

# Acknowledgements

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Keeping  
more than  
**hope** alive

## Foreword

This booklet was written by parents of the CHOC Childhood Cancer Foundation of South Africa (CHOC) - an association of parents whose children have been diagnosed with cancer or a life-threatening blood disorder. CHOC aims to ensure that the treatment for children with cancer is as good as it can be and that there is support for the whole family through what is a very traumatic experience for any family.

Cancer in children is a treatable disease and up to 70% of children with cancer can be cured. However, cancer remains a complex disease and treating it is therefore an extremely difficult and grueling process, both for the patient and the parents.

As parents who have been down this road before, we understand the fear, frustration and panic felt by those who have been told that their child has cancer. We know that there will be many questions that you want to ask.

This booklet aims to give you, as parents, some of the answers and general information you seek. In addition, you will need to talk at length with the doctors and other members of the hospital team involved in caring for your child. We believe that knowledge is the key. By learning all you can about your child's disease and its treatment, fear is quelled, hope is heightened and you can play an active role in your child's treatment.

We understand that your greatest fears are that your child might die and that you may not be able to cope. We hope this booklet will help you to cope and that it will reassure you by showing you how much help is available. We here at CHOC want to help you and your whole family with **“Keeping more than hope alive”**.



# Contents

## **Open letter to a parent**

<b>Chapter 1</b>	What is cancer?	1
<b>Chapter 2</b>	Incidence of childhood cancer	3
<b>Chapter 3</b>	The team caring for your child	5
<b>Chapter 4</b>	Common childhood cancers	10
<b>Chapter 5</b>	Treatment of childhood cancers	22
<b>Chapter 6</b>	Stem cell and stem cell treatment	26
<b>Chapter 7</b>	The side effects of treatment and how to deal with them	28
<b>Chapter 8</b>	Non-malignant haematological conditions of childhood	36
<b>Chapter 9</b>	Diet and nutrition	39
<b>Chapter 10</b>	Hospital and ward life	44
<b>Chapter 11</b>	How to cope with your child's cancer	47
<b>Chapter 12</b>	How will your child cope?	53
<b>Chapter 13</b>	Going home	57
<b>Chapter 14</b>	School: infectious diseases, vaccinations and inoculations	59
<b>Chapter 15</b>	After-cancer therapy	61
<b>Chapter 16</b>	Financial matters	63
<b>Chapter 17</b>	CHOC and other sources of support	65
<b>Chapter 18</b>	Should/if cancer comes back – relapse	68
<b>Chapter 19</b>	Palliative and end-of-life care	73
	<b>Commonly used Chemotherapy drugs and other supportive drugs</b>	78
	<b>Side effects of Chemotherapy drugs</b>	79
	<b>Glossary of medical terms</b>	83

# Open letter to a parent

You have just started one of the periods in your life that you will always remember. You probably never thought that something like this could happen to your child. Perhaps you believed it was your right that your child would grow to adulthood with only the occasional illness or broken limb. You probably never anticipated an illness that could take your child's life. Now you know differently. If you are like most of us who have been down this path then your outlook on life will probably be changed forever from this week onwards.

## Common reactions

During the next few weeks you will go through many emotions:

- anger at the unfairness of it;
- grief that all of the dreams you had for your child could come to nothing;
- bargaining with God to cure your child;
- blaming yourself for causing the illness;
- regret at not doing the things with your child that you intended to;
- feeling lost and confused by lots of medical jargon and new words;
- agonising over what you should tell your children, your parents, your friends;
- wondering how you will cope with it all.

In other words, you will react just like the many other parents who have been in your situation.

## Learning to cope

You will need to develop your own methods for coping, depending on your own personal situation. However, you may find the following guidelines a useful starting point.

Be honest and open about the illness to your relations and friends, to your child's school, to your employers, but most of all to yourselves and your children. Your children will know that they are ill; don't make them hide their feelings to try to protect you.

Your family and friends will not at first know what to say to you and they may be very uncomfortable with you. The more openly you talk about things, the easier it will be for others to respond to you and give you the help that you will need so much in the coming months.

Get used to saying the name of the illness out loud. Words like 'cancer' and 'leukemia' are normally only spoken in hushed voices and never in the presence of someone who has them. The disease will be with you for a long time, so get used to saying its name and even to talk about death. It will be much easier for your family and friends to talk openly if you do.

Don't be ashamed to feel or show emotion; it just shows that you are human. It would be very unusual if you didn't feel angry, sad, confused and many other emotions when you learned of the diagnosis.

Don't forget that both your sick child and your other children will have to cope with many new experiences and emotions. Let them see that it's all right to feel afraid, to be unsure and to cry at times.

