school's help and support for your children. The teachers will understand that feelings may be expressed through behaviour at school, once they're aware of the stresses facing the family.

If a sibling is obviously having difficulty dealing with the situation, talk about it with staff at the hospital such as the specialist nurses or the social worker. They can arrange for counselling, help and support for you and your other children. Some hospitals have support groups for siblings.

**i** CCLG has a range of information for brothers and sisters of children with cancer, including a leaflet for parents called 'Helping brothers and sisters'.



### After treatment and follow-up

Understandably, children who have been in hospital can often be difficult and demanding when they go home. Younger children may behave in a more childish way, whereas older children may be aggressive or jealous of their healthy brothers and sisters. Maintaining discipline and having their friends over to visit can help children get back into everyday life.

While it's often a relief to get to the end of treatment, you may find that you feel more anxious and worried now that you and your child are not attending the hospital so regularly. This is normal – all of a sudden you don't have the reassurance from the doctors and other staff.



You may also be worried that symptoms will return once treatment ends. Remember, the hospital staff are still there to help you and will understand your concerns. It's important to contact them if you have any worries about your child's health. Despite all the improvements in cancer treatment, sometimes it doesn't work. In this case another treatment may be available, but this isn't the case for all children.

There's a lot of support for families when a cancer comes back. Further information is available from CCLG, Macmillan and CLIC Sargent.

**i** CCLG booklet for parents entitled 'My child has finished treatment' helps answer some of the questions and concerns that arise when a child finishes their cancer treatment.



# Drug information and glossary

## **Chemotherapy drugs and their possible side effects**

Here we list some of the drugs used to treat children's cancers, along with their side effects.

This section also contains an explanation (glossary) of some of the medical terms you will encounter.

Chemotherapy drugs and their possible side effects

Drug	Possible temporary side effects	Possible long-term side effects
Bleomycin	High temperature; nausea; tiredness; breathlessness; sore mouth and skin	Lung damage
Carboplatin	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting	Damage to kidneys; hearing loss
Chlorambucil (Leukeran®)	Low resistance to infection; anaemia and bleeding or bruising; tiredness	Risk of reduced fertility
Cisplatin	Low resistance to infection; tiredness; anaemia and bleeding or bruising; nausea and vomiting; changes in kidney function	Damage to kidneys; hearing damage; risk of reduced fertility
Crisantaspase (Erwinase®) asparaginase L-asparaginase	Allergic reaction; tiredness; risk of bleeding or of blood clots	
Cyclophosphamide and Ifosfamide (Mitoxana®)	Low resistance to infection; anaemia and bleeding or bruising; hair loss; tiredness; bladder irritation; nausea and vomiting	Damage to kidneys or bladder; risk of reduced fertility
Cytarabine (cytosine arabinoside, Ara-C)	Low resistance to infection; anaemia and bleeding or bruising; hair loss; diarrhoea; tiredness; nausea and vomiting; raised temperatures; sore eyes	
Dacarbazine	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting; loss of appetite	
Dactinomycin (Cosmegen Lyovac®, Actinomycin D)	Low resistance to infection; anaemia and bleeding or bruising; hair loss; nausea and vomiting; tiredness; occasional liver damage; loss of appetite	

Drug	Possible temporary side effects	Possible long-term side effects
Daunorubicin, Doxorubicin, (Adriamycin®), Epirubicin (Pharmorubicin®) and Idarubicin (Zavedos®)	Low resistance to infection; anaemia and bleeding or bruising; hair loss; tiredness; nausea; sore mouth	Weakening of the heart muscle
Etoposide (VP-16, Etopophos®, Vapesid®)	Allergic reaction; low resistance to infection; anaemia and bleeding or bruising; hair loss; tiredness; nausea and vomiting	
Mercaptopurine (Puri-Nethol®)	Low resistance to infection; anaemia and bleeding or bruising; tiredness; skin rashes	
Methotrexate	Low resistance to infection; anaemia and bleeding or bruising; tiredness; diarrhoea; mouth ulcers; nausea and vomiting; skin sensitivity to sunlight	
Mitoxantrone	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting	Weakening of the heart muscle
Prednisolone and Dexamethasone (steroids)	Big appetite; weight gain in the face; risk of infection; raised blood sugar; change in behaviour; raised blood pressure	
Procarbazine	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting	Risk of reduced fertility
Temozolamide (Temodal®)	Low resistance to infection; anaemia and bleeding or bruising; tiredness	
Thiotepa	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting	
Topotecan (Hycamtin®)	Low resistance to infection; anaemia and bleeding or bruising; tiredness; hair loss	
Vincristine (Oncovin®), Vinblastine (Velbe®) and Vinorelbine (Navelbine®)	Constipation; hair loss; tiredness; pain in the jaw; tingling fingers; weak ankles (occasionally)	

Medical terms explained (glossary)

Doctors may use unfamiliar words that you don't understand. Here are some of the most common ones explained (alphabetically).

