

A practical guide to living
with and after cancer

A PARENT'S GUIDE TO CHILDREN'S CANCER

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A parent's guide to children's cancers

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Introduction

This booklet is for parents and carers of a child who has been diagnosed with cancer. This is obviously a very distressing time and there may be many questions that you want to ask.

The booklet gives you information about children's cancers. It discusses their treatment and side effects, and the possible effects on the rest of the family. This information may answer some of the questions that you have, but you will need to talk in detail with the doctors and nurses who are looking after your child. They will also have written information for you about your child's specific type of cancer.

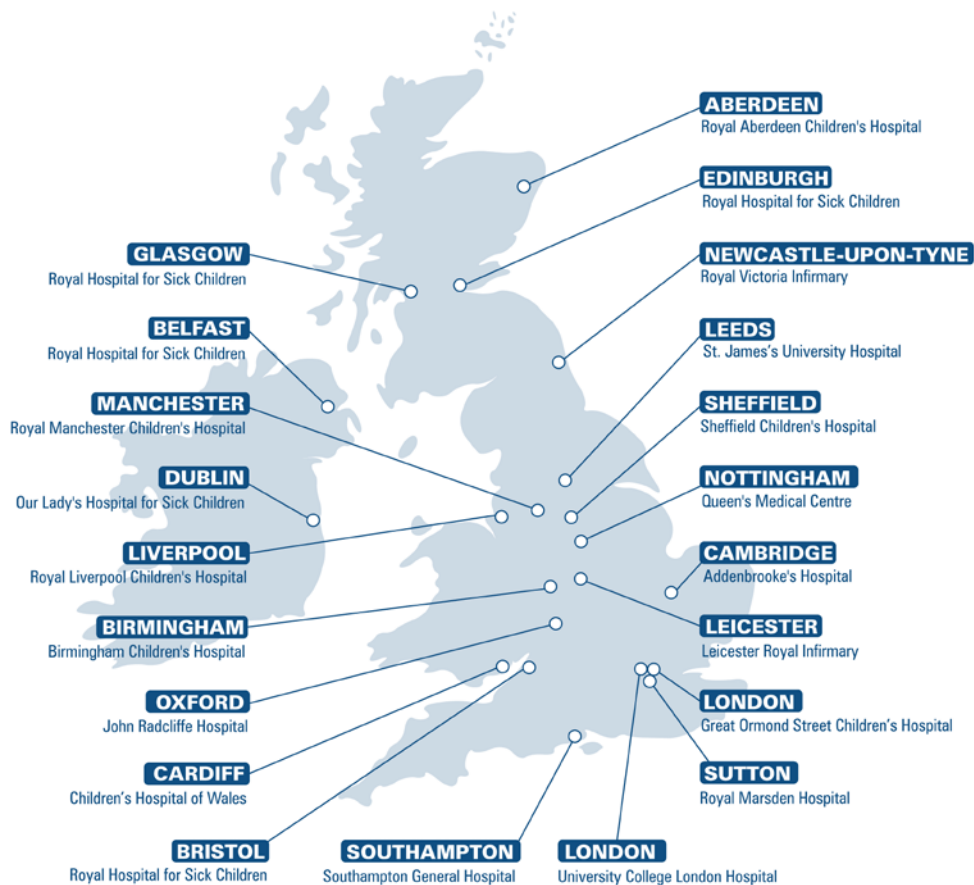
We hope that this booklet will help you to support your child through their treatment and to be aware of the possible effects of the treatment. You will find some useful addresses and details of helpful books and websites on pages 66–77.

Although many children with cancer can be cured, it is still devastating to be told that your child has cancer, and you may have many different experiences and emotions. The emotional effects and ways of dealing with them are discussed on pages 55–60.

If this booklet has helped you, you could pass it on to any of your family and friends. They too may want information so that they can help to support you.

You can get information about all aspects of children's cancers from our cancer support specialists on freephone 0808 808 00 00 or by calling the CCLG (see page 67). You can also email info@cclg.org.uk. Information is available at macmillan.org.uk or cclg.org.uk

Map of CCLG Centres



For details of CCLG centres visit their website at www.cclg.org.uk

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Children's cancers

Children's cancers are rare. In the UK, only 1 in every 600 children under 15 years of age develops a cancer. This means that approximately 1700 children (up to the age of 15) in the UK are diagnosed with cancer each year. These cancers are quite different from cancers affecting adults in that 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.

Cure rates for children are much higher than for most adult cancers and over 70% (more than 7 in 10) of all children can now be completely cured.

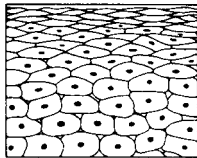
Fact sheets about the different types of children's cancer are available from Macmillan and the CCLG – see inside back cover for a full list.

To place an order call Macmillan on freephone 0808 808 00 00 or the CCLG on 0116 249 4460.

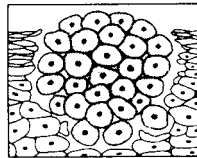
What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. It is important to realise that cancer is not a single disease with a single cause and a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Although cells in different parts of the body may look and work differently, most repair and reproduce themselves in the same way. Normally, this division of cells takes place in an orderly and controlled way. If for some reason the process gets out of control, the cells will continue to divide, developing into a lump which is called a **tumour**. Tumours can be either benign (non cancerous) or malignant (cancerous). Doctors can tell whether a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a **biopsy**.



Normal cells

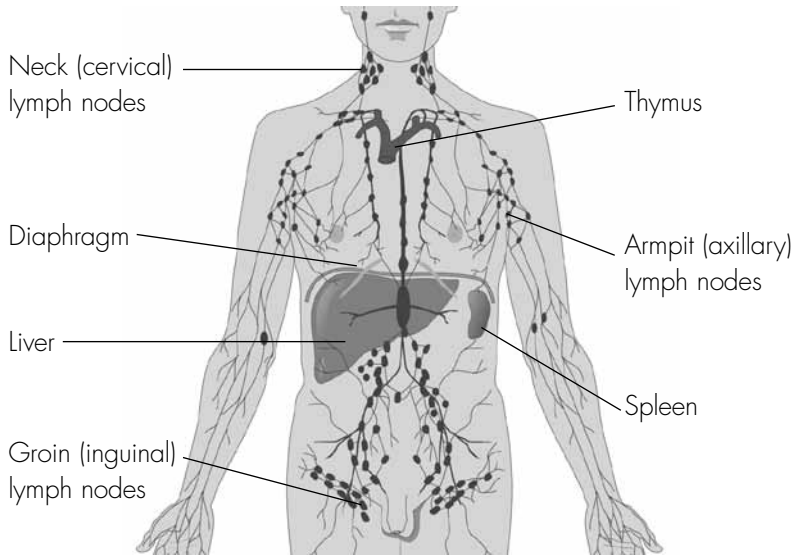


Cells forming a tumour

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

A **malignant** tumour consists of cancer cells that have the ability to spread beyond the original area of the body. If the tumour is left untreated, it may spread into and destroy surrounding tissue.

Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system. The **lymphatic system** is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs such as bone marrow, the thymus and the spleen, and lymph nodes. Lymph nodes are a network of small glands throughout the body connected by a network of tiny lymphatic ducts.



The 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** or a **metastasis**.

Leukaemias are a type of cancer of the bone marrow in which too many white blood cells are produced. Leukaemia is the most common type of cancer found in children.

Causes of cancer

The causes of childhood cancers are mainly unknown, although there are many theories. Research is being carried out to try to find the causes of the different types of cancer.

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

Cancers are not infectious, so they can't be passed on to anyone who comes into contact with your child.

Most cancers are not caused by an inherited faulty gene and so it is extremely rare for a second child in a family to develop cancer.

Parents often worry that something they did or did not do may have caused their child's cancer. This is not the case, and parents should not feel guilty or that they are to blame for their child developing cancer.