Remember that you are in this situation as a family. Many couples who have a good marriage to start with find that they are strengthened by the experience. However, it is not unusual for a marriage to become very stressed by the extra demands that an illness like cancer brings.

Call on all the resources that you have. Use your family and friends – if they are true friends they will be only too glad to help you now that you really need them. Use your church; ask people to pray for you and your child. You will be surprised by how much and how readily people will open up and help you if only they know how. You need to make your needs known.

There are no guarantees. The medical staff will do their best and there may be a very good prognosis for your child, but the illness is still life threatening and you will live with this threat for a long time.

Don't be afraid to ask the medical staff. You will probably not take in half of what is said in the early discussions and there is a whole new vocabulary to learn. Keep note of the questions you want to ask. There is a lot of literature and you may want to gain as much knowledge as possible, so ask the staff what they recommend.

There will be times when everything seems very dark and some times are very happy. The best way to get through the coming weeks and months is to take one day at a time.

We sincerely hope that you find strength in yourself, your family and your friends to grow through this difficult time.

From parents who have been there before you.

**Julian Cutland**

**(National Chairman, CHOC Childhood Cancer Foundation of South Africa)**

**2000-2004 and 2007-8**

# What is cancer?

Cancer begins when a particular cell or group of cells in the body begin to multiply and grow without control. Oncology is the study of these cells.

The cancerous cells stop working properly and as their numbers increase they form a lump or tumour. Eventually, the normal cells will be crowded out and the cancerous cells, if not treated, will take over. When cancer cells break away and spread to other parts of the body they may produce secondary tumours known as metastases.

Sometimes the cancer will affect the blood, causing leukaemia; other cancerous cells form tumours. When these tumours form in bone or muscles they are known as sarcomas. Cancers which affect the lymphoid organs such as the lymph nodes, spleen and thymus are known as lymphomas.

Childhood cancers are quite different from cancers affecting adults. They tend to occur in different parts of the body, look different under the microscope and respond differently to treatment. Cure rates for most childhood cancers are much higher than those for most adult cancers. Today, the majority of childhood cancers can be treated very effectively, and 65-70% can now be completely cured.

### Treating childhood cancer

A Paediatric Oncologist specialises in the diagnosis and treatment of childhood cancers, which is a highly specialised service. Your child should be looked after by a multidisciplinary team headed by a Paediatric Oncologist.



**Children's cancer should only be treated by a Paediatric Oncologist at a specialised unit, attached to or affiliated with an Academic Hospital.**

No one knows what causes childhood cancer, although there are many different theories. A huge amount of research is being carried out worldwide, with studies into a number of possible causes. Cancer is not contagious, nor, for most cancers, is there any evidence that they are inherited. It is exceptionally rare for a second child in a family to develop cancer.

It is reassuring to know that nothing you did or did not do as parents caused your child's cancer.



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## What to watch out for

This list has been compiled by the South African Children's Cancer Study Group and is now used throughout the world.

# S I L U A N

- **Seek:**  
Medical help early for persistent symptoms.
- **Eye:**  
White spot in the eye, new squint, blindness, bulging eyeball.
- **Lump:**  
Abdomen and pelvis, head and neck, limbs, testes, glands.
- **Unexplained:**  
Fever for over 2 weeks, loss of weight and appetite, pallor, fatigue, easy bruising or bleeding.
- **Aching:**  
Bones, joints, back, and easy fractures.
- **Neurological Signs:**  
Change or deterioration in walking, balance, speech or behaviour, regression of milestones, early morning vomiting and/or headache for more than a week, enlarging head.

## Saint Siluan\* Warning Signs

Many children in our country are never diagnosed because their symptoms are not recognised, or they are diagnosed too late for effective treatment.

To help solve this problem, the South African Children's Cancer Study Group has prepared this list of Warning Signs, for distribution to primary health care centres.

CHOC has supported the printing and distribution of posters. They have been adopted by the International Society of Paediatric Oncology (SIOP), for distribution throughout developing countries.

\*Saint Siluan was a Russian monk who died on Mount Athos in 1938. He prayed ceaselessly for all humanity.

This list has been compiled by the South African Children's Cancer Study Group and is now used throughout the world.

*A poster funded by CHOC describing the early warning signs of cancer.*

# Incidence of childhood cancer

Cancer in children is rare. Worldwide, 150 children per million are diagnosed with cancer each year.

In South Africa, accurate figures have not yet been published, but some data suggests that only 70-80 children per million are diagnosed with cancer each year – a total of between 500 and 600 children each year. This is approximately half the worldwide figure.