If you don't understand the words a doctor or nurse uses at any time, don't feel embarrassed to ask them to explain them to you.

**Alopecia** Hair loss

**Anaemia** A reduced number of red blood cells

**Anaesthetic** Drugs that put a person to sleep (general anaesthetic) or that numb a part of the body (local anaesthetic) while they have an operation or procedure

**Benign** Describes a tumour or growth that is not cancerous but may still be capable of causing problems

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

**Blood count** A blood test to check the number of different cells in the blood (sometimes called a full blood count or FBC)

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

**Cardio** To do with the heart

**Catheter** A thin, flexible tube used to give fluid into the body or to drain fluid from the body (for example, a urinary catheter or a central venous catheter)

**Cerebrospinal fluid** (CSF) Fluid produced in the brain that surrounds the brain and spinal cord

**Chemotherapy** Drug treatment that kills cancer cells

**Chromosome** Structure in the nucleus of the cell that contains the genes

**Congenital** Any condition existing at birth

**Cytogenetics** The study of chromosomes in cells

**Electrolytes** The minerals and salts in the body – for example, sodium, potassium and calcium

**Endocrine** To do with hormones

**Excision** Cutting out

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

**Haematology** The study of blood and blood disorders

**Haemoglobin** The substance in red blood cells that carries oxygen around the body

**Histopathology** The study of body tissues

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

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

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

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

**Immunosuppressive** Lowering the body's ability to fight infection

**Intravenous** (IV) Into a vein

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

**Lymphocyte** A type of white blood cell that fights infection

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

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

**Microbiology** The study of germs

**Nausea** Feeling sick

**Neuro** To do with the nerves or nervous system

**Neutropenia or neutropenic** Low levels of neutrophils

**Neutrophils** White blood cells that fight infection

**Oncology** The study and treatment of cancer

**Ophthalmology** The study of the eyes

**Oral** To do with the mouth

**Osteo** To do with the bones

**Paediatric** To do with children

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

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

**Prognosis** The expected outcome of a disease and its treatment

**Prosthesis** An artificial replacement of something – for example, a bone

**Pulmonary** To do with the lungs

**Radiotherapy** The use of high-energy x-rays to destroy cancer cells

**Refractory** Resistant to treatment

**Relapse** The return of a disease after previous treatment

**Remission** There is no evidence of the disease using the available tests

**Renal** To do with the kidneys

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

**Subcutaneous** Under the skin

**Therapy** Treatment

**Thrombocytopaenia** Low levels of platelets in the blood

# Help and support

Help and support are vital at this difficult time and there are a variety of charities, support organisations and helplines who offer advice and information to families.



About the Children’s Cancer and Leukaemia Group

The CCLG supports the 1,700 children who develop cancer each year in the UK. It gives support to healthcare professionals involved in caring for children with cancer and is key to the development of high standards of care.

Publications

CCLG produces an extensive range of accredited award-winning information resources for families (see [www.cclg.org.uk](http://www.cclg.org.uk) for a full list or to download publications) including *Contact* magazine – a free quarterly magazine featuring both information articles and personal stories.

Family and Friends Days

Our Family and Friends Day is a free annual event for anyone who wishes to learn more about childhood cancer. The day offers an excellent opportunity to learn about latest developments in the field, and also allows attendees to chat with others and ask the experts those all-important questions.

Presentations from the day are uploaded onto CCLG’s YouTube channel: [ChildCancerCCLG](#).

Principal Treatment Centres

Our members who work in the network of Principal Treatment Centres (see map on page 13) make sure families across the UK have access to the best possible treatment and care.

Research

Over 80% of children with cancer are now cured. This is largely due to the success of clinical trials and research conducted over many years by CCLG and its members. Research continues with the aim to cure even more children and ensure a normal future for those survivors.

CCLG manages a national Tissue Bank. For more information about this see the factsheet: ‘Donating your child’s tissue for research’.