Survival rates

There have been huge improvements in the treatment of children's cancer over the past 50 years. More than 7 in 10 (over 70%) of children with cancer are now cured, compared with fewer than 3 in 10 (less than 30%) in 1962–66. Research is continuing to improve treatments and reduce side effects.

To compare the results of treatments, doctors use five or 10-year survival rates. Five-year survival means the percentage of patients alive five years after they are found to have cancer.

Diagnosis

Diagnosis means finding out if a child has cancer, and what type of cancer they have. Doctors will do this by looking at your child and the symptoms they have and by doing tests.

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

- a doctor who specialises in treating children (**a paediatrician**) or
- a doctor who specialises in treating children with cancer (**paediatric oncologist**) or
- a doctor who specialises in treating blood disorders (**a haematologist**).

Most children with cancer will be treated in a Children's Cancer and Leukaemia Group (CCLG) unit within a hospital (see page 19). Various tests will be done to diagnose the cancer.

Tests

Tests are done for a number of reasons:

- So that the cancer or leukaemia can be diagnosed accurately. Sometimes it is hard to tell the difference between specific types of cancer. Your child's doctor may speak 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 also whether it has spread.
- To assess your child's general health, as this may affect the treatment that is given.

The tests may mean that treatment can't be started for a few days. However, it's important to have the information from the tests, so that the right treatment can be chosen. Generally, cancer develops slowly and waiting to start treatment for a short time will not make the treatment less effective.

With some types of cancer it is very important to start treatment straight away. If this is the case, your child's doctor will discuss this with you.

It is important to get all the necessary information together from the tests to make sure that the best treatment is given.

Some common tests are described here. Several of these tests are carried out again during the course of treatment, to see how the treatment is affecting the cancer. Some tests can also check for any side effects of treatment.

Biopsy

If your doctor thinks that a tumour may be a cancer, the surgeon may remove part of it to look at under a microscope.

Needle biopsy A special needle is put into the tumour through the skin to remove a small part of the tumour.

Open biopsy A tiny piece of the tumour is taken during a small operation.

The sample of cells is sent to a laboratory to be examined by the **histopathologist** (a person who studies body tissues). The histopathologist can tell if it is a cancer and exactly what type of tumour it is. It usually takes several days to get the results of biopsies. With an open biopsy, the surgeon may sometimes be able to remove the whole tumour rather than just taking a sample.

Blood tests

There are lots of different types of blood tests. Blood samples will be sent to different laboratories depending on the type of test. Blood tests may be done when your child is diagnosed, during treatment and afterwards at follow-up appointments.

Full blood count The numbers of different types of blood cells in the blood are counted in the haematology laboratory. This is called a full blood count. This is one of the main ways to monitor the side effects of treatment.

Blood chemistry The blood may also be looked at in the laboratory to measure the levels of certain chemicals. This gives information about how well organs of the body, such as the liver and kidneys, are working.

Blood 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.

Blood culture This is when microbiologists (people who study types of infection) check a sample of blood to see whether there is any infection.

Blood may also be taken to see if your child has had any viruses in the past, such as measles, hepatitis or German measles (rubella).

Bone marrow test

In several types of cancer, the bone marrow may be affected. Bone marrow is the area of soft spongy cells in the middle of some of the bones. It produces cells (called **stem cells**) which develop into the three different types of blood cells:

- red blood cells, which carry oxygen to all cells in 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 sample of bone marrow, a needle is put into the bone of the hip and some of the marrow is drawn out using a syringe. This is sent to be looked at in a laboratory. This test (also known as a **bone marrow aspirate**) 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 can feel very sore for a few days after the test.

Lumbar puncture

In some conditions, such as leukaemia or lymphoma, cancer cells can pass into the fluid that surrounds the brain and the spinal cord - **the cerebrospinal fluid** or CSF. To see whether this has happened, 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 CSF is examined to see if any cancer cells are there.

Sometimes, as part of the treatment, drugs are injected into the CSF at the same time. This is known as **intrathecal chemotherapy**.

X-rays

On an x-ray a tumour often looks different from healthy tissue. An x-ray can show if there is a tumour in the chest, tummy (**abdomen**) or bones. Sometimes special dyes are injected into a vein to make particular parts of the body show up better on the x-ray.

Ultrasound scan

This uses sound waves to build up a picture of the inside of the body. A gel will be spread onto 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 used particularly to look at the tummy (**abdomen**) and heart.

CT (computerised tomography) scan

A CT scan shows up areas of the inside of the body. The CT scanner takes a series of x-rays from different angles. A computer uses the x-rays to build up a 3-D picture of the inside of the body. CT scans are painless but your child may be given a sedative or general anaesthetic to make sure that they lie still.

MRI (magnetic resonance imaging) scan

This scan is similar to a CT scan but uses magnetism instead of x-rays to build up the pictures. The scan is painless, but the machine is very noisy. It can look frightening, as your child has to lie in a narrow tunnel. They may be given a sedative or general anaesthetic to make sure that they lie still. They will also be given earplugs or headphones to wear. Some scanners can show videos as the scan is being done. It may be possible for you to stay in the room with your child while they have the scan.



An MRI Scanner in a children's ward

Bone scan

If your child has a bone tumour or a tumour which has spread to bone, this scan will show how much of the bone is affected. Small doses of a radioactive substance are injected into a vein, usually in the arm. The radioactive substance is taken up by the bone. Abnormal areas of bone absorb more of the substance than healthy bone and are highlighted on the scanner as **hotspots**.

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.

Staging of cancer (solid tumours)

The stage of a cancer means the size of the tumour and whether it has spread beyond where it started in the body. Knowing the extent of the cancer helps the doctors to decide on the best treatment for your child.

Generally, cancer is divided into four stages:

- **Stage 1** – small and localised
- **Stage 2 or 3** – when the cancer has spread into surrounding structures
- **Stage 4** – when it has spread to other parts of the body

If the cancer has spread to distant parts of the body this is known as **secondary** or **metastatic** cancer.

Leukaemia

There are two main types of leukaemia in children:

- acute lymphoblastic leukaemia (ALL)
- acute myeloid leukaemia (AML).

Each type can be divided into different sub-types. Blood and bone marrow samples will be checked to find out which type of leukaemia a child has. Doctors will look to see exactly which type of cell has been affected (become leukaemic) and at which stage of its development. The cells may be tested with antibodies to see if they have certain proteins on their surface. This is known as **immunophenotyping**.

Almost all of the cells in our body contain chromosomes. Chromosomes are made up of genes which control the activities of the cell. There are often changes in the structure of the chromosomes (genetic changes) in leukaemia cells. Testing the cells for any genetic changes is known as **cytogenetics**.

Knowing the exact type of leukaemia helps the doctors to know which treatment is likely to be most effective.

Being in hospital

There are 21 hospitals in the United Kingdom and the Republic of Ireland that are specialist centres for diagnosing and treating children's cancers. If the doctors at your local hospital think that your child has a cancer, they are likely to send your child to one of these centres. Often, some of the later treatment can be given at your local hospital under the guidance of the nearest specialist centre. This is known as **shared care**.

Many people will be involved in looking after your child, both at home and while they are in hospital. Some of the people and their roles are described below. Although you may not meet all of the people listed, you will probably come into contact with many of them.

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

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

GP (general practitioner) Your own family doctor may have been the first to suspect that your child could have a cancer and refer you to a specialist. As childhood cancer is rare, your GP can't possibly know all the details of diagnosis and treatment. You may like to show your GP a copy of this booklet so that they are aware of the information that you have. Your hospital doctors will write regularly to your GP to keep them up to date with your child's progress.

Haematologists are doctors who specialise in blood disorders, including leukaemias and lymphomas. They examine samples of blood in the laboratory and also work on the ward looking after patients.

Nurses The sister, ward manager, or charge nurse is in charge of the ward. Staff nurses, student nurses and health care assistants work under the sister/ward manager/charge nurse's direction. There may be a specialist nurse in your hospital who works only with children who have cancer. There may also be community nurses who can visit your child at home.