It is therefore estimated that a further 500 children die of childhood cancer in South Africa each year before it is diagnosed or treated. Why is this?

Childhood cancer sometimes goes undiagnosed and untreated because people don't have access to the specialised medical services they need. This is especially true in rural areas or in very poor communities, where people do not have the means (finances or transport, etc.) to seek medical help.

Lack of awareness of childhood cancer is another reason. Many parents don't recognise the early warning signs and symptoms. Doctors sometimes lack knowledge because childhood cancer is a rare disease and few family physicians (GPs) see any cases in their practice. Making the public, doctors and medical personnel more aware of childhood cancer and its early warning signs and symptoms is one of the aims of *CHOC*.

### **Raising awareness**

Every year in February, International Childhood Cancer Day is held worldwide to create awareness. To support this, *CHOC* has funded the printing of posters describing the early warning signs (see page 2) and pays for a toll-free helpline for queries about childhood cancer.

*CHOC* is also helping to raise the funds needed to support the Childhood Cancer Registry, which is operated by the SA Children's Cancer Study Group. This will enable them to keep accurate records and make this registry a very effective and reliable source of information about childhood cancer in South Africa.



*My doctor, by Thabang Baloyi, 12 years old.*

## Chapter 3

# The team caring for your child

The members of the multidisciplinary team caring for your child may vary from one unit to another, but the head of this team will always be a Paediatric Oncologist. Other members are the nursing staff on the ward, surgeons, haematologist, pathologist, radiologist, radiotherapist, occupational therapist, physiotherapist, social worker, psychologist, dietician, pastoral care team, volunteers from CHOC, your GP or paediatrician as well as yourself (the child's parents), your family and friends.

### **Paediatric Oncologist**

The head of the medical team caring for your child. Oncology (the study of tumours) is a specialist field in medicine and a Paediatric Oncologist is a doctor who specialises in treating childhood cancer. The Paediatric Oncologist will have the knowledge to diagnose your child's cancer and decide on the best treatment.

Paediatric Oncologists from around the world meet on a regular basis to discuss new developments in the treatment of childhood cancers. Often, they belong to a medical faculty at a University, since most of the childhood oncology units in South Africa are attached to or affiliated with an Academic Hospital. You can therefore be assured that the doctor is not working in isolation and that your child is getting the most up-to-date treatment available.

### **The Ward Sister** (Professional Nurse)

The head of the nursing staff on the ward who co-ordinates the day-to-day care of your child. Ward Sisters are primarily responsible for ensuring that your child receives the highest quality of nursing care while hospitalised. It is also their task to give drugs and ensure that doctor's orders are carried out.

### **Staff nurses and student nurses**

They provide basic nursing care to meet both your child's and your own needs while in hospital. They are not allowed to start intravenous lines, draw blood or give drugs, especially intravenously, because they are not trained to do so.

### **Surgeons**

Specialised doctors who do operations, biopsies and put in central lines (e.g. Hickman lines or portacath).

### **Haematologist**

A doctor with specialised knowledge of the blood. Usually haematologists work in the laboratory where they examine blood samples, but they sometimes also look after patients on the ward.

## **Cytologist**

Cytologists look at cells, often obtained by a fine needle aspiration (FNA), under a microscope.

## **Pathologists**

These doctors mostly work in the laboratory examining samples taken from patients.

- Microbiologists are involved in isolating germs; for example, when your child has a high temperature and the doctor suspects an infection.
- Chemical pathologists look at chemicals; for example, when blood tests are done to assess your child's liver or kidney functions.
- Histopathologists look at surgical specimens; for example, when a biopsy has been taken from a tumour or a whole tumour has been removed.

## **Radiologist**

A doctor who has expert knowledge to take x-rays and other scans of the body and then read (interpret) these images. X-rays are taken by radiographers.

## **Radiotherapist**

If your child's treatment plan includes radiation treatment (radiotherapy), this will be planned by a radiotherapist. This is a doctor with specialised knowledge of radiotherapy. The treatment will be given by specially trained radiographers.

## **Occupational therapist**

An occupational therapist can be heaven-sent for a parent while your child is hospitalised. This person will assist your child in play and recreation, introducing fun activities to fill some of the long hours in hospital. The occupational therapist may also offer therapeutic play sessions to help your child cope with the hospital experience.

Sometimes children may experience developmental problems (physically, mentally or intellectually) because of their illness and/or long periods spent in hospital. If your child has any such problems, especially younger children, the occupational therapist will develop a treatment program for these problems. If necessary, you will also be given a program to follow with your child at home.