Children’s Cancer and Leukaemia Group

University of Leicester  
3rd Floor, Hearts of Oak House  
9 Princess Road West  
Leicester LE1 6TH  
Tel: 0116 249 4460  
Email: [info@cclg.org.uk](mailto:info@cclg.org.uk)  
[www.cclg.org.uk](http://www.cclg.org.uk)

Support for children and families

Action for Sick Children

32b Buxton Road, High Lane, Stockport SK6 8BH  
Helpline 0800 074 4519  
Tel 01663 763 004  
Email [enquiries@actionforsickchildren.org](mailto:enquiries@actionforsickchildren.org)  
[www.actionforsickchildren.org](http://www.actionforsickchildren.org)

Provides advice and information for parents with children going to hospital. Offers counselling for parents and has leaflets and videos for children going into hospital.

The Brain Tumour Charity

Hartshead House, 61-65 Victoria Road, Farnborough GU14 7PA  
Tel 0808 800 0004  
Email [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)  
[www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)

Offers information and support, and a helpline for people living with, or affected by, brain tumours.

Childhood Cancer Parents Alliance (CCPA)

SDVS, 131–141 North Walls, Stafford ST16 3AD  
Tel 01785 220 637  
Email [ro@ccpa.org.uk](mailto:ro@ccpa.org.uk)  
[www.ccpa.org.uk](http://www.ccpa.org.uk)

Provides parent and family input into national and international issues affecting children with cancer. Offers advice and support to parents and healthcare professionals by setting up support groups.

Childhood Eye Cancer Trust

The Royal London Hospital, Whitechapel Road, London E1 1BB  
Tel 020 7377 5578  
Email [info@checht.org.uk](mailto:info@checht.org.uk)  
[www.checht.org.uk](http://www.checht.org.uk)

A UK-wide charity for families and individuals affected by retinoblastoma. Offers support and information, funds research and raises public awareness of this rare cancer.

Children with Cancer and Leukaemia, Advice and Support for Parents (CCLASP)

Unit 7, North Leith Sands, Edinburgh EH6 4ER  
Tel 0131 467 7420  
Email [info@cclasp.net](mailto:info@cclasp.net)  
[www.cclasp.net](http://www.cclasp.net)

A children’s charity run by parents whose children have been affected by cancer. Provides information, a helpline, transport to clinics, family holidays, and fun events for families.

Christian Lewis Trust Kids Cancer Charity

62 Walter Road, Swansea SA1 4PT  
Tel 01782 480 500  
Email [enquiries@christianlewistrust.org](mailto:enquiries@christianlewistrust.org)  
[www.christianlewistrust.org](http://www.christianlewistrust.org)

Provides emotional and practical support to families including befriending, bereavement support, play therapy, and holiday programmes.

**CLIC Sargent: Caring for Children with Cancer**  
Horatio House, 77–85 Fulham Palace Road,  
London W6 8JA  
Helpline 0300 330 0803 (Mon–Fri, 8.30am–5.30pm)  
Email [info@clicsargent.org.uk](mailto:info@clicsargent.org.uk)  
[www.clicsargent.org.uk](http://www.clicsargent.org.uk)

Provides a variety of support to children with cancer.  
Also supports families and carers both during and after  
treatment, in hospital and at home.

**Lennox Children's Cancer Fund**  
Lennox House, 57 Mawney Road, Romford RM7 7HL  
Tel 01708 734 366  
Email [info@lennoxccf.org.uk](mailto:info@lennoxccf.org.uk)  
[www.lennoxccf.org.uk](http://www.lennoxccf.org.uk)

A national charity that provides financial, practical and  
emotional support to children and their families affected  
by cancer. Offers respite breaks and care grants.

**Leukaemia CARE**  
One Birch Court, Blackpole East, Worcester WR3 8SG  
CARE Line 0808 801 0444  
Email [care@leukaemiacare.org.uk](mailto:care@leukaemiacare.org.uk)  
[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

Provides care and support to people whose lives are  
affected by leukaemia, lymphoma and the allied blood  
disorders. Has a 24-hour telephone helpline, holiday  
programmes and can provide financial assistance.

**Leukaemia & Lymphoma Research**  
39–40 Eagle Street, London WC1R 4TH  
Tel 020 7405 0101  
(Mon–Fri, 9am–5pm)  
Email [info@beatingbloodcancers.org.uk](mailto:info@beatingbloodcancers.org.uk)  
[www.beatbloodcancers.org](http://www.beatbloodcancers.org)

Supports research into the treatment of leukaemia  
and other related blood disorders in both children and  
adults.

**Lymphoma Association**  
PO Box 386, Aylesbury HP20 2GA  
Helpline 0808 808 5555 (Mon–Thurs, 9am–6pm, Fri,  
9am–5pm)  
Email [information@lymphomas.org.uk](mailto:information@lymphomas.org.uk)  
[www.lymphomas.org.uk](http://www.lymphomas.org.uk)

Provides information and emotional support to anyone  
affected by lymphoma. Produces a variety of free  
publications.