Paediatric oncologists are doctors who treat children with cancer. They are specialists in planning and giving cancer treatment.

Pathologists analyse tissues samples (such as tissue taken at biopsy) under the microscope, to diagnose illness or see how an illness is being affected by the treatment.

Pharmacists are responsible for preparing and dispensing the medicines your child will be given. Pharmacists are based in the hospital pharmacy department and may also visit the ward.

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

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

Psychologists may be able to help children who have difficulties with behaviour or learning during their treatment. Psychologists also support the child's family.

Radiographers take x-ray pictures and some may give radiotherapy.

Radiologists interpret x-rays and scans.

Social workers can help with practical, emotional and financial problems that you may have. The CLIC Sargent organisation (see page 68) provides social workers who specifically support children with cancer and their families.

Surgeons carry out operations. They may take a biopsy (remove a piece of tissue from the tumour for examination under the microscope) and/or remove the whole tumour. They also put in central lines (see page 27).

Teachers Each children's hospital has a school which provides education for children when they are in hospital. The hospital school will contact your child's school and the hospital and school teachers work together to plan an education programme for your child.

Ward doctors In the hospital you will meet doctors who are at different stages of specialising in looking after children with cancer. Some will be registrars and some senior house officers. Most of the tests and treatment are done by these doctors, under the supervision of the paediatric oncologist.

Hospital and ward life

Your child will probably need to spend some time in hospital during their treatment. Children's wards are relaxed and friendly places aiming to give you and your child as positive an experience as possible. You are likely to get to know the staff well.

Almost all children's wards have a room where parents can stay. Brothers and sisters may be able to stay too. Most children, especially younger ones, want their parents to spend as much time as possible with them.

More and more hospitals now have special wards or areas for teenagers with cancer. The surroundings and experience of staff may be better suited for older children.

Your child may seem upset when you arrive or leave, and this can be difficult for you. Don't let this affect how often you go to see them though, as this could make them feel abandoned. If you have to leave, make sure that you say goodbye and tell your child and the ward staff exactly when you will be back.

It can help to try to get out of the ward for a short break during the course of the day. Being in the same surroundings all day where everyone is worried and frightened can be a great strain. The nursing staff will understand this and encourage you to take regular breaks.

Usually you can visit children in hospital whenever you want - the ward staff will be able to tell you if there are any restrictions. Visits from healthy school friends can be very good for your child. But remember it can sometimes be tiring for a sick child if there are too many people visiting at the same time.

Do talk about your feelings or worries with the ward nurses or perhaps the 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 (see pages 52-55).

Treatment

At present, there are three main ways of treating cancer:

- The tumour can be cut out during an operation (**surgery – see page 25**).
- Cancer cells can be killed with drugs (**chemotherapy – see page 26**).
- Cancer cells can be killed by radiation (**radiotherapy – see page 39**).

Your doctor will discuss with you which treatment, or combination of treatments, is appropriate for your child. More information about treatment is given in the individual fact sheets about specific childhood cancers.

Health and activities during treatment

While having treatment, your child should be able to continue with most of their usual activities if they feel able to, as long as you are aware of some basic precautions. The hospital staff will give you guidance on anything you should do, or anything you need to know, related to your child's particular treatment.

While your child is having cancer treatment, you should not give them any other drugs or medicines without first discussing these with your child's doctors. This includes any complementary or alternative treatments. While your child is having treatment they must not have vaccinations or immunisations.

Giving consent to treatment

Before your child has any treatment, their doctor will explain the aims of the treatment to you and 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 do discuss any concerns you have with your doctor.

Before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment recommended for your child
- the advantages and disadvantages of the treatment
- any other types of treatments that may be appropriate
- any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straight away so that they can explain again. Many cancer treatments are complex, so it is not unusual for people to need repeated explanations.

You may also find it useful to write down a list of questions before you go for your appointment.

People often feel that hospital staff are too busy to answer their questions. However, it is important for you to be aware of how the treatment is likely to affect your child and any possible side effects that the treatment may cause. The staff should be willing to make time for you to ask questions.

You can always ask for more time to discuss or to decide about the treatment if you feel that you can't make a decision when it is first explained to you. In emergencies, decisions may have to be taken quickly, but otherwise it is usually possible to take as much time as you need.

Surgery

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

Often, a biopsy of the tumour is taken first to make the diagnosis. A biopsy involves taking a piece of tissue from the tumour so it can be looked at in the laboratory (see page 12).

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

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs are carried in the blood, and so can reach cancer cells all over the body. Chemotherapy drugs affect dividing cells. This includes some normal cells such as in the lining of the mouth, the bone marrow (which makes blood cells), the hair follicles, and the digestive system. Healthy cells can repair the damage caused by chemotherapy but cancer cells can't and so they eventually die.

Chemotherapy can be given in different ways: either as tablets or capsules which are swallowed, or by injection into a vein. There are many technical terms used to describe how the drugs are given and you will see these on your child's drug chart and on treatment plans (protocols). The common terms are:

- **intravenous or IV:** injection into a vein
- **oral, PO, O or by mouth:** as tablets or capsules
- **intramuscular or IM:** injection into muscle
- **subcutaneous or SC:** injection just under the skin
- **intrathecal or IT:** by lumbar puncture (see page 14).

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

Chemotherapy treatment plan

Chemotherapy has to be planned carefully. It is 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 is usually a rest period so that the healthy cells can recover before the next dose is given. 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 and it may sometimes be given intensively in high doses over a short period or in lower doses over a longer period.

Intravenous chemotherapy

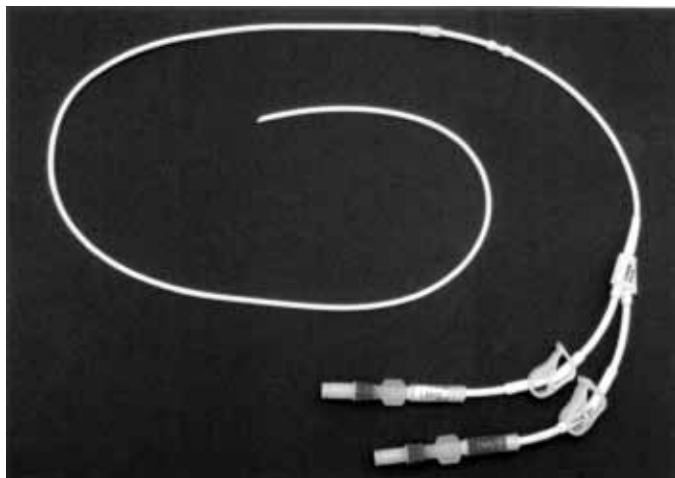
A common way of giving chemotherapy into a vein is through a central line, PICC line or implantable port. These are tubes that are inserted into a vein and can stay in place for some months. They can be used for taking blood as well as giving treatment and other medicines. This means that your child won't need to have a needle inserted each time, something which can be painful and distressing for a child. The chemotherapy drugs are usually diluted into a bag of liquid such as salt water (**saline**) and the drip is attached to the end of the central line, PICC line or implantable port.

Occasionally, treatment may be given through a thin tube that is inserted into a vein and then taped firmly to your child's arm. This tube is called a **cannula**.

Central lines

A **central line** (central venous catheter) is a thin, flexible, plastic tube, which is inserted into a vein near the collar bone. It is put in under a general anaesthetic. The surgeon makes a small cut into a vein in the neck and feeds the tube down until the tip is in one of the large veins near to 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

PICC lines

Instead of a tunnelled central line, 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)**. The doctor or chemotherapy nurse will explain the procedure to you. The line is 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.

As with a tunnelled central line, having a PICC line means that your child does not need to have needles put into the vein to take blood or give chemotherapy. They will be able to bath or shower, although

you should avoid water getting onto the area around the tube – a plastic dressing can be used for this.