## **Physiotherapist**

A physiotherapist uses special exercises and other treatments to help patients recover after operations or injuries. For example, if your child develops a lung infection and has a lot of phlegm in the lungs, the physiotherapist will do chest percussion. This helps loosen the phlegm so that your child can cough it out more easily.

## **Social worker**

The input of the social worker at the hospital or unit where your child is treated can be of great help. A social worker is a professional counsellor, trained to deal with the impact of illness and hospitalisation on families. You can discuss with this person the many questions you have, any difficulties you experience in coping with your child's illness and how it affects the rest of your family. You can draw on the social worker's advice on how to talk about your child's illness to your child, your other children, relatives, friends and the school. Where necessary the social worker can provide direct intervention, play therapy or other therapeutic services. Apart from counselling, the social worker may also be of assistance with practical problems and can give advice on services you could approach for help.

# The team caring for your child

## **Psychologist (and/or Child Psychologist)**

A psychologist is a professional who will listen without judging, and has the knowledge to help you find ways to cope with the stresses of your experience. This person can be a great source of support in helping you and your child cope throughout the treatment and recovery process. A psychologist can provide valuable information which can be helpful in recognising and meeting the emotional and developmental needs of your sick child, as well as your other children at home.

Sometimes parents find it difficult to speak openly and frankly about their feelings, both to each other and to family members, perhaps because they do not want to cause the other person more pain or stress. You might find talking about your feelings and fears to a 'stranger' easier, because you can say exactly what you feel without holding back.

Cancer is a very traumatic experience for you, your sick child and your whole family. The overall aim of working with a psychologist is to enable the children and you to feel supported, to minimise stress and to help all of you emerge with positive, well-integrated personalities.

## **Dietician**

A healthy, well-balanced diet is very important to any growing child and it is even more crucial when your child is sick and undergoing treatment. Your child's diet should be adequate to help prevent and fight infections and to promote normal growth and development. A dietician can give you advice on how to best meet your child's dietary needs. They will help you to decide which nutritional supplements are appropriate for your child and to deal with common dietary problems caused by treatments, such as loss of appetite, nausea and the refusal to eat or drink certain foods.

## **Pastoral care team**

Every hospital usually has a chaplain or other religious representative who is available to take care of the spiritual needs of the child and their family. Such people are available 24 hours a day to talk, listen, pray, share burdens and help you discover the healing and strength there is in the presence of God during times of illness and grief. Your own spiritual leader is also welcome to visit you in hospital at all times. Additionally, you may find tremendous comfort and strength in asking members of your spiritual community to pray for you and your child.

## **Volunteers**

Volunteers are trained to help in the Paediatric Oncology Unit. They offer support to parents, both emotional and practical. They are available to listen, to talk, to give practical help such as babysitting, or to give you a much needed break. Please feel free to share your feelings, fears and needs with them.

## **Your GP or Paediatrician**

Your own Family Physician (GP) must be fully aware of the details of your child's condition and treatment at all times. Your GP will be there to help and support you when your child leaves the hospital and returns home.

## **Your family and friends**

Your child's brothers, sisters, grandparents and other relatives, as well as your family friends, may all play a vital role in supporting and caring for your child. They will need to be informed about your child's illness and needs. The more they know and understand your child's illness, the better they will be able to help both you and your child. Talking to the doctors or nursing staff might help.



## You, the child's parents



### **You are your child's greatest source of strength.**

The most important members of the team caring for your child are you, the child's parents. Even though you may not have any medical training or knowledge, don't let that worry you. Your child has always looked to you for comfort and support and needs you now more than ever. Just love and be there for your child, like you always have.

Learn as much as you can about your child's illness and treatment. By learning all you can about the disease and its treatment, fear is eased, hope is heightened and you can play an active role in your child's treatment.