**Macmillan Cancer Support**  
89 Albert Embankment, London SE1 7UQ  
Helpline 0808 808 00 00 (Mon–Fri, 9am–8pm)  
[www.macmillan.org](http://www.macmillan.org)

Offers support and advice to those affected by cancer.

**Neuroblastoma Society**  
Helpline 020 8940 4353  
[www.nsoc.co.uk](http://www.nsoc.co.uk)

Provides advice and support for parents and offers a  
befriending service.

**React**  
St Luke's House, 270 Sandycombe Road, Kew TW9 3NP  
Tel 020 8940 2575  
Email from the website  
[www.reactcharity.org](http://www.reactcharity.org)

Helps children with life-limiting illness. Aims to give  
children comfort, dignity and, where possible, greater  
independence. Provides practical assistance and  
equipment, and financial help.

**Sarcoma UK**  
49–51 East Road, London, N1 6AH  
Tel 020 7250 8271  
Email [info@sarcoma.org.uk](mailto:info@sarcoma.org.uk)

Aims to provide the best possible standard of treatment  
and care for patients with sarcoma.

**Teenage Cancer Trust**  
Third Floor, 93 Newman Street, London W1T 3EZ  
Tel 020 7612 0370  
(Mon–Fri, 8.30am–5.30pm)  
Email from the website  
[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

A charity devoted to improving the lives of teenagers  
and young adults with cancer.  
Runs a support network for young people with cancer  
and their friends and families.  
Also raises funds to build dedicated teenage cancer  
units in hospitals.

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent, others have misleading or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

**Children's Cancer and Leukaemia Group (CCLG)**  
[www.cclg.org.uk](http://www.cclg.org.uk)  
Contains patient information and useful links for parents who have a child with cancer.

**Macmillan Cancer Support**  
[www.macmillan.org.uk](http://www.macmillan.org.uk)  
Find out more about living with the practical, emotional and financial effects of cancer. The Macmillan website contains expert, accurate and up-to-date information on cancer and its treatments.

[www.cancer.gov/cancertopics/youngpeople](http://www.cancer.gov/cancertopics/youngpeople)  
(National Cancer Institute – National Institute of Health – USA)  
Gives comprehensive information for parents who have a child with cancer.

[www.cancer.org](http://www.cancer.org) (American Cancer Society)  
Voluntary organisation dedicated to eliminating cancer. Aims to do this through research and education.

[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk) (Cancer Research UK)  
Contains patient information on all types of cancer and has a clinical trials database.

[www.healthtalkonline.org](http://www.healthtalkonline.org)  
[www.youthhealthtalk.org](http://www.youthhealthtalk.org) (site for young people)  
Both websites contain information about cancer, and have video and audio clips of people talking about their experiences.

**Jimmyteens.tv**  
Offers a valuable resource of short films from young people with cancer and organisations and is supported by the Teenage Cancer Trust.

[www.nhs.uk](http://www.nhs.uk) (NHS Choices)  
NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website, giving people all the information they need to make decisions about their health.

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk) (NHS Direct Online)  
NHS information site for England. Covers all aspects of health, illness and treatments.  
[www.nhs24.com](http://www.nhs24.com) (NHS 24 in Scotland)  
[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk) (NHS Direct Wales)  
[www.n-i.nhs.uk](http://www.n-i.nhs.uk) (Health and Social Care in Northern Ireland)

[www.patient.co.uk](http://www.patient.co.uk) (Patient UK)  
Provides information about health and disease. Includes evidence-based information leaflets on a wide variety of health topics. Also reviews and links to many health- and illness-related websites.

Questions you might like to ask your child's doctor or nurse

You can fill this in before you see the doctor or nurse then use it to remind yourself of the questions you want to ask and the answers you receive.

Q:

A:

Q:

A:

Q:

A:

Q:

A:

Q:

A:

Notes

Use this page to make notes and jot down any useful numbers and information.



The CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families.

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#### **Children's Cancer and Leukaemia Group**

3<sup>rd</sup> Floor, Hearts of Oak House  
9 Princess Road West  
Leicester. LE1 6TH

**Tel:** 0116 2494460

**Fax:** 0116 2494470

**Email:** [info@cclg.org.uk](mailto:info@cclg.org.uk)

**Website:** [www.cclg.org.uk](http://www.cclg.org.uk)

 [@cclg\\_uk](https://twitter.com/cclg_uk)  [ChildrensCLG](https://www.facebook.com/ChildrensCLG)

Registered Charity No: 286669

If you have any comments on this booklet,  
please contact us at the address above.

CCLG booklets are available to download  
from our website.