Implantable ports

Some tubes do not come out through the skin. Instead, they end in a reservoir or **port** that is under the skin below the collar bone. To give chemotherapy, or take blood, a small needle is pushed through the skin into the port. The skin over the port can be numbed with anaesthetic 'magic' cream (Ametop® or Emla cream®). This is done about half an hour before the port is used.



An implantable port

Looking after a line or port

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

Advantages and possible problems with lines

Central lines can stay in place for many months and are a very good way of avoiding the discomfort of repeated injections. However, there are three main potential problems: falling out, blockage and infection.

Falling out Rarely, a tube may fall out because a child pulls on the tube by accident when they are playing or asleep. Fortunately, if a tube does fall out, the blood clots quite quickly to seal 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.

Blockage Occasionally, lines may seem to be blocked. This can be caused by the tip of the line lying at an odd angle against the wall of the vein. It can also be caused by the line becoming 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 that the line can be used again. Your child may have a lineogram (a special scan which shows the position of the tube).

Infection Despite being carefully looked after, some lines become infected. If infection occurs, antibiotics are given, but if these don't clear the infection the line may need to be removed.

Side effects of chemotherapy

Chemotherapy drugs can cause unpleasant short-term side effects. However, these are mostly temporary and there are often ways of controlling or reducing them. The main areas of the body that may be affected by chemotherapy are 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 of the common short-term side effects and ways of dealing with them are described below. Your child will not have all of the side effects described here, but may have some of them. Side effects of particular chemotherapy drugs are detailed in the table on pages 36–38.

Different children will be affected by chemotherapy in different ways. Your child's doctor or chemotherapy nurse will tell you about the side effects likely to occur during your child's treatment.

The possible longer-term side effects of chemotherapy are discussed on pages 45–48.

Effects on bone marrow

Low immunity to infection (neutropenia)

Some chemotherapy drugs can 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 can begin seven days after treatment has been given. If the chemotherapy is being given every 3–4 weeks, the number of white blood cells usually reaches its lowest point (nadir) about 10–14 days after the chemotherapy. The blood cells will then increase steadily and will usually have returned to normal before the next course of chemotherapy is due.

When the white cell count is low your child may become ill with an infection. In spite of this they will be able to overcome most minor infections.

You must contact the hospital straight away if:

- your child's temperature goes above a certain level (staff at the hospital will tell you which level)
- your child suddenly feels unwell, even with a normal temperature.

Your child will probably need to be admitted for intravenous antibiotics until the hospital is sure about the type of infection.

Your child will have a blood test before having more chemotherapy to make sure that their cells have recovered. Occasionally it may be necessary to delay treatment if their blood count is still low.

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

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 may make them feel very tired and breathless. 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, cells which help the blood to clot. Let your doctor know if your child has any unexplained bruising or bleeding such as nosebleeds, blood spots or rashes on the skin, or bleeding gums.

If the number of platelets in the blood is very low, a platelet transfusion can be given.

Effects on the digestive system

Feeling sick

Chemotherapy drugs may make your child feel sick (nauseated). Some drugs may make your child actually be sick (vomit). However, this can often be controlled with anti-sickness medicines known as anti-emetics. Tell the doctors if your child is having problems with sickness – changing the anti-sickness medicine can usually help.

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 needed they may be fed through a tube passed down their nose into their stomach (nasogastric tube), or a tube passed through their abdominal wall into the stomach (PEG tube). Sometimes, they may be fed through a central line.

Macmillan can send you information about these ways of giving nutrition.

Diarrhoea or constipation

Some drugs may change the way that the bowel works, so your child may have diarrhoea or constipation. Laxatives can be given for constipation. Diarrhoea can usually be controlled with anti-diarrhoea medicines.

Sore mouth

Some drugs can cause a sore mouth, which may lead to mouth ulcers. If this happens it usually starts about 5–10 days after the drugs are given and will clear up within 3–4 weeks. Your child's doctor can prescribe mouthwashes to help and the nurses will show you the best way to care for your child's mouth.

Taste changes

Chemotherapy can cause your child's taste to change; food may taste more salty, bitter or metallic. Their taste will return to normal after the chemotherapy treatment finishes.

Effect on skin and hair

Skin changes

Some chemotherapy drugs can cause skin rashes or a change in the colour of the skin. The skin may also become more sensitive to chemicals such as the chlorine in swimming pools.

Your child's skin may be more sensitive to the sun. Protect your child's skin from the sun by getting them to wear a hat and sunglasses, covering skin with loose clothing and using sunscreen cream on any exposed areas.

Hair loss

Some drugs will make your child's hair fall out. In some children all their hair may fall out, but in others the hair may just get thinner. There are lots of ways of dealing with hair loss - often children like to wear baseball caps, bandanas, hats or scarves rather than have a wig. But if you and your child want, a wig will be given to them by staff at the hospital. The hair always grows again quite normally

within a few months of stopping treatment. Macmillan can send you a booklet about dealing with hair loss.

Other effects

Kidney, liver or heart damage

Some drugs cause a change in the way that the kidneys, liver or heart work and this may be long-term (see chart on pages 36–38). Your child will have regular tests to check that their kidneys, liver and heart are working properly.

Behavioural changes

Some drugs can cause feelings of anxiety, restlessness, dizziness, sleeplessness or headaches. Some children also find it hard to concentrate on anything. If your child has any of these side effects, let your doctor know.

Some of the individual drugs and their side effects are described in the table on the following pages

Drug	Temporary side effects	Possible longer-term side effects
Actinomycin	Low resistance to infection; anaemia and bleeding or bruising; hair loss; nausea and vomiting; tiredness; occasional liver damage	
Asparaginase	Allergic reaction; tiredness	
Bleomycin	High temperature; hair loss; nausea and tiredness; breathlessness; sore mouth and skin	Lung damage
Carboplatin	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting	
Chlorambucil	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; hearing changes	Damage to kidneys and hearing
Cyclophosphamide and Ifosfamide	Low resistance to infection; anaemia and bleeding or bruising; hair loss; tiredness; bladder irritation; nausea and vomiting	Damage to kidneys; risk of reduced fertility

Drug	Temporary side effects	Possible longer-term side effects
Cytosine arabinoside (Ara-C)	Low resistance to infection; anaemia and bleeding or bruising; hair loss; diarrhoea; tiredness; nausea and vomiting	
Daunorubicin, Doxorubicin (adriamycin) and Epirubicin	Low resistance to infection; anaemia and bleeding or bruising; hair loss; tiredness; nausea; sore mouth	Weakening of heart muscle
Etoposide	Allergic reaction; Low resistance to infection; anaemia and bleeding or bruising; hair loss; tiredness; nausea and vomiting	
Mercaptopurine	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	

Drug	Temporary side effects	Possible longer-term side effects
Prednisolone and Dexamethasone	Big appetite; fat cheeks; risk of infection; raised blood sugar; change in behaviour	
Procarbazine	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting	Risk of reduced fertility
Temozolamide	Low resistance to infection; anaemia and bleeding or bruising; tiredness	
Thioguanine	Low resistance to infection; anaemia and bleeding or bruising; tiredness; nausea and vomiting	
Vincristine and vinblastine	Constipation; hair loss; tiredness; pain in the jaw; tingling fingers and weak ankles (occasionally)	

Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells in one area 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 to Friday, with a rest at the weekend. Each treatment takes about 10–15 minutes. Your doctor will discuss the treatment and possible side effects with you. How long treatment is given for depends on the type of tumour.

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 their treatment) to position them accurately. This makes sure that the treatment is given to exactly the right place each time.

Sometimes your child may have a clear plastic mould made to keep the affected part of the body still each time the treatment is given (see picture on page 40). If this is necessary, the doctor or specialist nurse will explain the process to you.