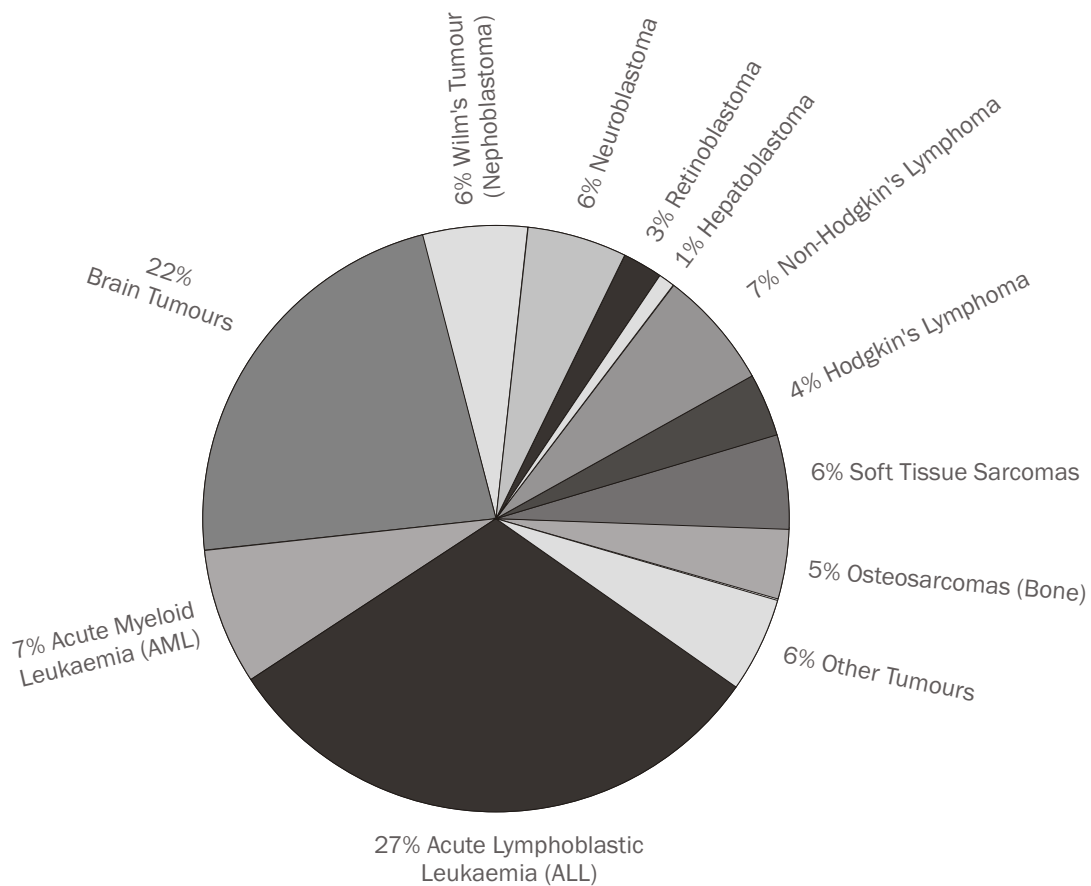
We understand that you may feel completely overwhelmed at times by the situation, but remember that you are not alone. There is a whole team of people to help care for your child.



# Common childhood cancers

The most common childhood cancer both worldwide and in South Africa is leukaemia, which accounts for about one third of all cases of childhood cancer. The next most common childhood cancers are brain tumours and lymphomas, followed by embryonal tumours and sarcomas.

The chart below gives an indication of the frequency of the most common childhood cancers in Western countries. Primary health care workers sometimes don't know much about childhood cancer because it is a rare disease and most primary health care workers don't see many (if any) cases in his or her practice.

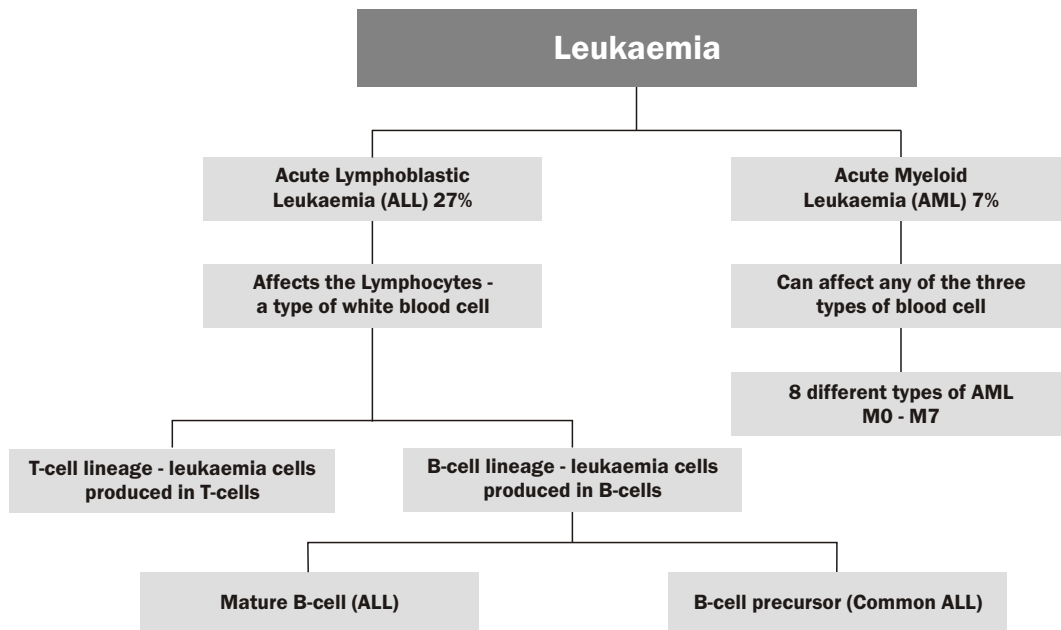


The common symptoms, methods of diagnosis and treatments for each type of cancer are described on pages 11-21.

# Common childhood cancers

## Leukaemia

When cancer affects the blood it is called leukaemia. It is the most common cancer in children and accounts for 34% of all cancers.



*The different types of leukaemia in children*

Blood is mainly formed (made) in the bone marrow, a spongy material inside the long bones of the body, but the lymph glands, spleen and thymus gland (behind the breast bone) also play a role. There are three different types of blood cells:

- white blood cells (T-cells and B-cells) and neutrophils, which are important in fighting infections;
- red blood cells, which carry oxygen around the body;
- platelets, which help blood to clot and control bleeding.

In leukaemia, one of the types of blood cells is changed into a cancerous cell that is no longer under the body's control. These abnormal cells divide and multiply in number, taking over the bone marrow and spreading out into the blood, lymph glands and rest of the body.

### Most common symptoms

- The child may develop infections because the production of normal white blood cells decrease and thus the body's immune system cannot function properly.
- Bruising and even bleeding (especially nose and gums) as the platelet count falls.
- The child develops anaemia as the red blood cell count decreases.
- The child may feel generally unwell and weak.
- The child complains of aches and pains in the limbs (the marrow space is stretched) and abdomen (liver, spleen and nodes become full of cells).
- Usually symptoms are only noticed after 12 weeks; by then the child may be quite anaemic and pale.

## Diagnosis and tests

A blood test will reveal low numbers of normal cells and some abnormal cells, but a bone marrow examination is always required to confirm the diagnosis. Special staining and further examination of the marrow cells is required to identify the type of leukaemia involved. A lumbar puncture, to determine whether the spinal fluid contains leukaemia cells, is also necessary. Before treatment can begin, chest x-ray and blood tests will be carried out, to check how well the liver and kidneys are working. Other tests may be required depending on the child's symptoms.

## Treatment

Treatment consists of an intensive phase of chemotherapy lasting six or seven months followed by less intensive therapy, which lasts a further one and a half to two and a half years. Cure rates depend on the particular type of leukaemia and range from 40–90%.

## Commonly used chemotherapy drugs

Each type of leukaemia is treated with a different combination of chemotherapy drugs. The drugs most commonly used are: Cyclophosphamide, Methotrexate, Cytarabine, Steroids (Prednisone, Prednisolone or Dexamethasone), Vincristine, L-asparaginase, Anthracycline (Daunorubicin, Idarubicin or Epirubicin), 6-Mercaptopurine and Etoposide.

## Brain tumours

There are many different forms of brain tumour, some benign (non-cancerous) and others malignant (cancerous). They account for 22% of all childhood cancers. Brain tumours do not usually spread throughout the body.

## Most common symptoms

The different forms of brain tumour do not behave in the same way, so your child will not necessarily have all of the symptoms described below.

The skull is like a closed box. Any tumour growing inside will increase the pressure on the brain. As a result of this increased pressure, your child may have the following symptoms:

- headache;
- vomiting (may only be once or twice a day);
- drowsiness;
- hydrocephalus, which is the result of spinal fluid damming up inside the brain (normally the spinal fluid escapes through very narrow channels at the base of the brain) because a tumour blocks the flow of spinal fluid;
- irritability;
- loss of appetite;
- loss of interest in school and other activities;
- some brain tumours disturb hormone production in the body, which can slow down growth in the child, delay the onset of puberty and produce large quantities of urine.

# Common childhood cancers

If the tumour presses on certain brain cells or nerves your child may have some or all of the following symptoms:

- muscle weakness, unsteadiness when walking or running, clumsiness and/or shaking in the use of one arm or leg;
- double vision or squint;
- difficulty swallowing;
- slurred speech;
- convulsions.

If a young baby has a brain tumour the soft spot on the top of the head may bulge and the whole head may increase in size.

## Diagnosis and tests

To diagnose a brain tumour a CAT or MRI scan of the brain is almost always done. A lumbar puncture may be necessary to look for tumour cells in the spinal fluid.

An ophthalmologist (eye specialist) will examine your child if vision is disturbed. Blood and urine tests will be done if the tumour is affecting the hormones.

## Treatment

Treatment consists of surgery often followed by radiotherapy and/or chemotherapy. Cure rates vary depending on the type of tumour.