Child and mask for radiotherapy

Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position your child carefully on the couch, and make sure they are 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. You can be with the radiographer, so you can see your child and talk with them. Often, story tapes can be played, or you can read stories over the communication system.

Radiotherapy is not painful but your child has to lie completely still for a few minutes while the treatment is being given. With young children, or if children are not able to keep still, they may be given a sedative. Occasionally they may need to have a short general anaesthetic to allow the treatment to be given.

Possible general side effects

The immediate side effects of radiotherapy are usually very mild.

Tiredness

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

Loss of appetite

You may find that your child loses their appetite. It may help for them to have frequent small snacks throughout the day, rather than large meals.

Effect on 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 thought likely in your child's case they will have regular blood tests during their treatment, to check their blood cell levels. If these are low, they may feel very tired and lethargic.

Effects on skin

Some children develop a skin reaction, similar to sunburn, while having radiotherapy. This may happen after 3–4 weeks. 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 amount of the reaction depends on the area being treated and the individual child's skin type. Some children have no skin problems at all. Your child's radiographers will be looking for these reactions but you should also let them know as soon as you see any soreness.

Long-term side effects

Radiotherapy can cause some other longer-term side effects, which will start gradually, months or sometimes years after the treatment (see page 45–48). As time goes by, the effect of radiotherapy to any growing tissues may become more noticeable. In particular, radiotherapy to the brain can affect growth and development. Your doctor will be able to discuss this with you in detail.

Macmillan can send you information about radiotherapy and how to deal with any side effects.

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

A blood stem cell or 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. Very high doses of chemotherapy, sometimes with radiotherapy to the whole body (total body irradiation, or TBI), are given over a few days.

Bone marrow and stem cells

Bone marrow is a spongy material that is found inside some hollow bones.

The bone marrow contains **stem cells** which develop into the three different types of blood cells:

- red blood cells, which carry oxygen to all cells in the body
- white blood cells, which are essential for fighting infection
- platelets, which help the blood to clot and prevent bleeding.

When the cells are fully mature they are released into the bloodstream. Stem cells can be collected from either bone marrow or blood.

Very high doses of chemotherapy destroy the bone marrow. So after high-dose chemotherapy, your child is given stem cells as a drip into their central line. The stem cells make their way into your child's 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 or bone marrow – it is also known as high-dose treatment and blood stem cell support.

Allogeneic

This uses stem cells or bone marrow from a donor – it is also known as an allograft. An allogeneic transplant is a more complicated procedure and is carried out in specialist hospitals. Recovery may take several months or more.

Macmillan can send you information about bone marrow and stem cell transplants and how to deal with the side effects.

Long-term side effects of treatment

Most children will not have any serious long-term problems after having treatment for cancer. However, it is very important for them to attend a follow-up clinic to check for any problems that may occur.

Puberty and fertility

Certain treatments may affect puberty and fertility. These are:

- radiotherapy to the brain
- radiotherapy to the lower abdomen or pelvis, including the ovaries and 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 for signs of puberty. If this appears to be delayed, hormone replacement therapy may be needed so that puberty can occur.

Infertility

Some treatments for cancer can cause problems with fertility. It can be very distressing to think that your child may not be able to have children in the future. Your child may also find this difficult to cope with, either now or in the future as they move toward adulthood.

For children who have already reached puberty, it can be difficult

to know whether cancer treatment has affected fertility until they are old enough for hormone tests to be carried out. This will be discussed at follow-up clinics.

If fertility is likely to be a problem, older boys may be given the option of sperm banking before they start treatment. The hospital staff can tell you more about this.

Macmillan has a booklet about sex and fertility for teenagers and young people.

Growth and development

Radiotherapy can have important effects on growth and development. It may affect growing bones: for example, if radiotherapy is given to the spine, your child may not grow quite as tall as expected. If radiotherapy is given to a leg, then that leg may be shorter than the other.

Radiotherapy to the brain may affect the production of growth hormone by the pituitary gland. The pituitary gland produces hormones and helps to regulate growth and development from childhood to adulthood. If your child does not produce enough growth hormone, they will not grow normally and may need treatment with man-made growth hormone.

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

Heart and lungs

Certain treatments can affect the heart and lungs, and the effects may not be seen for some time after treatment has ended. These

treatments include some chemotherapy drugs and radiotherapy. If your child is at risk of these problems they will be regularly followed up with **echocardiograms** (heart ultrasound). Sometimes it is necessary to do special tests on the lungs (lung function tests).

Kidney problems

These can occur after some types of treatment for childhood cancer but fortunately they are not usually severe. Removal of one kidney as part of treatment does not usually cause any problems because the remaining kidney can make up for the one removed.

Certain chemotherapy drugs can cause problems for the kidneys. If your child has had these drugs, their doctor will arrange checks on their kidneys from time to time. Children whose kidneys are working well at the end of treatment should not 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. You can discuss this with the 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 go on to develop another, 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 rare. Secondly, some cancer treatments can themselves increase the risk of other cancers. Your child's doctor will be able to discuss any worries you may have about this.

Research – clinical trials

Cancer research trials 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 continue to be a really important reason why there are better results for curing children's cancer, compared with just a few years ago. You may wish to ask your child's doctor about which trials are available.

Clinical trials may be carried out to:

- look at new combinations of existing treatments, or change the way they are given, in order to make them more effective or to reduce side effects
- test new treatments, such as new chemotherapy drugs, gene therapy or cancer vaccines
- compare the effectiveness of drugs used for symptom control
- find out how cancer treatments work
- see which treatments are the most cost-effective. Trials are the only reliable way to find out if a different operation, or type of chemotherapy or radiotherapy, is better than what is already available.

Taking part in a trial

You may be asked for your consent for your child to take part in a research trial. There can be many benefits in doing this. The trials help to improve knowledge about cancer and the development of new treatments. Your child will also be carefully monitored during and after the study. 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 patients to have the different treatments in the trial. This is done so that each treatment group has a similar mix of patients of different ages, sex and state of health.

If it were left to the researchers 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 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

Many blood samples and bone marrow or tumour biopsies may be taken to help make the right diagnosis. You may be asked for

your permission to use some of your child's samples for research into childhood cancer. Some samples may be frozen and stored for future use when new research techniques become available.

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

'Wonder cures'

From time to time you may see claims for some new 'wonder cure', often from abroad, in the newspapers or on television. Occasionally the reports are about genuine developments in cancer treatment by reputable people, and as a rule the doctors at your child's hospital will 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 your questions seriously and give you honest advice.

Children's cancers are rare and the doctors working in specialist children's hospitals know about treatments and new research trials going on in other hospitals. In this way, if any better treatment becomes available, everyone is aware and can change. There is also close contact with healthcare staff in the rest of the world, so that everyone is kept up-to-date with progress.

Effects on your child

When a child is diagnosed with cancer, this obviously has a big effect on the whole family. Your child may be very frightened as well as having symptoms of the cancer or side effects of treatment to cope with.

They may become very clingy, argumentative and difficult. Maintaining normal discipline is reassuring for your child and can help them feel more secure.

Your child's whole routine is likely to change, with stays in hospital and going to hospital for appointments. The treatment may make them feel very unwell for a time and may cause changes in their appearance, such as weight loss or their hair falling out. These changes can affect their confidence – especially in older children and teenagers.

Talking to your child

Perhaps one of the hardest parts of caring for a child with cancer is knowing how to talk to them about it. Answering questions honestly is best. Although some children do not ask questions, this does not mean that they do not want to know what is happening. They may be frightened and uncertain of many things.

Younger children may be very frightened about being separated from their parents. It is important to reassure them that this will not happen. Older children may be more frightened of pain. It can help to reassure them that effective pain control is almost always possible. Doctors and nurses will be happy to explain how this can be managed and can help you to reassure your child.

School

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

As your child's health improves and treatment allows, going back to school may be either a relief or a challenge. For many children, school is a refuge from the world of hospitals and procedures - a place for fun, friendship, 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 being away may have changed their relationships with their friends or affected their standing within their group.