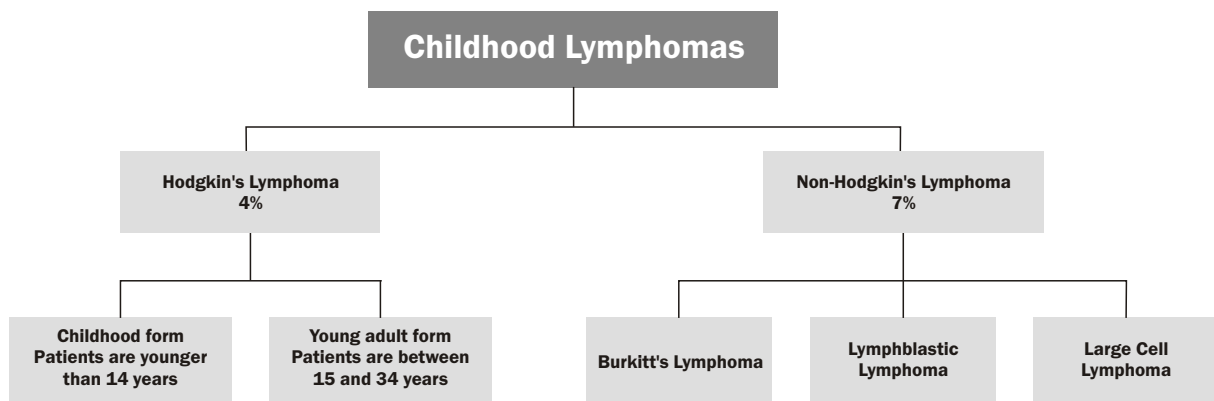
## Commonly used chemotherapy drugs

New chemotherapy drugs to treat brain tumours are constantly being evaluated. These new drugs may replace current drugs or be used in combination with drugs such as Cyclophosphamide, Vincristine, Cisplatin, Carboplatin, Etoposide and CCNU.

## Lymphomas

Tumours that start in the lymph glands are called lymphomas and these account for 11% of all childhood cancers.

The body's lymphatic system is made up of a collection of lymph nodes, each the size of a pea. These nodes are connected by lymphatic vessels (similar to veins) which circulate fluid and cells. The main function of the lymphatic system is to control infection and provide a collecting and transporting system for white blood cells and help fight infections in the body. There are two main types of lymphomas in children, as shown below.



*The different types of childhood lymphomas*

## Most common symptoms

Both types of lymphoma present in the same way: the enlargement of a group of glands somewhere in the body, perhaps in the neck, chest or abdomen. Other symptoms include:

- fever;
- tiredness;
- anaemia;
- loss of appetite and weight loss.

## Diagnosis and tests

The diagnosis is usually established as a result of a biopsy carried out on one of the affected glands. A bone marrow examination and a lumbar puncture is also required to establish the stage of the disease. X-rays, CAT and nuclear scans may also be necessary.

## Treatment

- *Non-Hodgkin's Lymphoma*: treatment usually consists of chemotherapy lasting between six months and two years. It may also include surgery and radiotherapy. Cure rates depend on the extent and type of lymphoma and range between 50-100%.
- *Hodgkin's Lymphoma*: all children with Hodgkin's Lymphoma are treated with chemotherapy. Radiotherapy may be added to treatment depending on the disease's stage and the protocol used.

## Commonly used chemotherapy drug

Various combinations of the following drugs are used; Nitrogen Mustard, Vincristine, Procarbazine, Prednisone, Adriamycin, Bleomycin, Vinblastine and Dacarbazine for Hodgkin's Lymphoma. For Non-Hodgkin's Lymphoma the same drugs are administered as those for leukaemia.

## Wilm's tumour (Nephroblastoma)

Wilm's tumour is one of the types of embryonal tumours which account for 14% (in South Africa) of all childhood cancers. Wilm's tumour affects the kidney and accounts for 6% of all embryonal tumours. It is quite different from the cancers that affect the kidneys of adults. Most patients are under 5 years old and usually only one kidney is affected; it is very rare that both kidneys are affected.

## Most common symptoms

Symptoms are usually non-specific and parents usually only become suspicious when they notice the child's tummy becoming swollen or feeling particularly firm or hard. Sometimes the child may have pain in the abdomen, fever or blood in the urine.

## Diagnosis and tests

An ultrasound and/or CAT scan of the abdomen will determine the exact location of the tumour and evaluate the opposite kidney. Blood tests and chest x-rays will determine if the cancer has spread to the lungs. This type of tumour is diagnosed through a biopsy of the tumour and then looking at the cells under a microscope.