If treatment has affected a 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 is 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 is happening. It can help to let the school know about

the plans for treatment, so that they can let the hospital education department know which work your child will be missing. This can then be covered in the hospital.

It also helps for the teachers at the hospital to let the school know if your child is emotionally or physically fragile. The teachers there can then take this into account. Your child should be involved in letting the teacher know which information they would like to be shared with their classmates.

A pack is available for teachers, to help them deal with issues when a child in their class has cancer – call 0808 808 00 00 for more information.

Risk of infection at school

Infectious illnesses such as chicken pox, measles, mumps, or flu can be dangerous to children who have a low immunity due to cancer treatment. If your child is attending school, it is important that the teachers are aware of this, and that they let you know immediately if any child in the school develops an infectious illness. If your child has been exposed to chicken pox, and has not had chicken pox before, they should have an injection of varicella zoster immune globulin (VZIG) within 72 hours. The school can develop a system to let the classmates' parents know that they should notify the teacher if their child develops an infectious illness.

Helpful tips

- You could ask the children's cancer nurse or social worker to talk to your child's class about what is happening to your child and how they will look and feel when they go back. This should include a question-and-answer session to clear up misunderstandings and reassure the children. Teenagers should be involved in deciding what information should be

given to their classmates.

- You could 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 notes, phoning, texting, emailing, sending class pictures or making a scrapbook.

Keeping up with schoolwork

Whenever your child is able, it is important for them to try and keep up with schoolwork. Learning can continue even outside school. It is important for you to speak regularly to the teacher, so that you know which subjects are being covered in school. Often, the teacher will send assignments and materials home with siblings, or arrangements can be made to collect them.

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. You can get information about the education of children with special needs from the government website at: www.hmso.gov.uk/acts/acts2001/10010-b.htm#2

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 that they have less chance for social growth and development but if they stay at nursery there is a risk of infection. There is no 'right' decision – it is a personal choice. The following questions may help you to decide:

- Is your child already settled in well at nursery or pre-school?
- Can their social needs be met by siblings and/or other children?
- Is your child well enough to attend nursery or pre-school?
- Has your child already had chicken pox?

Effects on parents

As a parent, the fact that your child has cancer is one of the worst situations to face. Everyone will be worried and under considerable stress. You will worry that your child will suffer and that your family life is going to be completely disrupted. At first, you may think that the diagnosis is a death sentence. When you are told the diagnosis, you may feel numb or as though you have been hit physically. You may feel confused, or unable to hear, remember or think clearly when you are given information about your child's diagnosis or treatment. The numbness may alternate with feeling overwhelmed by very painful and powerful emotions. These are very normal reactions.

Feelings and emotions

There is not enough space in this short booklet to discuss all the feelings and emotions that you may have, but some are described briefly below. The feelings are likely to change over time, and you may not feel all the emotions described here.

Fear and denial

You may feel very scared, anxious and panicky about what is going to happen and what the future holds. Parents often, understandably, want to deny that such a terrible thing as cancer

could happen to their child. Some people may feel tempted to take their child from one doctor to another. At times, you may feel that 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 is normal to feel sad or depressed at times when your child has cancer. Every parent wants their child's life to be healthy, happy, and carefree. Cancer and its treatment 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 cannot be avoided, and you are likely to have them at various periods during your child's illness. It is important to have support to help you through these times.

Guilt

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

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

Anger

It is also 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 with having to cope with uncertainty, and the unfamiliar world of hospitals, doctors and nurses. Some parents find that they are even angry with their child, as it is their illness which is causing so many problems for the family. This can be distressing but it is also very normal. Parents can feel angry at each other, especially if they have different ways of coping with the cancer. For example, if one parent wants to talk about it a lot and the other just wants to get on with normal life as much as possible.

You may also feel angry with family or friends who:

- make thoughtless remarks
- are too busy to give you support
- avoid you because they don't know what to say.

Information and support

There are many people who can help you deal with these difficult feelings and emotions. The staff at the hospital, including social workers, specialist nurses and doctors, can listen to and talk to you. You can also talk things through with Macmillan's cancer support specialists on 0808 808 00 00.

Some of the books listed on pages 74–75 give help and advice on coping with the feelings and emotions that you may have. There are also organisations that offer support to parents of a child with cancer (see the list of useful organisations on pages 66–77). 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. The Lennox Children's Cancer Fund and Leukaemia CARE both provide financial support and practical help (see page 69).

Looking after yourself

It is important to take care of your own needs. For example, eating and sleeping well, exercising if possible, dealing with any health problems and taking regular breaks will help you to 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 can bottle up their feelings, become tense and quarrel more than usual. If you can, try and talk to each other as openly as possible.

Socialising

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

Some people may not know what to say to you and 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.

Close family relatives 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 is happening and, if

possible, asked to give help and support. The CCLG can send you a booklet for grandparents of a child with cancer (see page 74).

Talking to others

One of the first 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, perhaps also giving some of the information in this booklet. If people close to you and your child know what is going on, it is easier for them to understand any changes in behaviour and to offer suitable help and support.

Effects on brothers and sisters

The brothers and sisters of a child with cancer may have all of the same feelings and emotions that parents experience.

The CCLG has booklets about siblings of children with cancer – see page 74. Macmillan can give you details of other information for and about siblings.

If you need to spend a lot of time in the hospital with your child who has cancer, your other children may be cared for by other 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 that the ill child gets. This can make them feel very left out and angry. It can help if you plan some time with your other children when they can be the centre of attention, perhaps by going out for a meal or to see a film. 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.

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 either in the hospital or at home. Many brothers and sisters keep their feelings bottled up inside, to avoid worrying 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 authority
- have arguments and fights with friends and other children in their class.

It will help to write to your children's head teachers, asking them to let your children's teachers 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 need to be aware of the stresses facing the family, and they will understand that feelings may be expressed by behaviour at school.

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 healthy children. Some hospitals have support groups for siblings.

After treatment

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

While it is 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 perfectly normal – all of a sudden you don't have the reassurance of seeing the doctors and other staff. Also once treatment ends you may be worried that symptoms will return. Remember the hospital staff are still there, and they will understand your concerns. It is important to contact them if you have any worries about your child's health.

The CCLG has two booklets about the end of treatment, one for parents and one for teenagers – see page 75.

If the cancer comes back

In spite of all the improvements in the treatment of cancer, sometimes treatment doesn't work. In this case another well-established treatment may be available. However, sometimes children still die from the disease. Occasionally this is the result of a severe infection caught during treatment, but usually it is because the disease comes back and no longer responds to treatment. There is usually some warning when this is happening so that careful plans can be made. There is a lot of support available for you in this situation.

You may be asked if you would like your child to be part of a trial trying out a new drug. This may or may not help your child, but could benefit future children. This is entirely your choice, and you may feel that the right decision for your child is to stop all treatment.

Often children and their families prefer it if they can spend their last days or weeks at home or in a hospice rather than in hospital. In this case, the child's doctor and the hospital staff will be in close communication. Any pain or other symptoms can usually be controlled by medicines so that death, when it does happen, is usually following a gentle lapse into a coma.

The death of a child is one of the most devastating experiences anyone ever has to face. Family doctors, community nurses and social workers will give advice and help with any arrangements that have to be made.

Macmillan or the CCLG can send you information about preparing for, and coping with, the death of a child, with details of all the support available.

Some medical terms explained

You may hear or read lots of medical words that you don't understand, or are unsure about. Some of the common ones are explained below. If you don't understand the words a doctor or nurse is using don't feel embarrassed to ask them to explain them.

Alopecia Hair loss

Anaesthetic Drugs to put a person to sleep (general anaesthetic) or to numb a part of the body (local anaesthetic)

Benign Not cancerous, although may be capable of causing problems

Biopsy A small sample of body tissue, taken to make a diagnosis

Blood count Blood test to check the number of cells of different types in the blood

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

Carcinogen A cancer causing agent

Cardio To do with the heart

Catheter A thin flexible tube used to pass fluid into the body or to drain fluid from the body (for example, urinary catheter, central venous catheter [long line])

Cerebrospinal fluid (CSF) The fluid produced within the brain which surrounds the brain and spinal cord

Chemotherapy Drug treatment to kill cancer cells

Chromosome Structure in the nucleus of the cell which contains the genes

Chronic Long-standing or long-lasting

Congenital Any condition existing at birth

Cyto To do with cells

Dysfunction Not working properly

Electrolytes The minerals and salts in the body, e.g. sodium, potassium, calcium

Endocrine To do with hormones

Excision Cutting out

Genetic Condition caused by abnormal genes (may be inherited)

Haematology The study of blood and blood diseases

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 system for fighting infection

Immunosuppressive Lowering the body's ability to fight infection

Intravenous (IV) Into a vein

Lymph Almost colourless liquid, part of the body's defence against infection, carried in a network of lymphatic vessels

Lymphocyte A white blood cell produced by a lymph gland, which fights infection

Malignant Cancerous. If a tumour is malignant it grows uncontrollably and can travel to other parts of the body

Metastases Tumours that have spread from a first (primary) tumour in another part of the body; also known as secondary tumours

Microbiology The study of germs

Morbidity The state of being diseased; ill effects

Nausea Feeling sick

Neuro To do with the nerves or nervous system

Neutropenic Low levels of neutrophils

Neutrophils White blood cells which 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 Blood cell which helps blood to clot

Prognosis The expected outcome of a disease and its treatment

Prosthesis An artificial replacement of, 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

Sarcoma A tumour of connective tissue, for example bone, muscle, fat, nerve sheath or blood vessels

Stage of a cancer The extent of a cancer (it's size and whether it has spread)

Stem cell Early (immature) blood cell

Subcutaneous Under the skin

Therapy Treatment

Thrombocytopenia A reduced number of platelets in the blood

Toxic Poisonous; causes unpleasant or dangerous effects, for example, cytotoxic drugs poison cells

Tumour An abnormal lump of tissue formed by a collection of cells. It may be benign or malignant

Further information

Information and support from Macmillan

Our cancer support specialists give information on all aspects of cancer and its treatment, and on the practical and emotional aspects of living with cancer. To contact them:

- Call our Freephone helpline: **0808 808 00 00**
Lines are open Monday–Friday, 9am–8pm.
A free interpreting service is available for people whose first language is not English. Calls to the helpline are confidential. Sometimes another member of our team may listen to a call for training purposes and to maintain quality.
- Write to: Macmillan Cancer Support, 89 Albert Embankment, London, SE1 7UQ

Scotland office, Suite 2, 3rd Floor, Cranston House, 104–114 Argyle Street, Glasgow, G2 8BH
Office tel: 0141 223 7676

Macmillan information online

www.macmillan.org.uk – our award-winning website includes the full text of all our publications, 1300+ Q&As, and a database of support groups and other services.

www.click4tic.org.uk – site for teenagers affected by cancer.

www.whatnow.org.uk – share your experiences of cancer and discuss the issues raised by our online family.

Children's Cancer and Leukaemia Group (CCLG)

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

Website: www.cclg.org.uk and www.childcancer.org.uk

The CCLG coordinates research and care for children with cancer and their families. There are 21 CCLG specialist centres for the treatment of childhood cancer covering all areas of the UK and Ireland. A map of the centres is on page 4 and on the CCLG website. The group's main activity is the organisation and running of national and international clinical trials and the registration of all childhood cancer cases in the UK (including leukaemia) seen by members of the group. The Group also produces an extensive range of booklets for affected families and a free magazine, *Contact*, for families of children and young people with cancer.

Other useful organisations

Many organisations provide information and support to children with cancer and their families. It is not possible to list them all here. For details of other organisations or local support groups, contact Macmillan on 0808 808 00 00. Some of the organisations listed below provide leaflets about their specific type of cancer and have websites with information.

Action for Sick Children

36 Jacksons Edge Road, Disley, Stockport, SK12 2JL

Freephone: 0800 0744519 (Head Office)

Tel: 0131 553 6553 (Scotland)

Tel: 01792 205227 (Wales)

Email: from website at www.actionforsickchildren.org/contact.html

Network of national groups. Provides advice and information for parents with children going to hospital, and counselling for parents. Has leaflets and videos for children going into hospital.

CLIC Sargent: caring for children with cancer

Griffin House, 161 Hammersmith Road, London W6 8SG

Tel: 020 8752 2800 (Main London office)

Child Cancer Helpline: 0800 197 0068 (Monday to Friday, 9am – 5pm)

Email: helpline@clicsargent.org.uk

Website: www.clicsargent.org.uk

Provides a range of support to children with cancer and to their families and carers – both during and after treatment, and in hospital and at home.

Childhood Eye Cancer Trust

The Royal London Hospital, Whitechapel Road, London, E11BB

Tel: 020 7377 5578

Email: info@chect.org.uk

Website: www.chect.org.uk

A UK wide charity for families and individuals affected by retinoblastoma (a tumour that grows in the light sensitive lining of the eye – retina). 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 24, North Leith Sands, Edinburgh, EH6 4ER

Tel: 0131 467 7420

Email: cclasp@hotmail.com

Website: www.cclasp.net

A children's charity run by parents whose children have been affected by various types of cancer. Provides information, a telephone helpline, transport to clinics, family holidays and fun events.

Christian Lewis Trust: Cancer Care for Children

62 Walter Road, Swansea, SA1 4PT

Tel: 01782 480500

Email: enquires@christianlewistrust.org

Website: www.christianlewistrust.org

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

Lennox Children's Cancer Fund

Lennox House, 57 Mawney Road, Romford, Essex, RM7 7HL

Tel: 01780 734366

Email: info@lennoxccf.org.uk

Website: www.lennoxccf.org.uk

A national charity that provides financial, practical and emotional support to children and their families affected by cancer. Has holiday homes for crisis breaks.

Leukaemia CARE

Tel: 01905 755977

CARE Line: 0800 169 6680

Email: enquiries@leukaemiacare.org.uk

Website: www.leukaemiacare.org.uk

Website: www.leukaemiacare.org.uk

Provides care and support to all whose lives are affected by leukaemia, lymphoma and the allied blood disorders. They have a 24 hour telephone helpline, holiday programmes and offer some financial assistance.

Leukaemia Research

Te 43 Great Ormond Street, London, WC1N 3JJ

Tel: 020 7105 0101

Email: info@lrf.org.uk

Website: www.lrf.org.uk

Supports research into the treatment of leukaemia and other related blood disorders in both children and adults. Produces patient information on cancers of the blood.

Lymphoma Association

PO Box 386, Aylesbury, Bucks, HP20 2GA

Tel: 01296 619400

Helpline: 0808 808 5555

Email: information@lymphoma.org.uk

Website: www.lymphoma.org.uk

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

MattDotCom

47 Bunkers Hill, Lincoln, Lincolnshire, N2 4QS

Tel: 01422 543 642

Email: support@mattdotcom.org.uk

Website: www.mattdotcom.org.uk

Provides the loan of a laptop, and peripheral equipment such as printers, to 12–19 year olds with a life-threatening illness to enable the continuation of school work within a 50-mile radius of Lincoln.

The National Alliance of Childhood Cancer Parent Organisations (NACCPO)

23 Meadowbank Walk, Stafford, ST16 1TA

Tel: 01785 603763

Email: ro@naccpo.org.uk

Website: www.naccpo.org.uk

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

React

St Luke's House, 270 Sandycombe Road, Kew, Surrey, TW9 3NP

Tel: 020 8940 2575

Email: react@reactcharity.org

Website: www.reactcharity.org

React helps children with life-limiting illness, to give comfort, dignity and where possible, greater independence. Gives speedy practical aid and financial help.

Samantha Dickson Brain Tumour Trust,

Saddlers House, 100 Reading Road, Yateley, Hampshire, GU46 7RX

Tel: 0845 130 9733

Email: enquiries@sdbtt.co.uk

Website: www.braintumourtrust.co.uk

Exists to find a cure for childhood and adult brain tumours through funding research and to offer support, hope and information to patients and their carers.

Siblinks

PO Box 2561, Coulsdon, CR5 2YA

Email: info@siblinks.org

Website: www.siblinks.org

Provides a network for 13–25 year olds who have, or have had, a family member affected by cancer. Provides activities to bring people together and give information. The website has a discussion forum.

Teenage Cancer Trust

3rd floor, 93 Warren Street, London, W1T 3EZ

Tel: 020 7612 0370

Email: tct@teenagecancertrust.org

Website: www.teenagecancertrust.org

Focuses on the particular needs of UK teenagers and young adults with leukaemia, Hodgkin's and cancer-related diseases. Funds and organises support and information services for patients, their families, schools and health professionals.

Brain Tumour UK

PO Box 27108, Edinburgh, EH10 7WS

Tel: 0845 4500 386

Email: enquiries@braintumouruk.org.uk

Website: www.braintumouruk.org.uk

Provides information, advice and support for anyone directly or indirectly affected by brain tumours.

'Special day' and holiday organisations

There are a number of organisations which arrange special days or holidays for children with cancer. These include:

Camp Quality UK
www.campqualityuk.org.uk

Dial a Dream
www.dial-a-dream.co.uk

Dream Flight
www.dreamflight.org

Dreams Come True
www.dctc.org.uk

Make a Wish
www.make-a-wish.org.uk

Starlight
www.starlight.org.uk

Rainbow Trust
www.rainbowtrust.org.uk

Over the Wall
www.otw.org.uk

Barretstown
www.barretstown.org

Donna's Dream House
www.donnasdreamhouse.org.uk

Helpful books and other resources

There are many books and leaflets about children's cancer and its treatment. If you would like information about helpful books, contact:

- Macmillan: 0808 808 00 00
- CCLG: 0116 249 4460

Booklets available from the CCLG:

- **Grandparents** – For grandparents of children and young people with cancer
- **How to Help Brothers and Sisters** – For anyone caring for siblings
- **My Brother has Cancer**– A short story about cancer for the under-9s
- **When your Brother or Sister gets Cancer** – Gives facts about cancer for 9–16 year olds brothers and sisters
- **Dexamethasone** – A guide for parents in managing the behaviour of children whilst taking Dexamethasone
- **Ben's Bone Marrow Transplant** – Aimed at young people preparing for a bone marrow transplant
- **Stem Cell Transplant** – For teenagers and young adults preparing for a stem cell transplant
- **Brain and Spinal Tumours** – A parent's guide to brain and spinal tumours in children and young people.
- **Children with Cancer and Pets** – Guidelines on reducing the risk of catching an infection from a pet.
- **After Cure** – For young people aged 16+ who have survived cancer

- **What's the point of coming to the clinic? A guide for young people who have had cancer** – Explains the importance of follow-up appointments and tests after cancer treatment.
- **End of Treatment What Happens Next?** – A guide for parents that aims to answer some of the questions that arise when a child finishes treatment
- **End of Treatment...what happens next?** – Aimed at 10–16 year olds, this helps to answer some of the questions that arise when young people finish their treatment

Macmillan publications

Macmillan has a wide range of booklets and factsheets about all types of cancer, cancer treatments and living with cancer. These include:

- **Peppermint ward** – Written for 6–9 year olds, the book aims to help children affected by cancer to understand and talk about what is happening to them
- **Relationships, Sex and Fertility for Young People affected by cancer**
- **Understanding Cancer Research Trials**
- **Understanding Chemotherapy**
- **Understanding Radiotherapy**
- **Cancer and Complementary Therapies**
- **Controlling the Symptoms of Cancer**
- **Coping with Fatigue**
- **Understanding High-dose Treatment with Stem Cell Support**
- **Understanding Allogeneic (donor) Stem Cell Transplants**

Helpful 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 below are considered by doctors to contain accurate information and are regularly updated.

www.macmillan.org.uk

- Contains over 4500 pages of accurate, up-to-date information on all aspects of cancer and a searchable database of other organisations.
- Allows you to send questions to our cancer support specialists by email and has a question-and-answer section.
- Contains all Macmillan's 100+ booklets and 270+ fact sheets included in full.
- Recommends further reading.
- Has a search engine for cancer research clinical trials available to cancer patients in the UK and Europe.
- Offers links to recommended cancer websites.

www.cclg.org.uk and www.childcancer.org.uk (Children's Cancer and Leukaemia Group)

Gives information about children's cancer, research into children's cancer and latest news. Has details of CCLG's range of booklets and leaflets and links to other helpful websites.

www.click4tic.org.uk (TIC – teen info on cancer)

Produced by Macmillan, this dynamic, interactive website gives information and support about cancer and its treatment. Designed and written specifically for teenagers with cancer, it also deals with issues such as education, emotions and sexuality. Teenagers

have been closely involved in developing the site. Users can set up their own web page within the 'share it' section, sharing their own stories and tips with others. Has links to other helpful websites.

www.cancerhelp.org.uk (Cancer Research UK)

Contains patient information on all types of cancer and has a cancer research clinical trials database.

www.lifesite.info

Section of the website of the Lymphoma Association aimed specifically at young people. Has information about lymphoma and all aspects of living with lymphoma.

www.royalmarsden.org/captchemo

The adventures of Captain Chemo. A website and computer game, aimed at cancer patients, relatives and friends. Explains cancer and its treatment.

www.macmillan.org.uk/whybother

An information website for children and young people.

www.cancer.gov/cancertopics/youngpeople

Comprehensive information for parents who have a child with cancer. Explains what to expect and the treatment and side effects. An American website from the National Cancer Institute.

www.cancer.gov/cancerinfo/when-someone-in-your-family (when someone in your family has cancer)

Information about the effects of cancer on family and relationships and how to cope.

www.rhabdomyosarcomabooklet.org.uk

A website for parents and families of children with rhabdomyosarcoma enabling them to access a booklet about this tumour type.

Cancerbackup editorial policy

Cancerbackup's policy is to provide up-to-date and accurate information about cancer and its treatments, in line with accepted national and international guidelines. Where no such guidelines exist, our information is based on scientific evidence such as data from published clinical trials, or combined analyses of trials. Where such evidence is not available, our information is based on a consensus view of experts. Each Cancerbackup publication is regularly reviewed and updated by cancer doctors, specialist nurses, other relevant health professionals and patients. The medical information is approved by a member of Cancerbackup's Clinical Advisory Board and the Medical Editor.

All Cancerbackup's booklets that describe treatments are produced to meet the criteria of the Discern Index, a nationally recognised measure of health information quality. Where trusts have used Cancerbackup's booklets in evidence to support their good practice, it has helped them to achieve compliance with the standards of the Clinical Negligence Scheme for Trusts. The content of Cancerbackup publications is independent of sponsorship.

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This booklet has been produced in accordance with the following sources and guidelines:

- *Improving outcomes with children and young people with cancer.* Cancer Service Guidance. National Institute for Health and Clinical Excellence. Aug 2005.

You can access up-to-date guidelines in the health professional section of Macmillan's website: www.macmillan.org.uk

Notes

Questions you might like to ask your doctor or nurse

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

1.

Answer.....

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2.

Answer.....

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3.

Answer.....

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4.

Answer.....

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5.

Answer.....

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6.

Answer.....

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Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care.

One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

**General enquiries 020 7840 7840
Questions about living with cancer?
Call free on 0808 808 00 00
(Mon–Fri, 9am–8pm)**

**Alternatively, visit macmillan.org.uk
Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.**

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Next planned review in 2011

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