## Treatment

Treatment always involves surgery to remove the tumour. It is usually necessary to remove the whole kidney, and it is perfectly possible to live a normal life with only one kidney. The surgeon will also examine the whole abdomen and take specimens of any lymph glands that might have been affected. In cases where the tumour is

# Common childhood cancers

difficult to remove or if both kidneys are affected, chemotherapy is given immediately to shrink the tumour, making it easier to be removed by surgery later.

After surgery, chemotherapy is given for 3-12 months. Radiotherapy is used if the disease is in a more advanced stage. Rates of cure are extremely high at around 85%. Sometimes if the tumour is very large, chemotherapy is given before surgery to shrink the tumour.

## Commonly used chemotherapy drugs

Depending on the extent of the disease and what the tumour looks like under the microscope, a combination of the following drugs are used: Vincristine, Actinomycin D (Dactinomycin), Doxorubicin (Adriamycin), Cyclophosphamide (Cytoxan), Etoposide (VP-16), Ifosfamide, and Carboplatin.

## Neuroblastoma

This tumour grows from nerve cells which run in a chain down the back of the child's neck, chest and abdomen. The most common site for this tumour is the abdomen. The second most common site is the chest (about 30%). In about 25% of patients the tumour starts in the adrenal gland, which sits on top of the kidney and in about 10% of patients the tumour starts in the neck. Most patients are younger than 5 years and it is very rare in children older than 10 years.

## Most common symptoms

- Initially the symptoms are rather vague and can easily be mistaken for a viral infection. Long before neuroblastoma is diagnosed the child may fail to gain weight, have recurrent and unexplained fever and complain of intermittent abdominal pain and fatigue.
- Sometimes the tumour is discovered by accident when a chest x-ray is taken to rule out pneumonia due to infection of the upper respiratory tract.
- A hard, painless lump may be felt in the abdomen or neck. The glands in the neck and groin may be enlarged.
- Children may appear to be chronically ill, irritable and in pain.
- Occasionally, an abnormally fast heartbeat, high blood pressure, sweating and fever can occur.
- If the abdomen is swollen the child may complain of a vague abdominal pain, fatigue, flu-like symptoms and loss of appetite.
- Pain in the limb or back and refusal to walk and limping, may be present if the tumour has spread to the bone or bone marrow.
- Leg weakness may occur if the tumour has spread into the spinal canal and is pressing on the spinal cord.
- A tumour in the chest or neck might press on a nerve causing a drooping eyelid, a dilated pupil and an inability to sweat on one side of the face (Horner's syndrome).
- In some cases the tumour produces a hormone that causes chronic and watery diarrhoea.

## Diagnosis and tests

To determine the exact site and size of the tumour a CAT scan, MRI scan and MIBG scan will be done. MIBG is a substance that is taken up by neuroblastoma cells and is therefore a helpful test to see if the disease has spread. It is injected and a special body camera is used to look for uptake organs.

To look for tumour spread, several other tests will be needed. These could include a bone marrow aspiration and biopsy, a biopsy of nearby lymph nodes and, if the tumour is in the abdomen, a biopsy of the liver may be necessary.

## Treatment

Treatment is based on the age of the child, the site and size of the tumour and whether it has spread. If the tumour is localised, surgery to remove the tumour may be all that is needed.

If the tumour has spread, chemotherapy will be given to shrink the tumour and then, after a few months, surgery is done. In some cases, radiotherapy is also used since neuroblastoma is generally a radiosensitive tumour.

## Commonly used chemotherapy drugs

Cyclophosphamide, Ifosfamide, Cisplatin, Carboplatin, Doxorubicin, Etoposide.

## Retinoblastoma

The light sensitive lining of the eye is known as the retina. A malignant tumour of the retina is called Retinoblastoma.

In about two-thirds of cases, only one eye (unilateral disease) is affected. Sometimes a tumour develops in the other eye some months after the first diagnosis. This is most common in children less than one year old and is not usually hereditary.

One-third of children develop tumours in both eyes (bilateral disease) but they usually have a genetic or hereditary form of retinoblastoma, which tends to develop during the first year of life.

## Most common symptoms

- “White reflex” or cat’s eyes, where the yellowish-white tumour can actually be seen through the pupil. Often this can be seen in photographs taken even before there is a diagnosis.
- Inward or outward turning of the eye.
- A squint and or visual impairment.
- Abnormal appearance of the eye.
- Change in eye colour.
- Unequal pupils.
- If the tumour has spread there can be swellings in the scalp and enlargement of lymph nodes in the neck or in front of the ears.

## Diagnosis and tests

Various tests are carried out to determine the exact site and size of the tumour. These include:

- An examination under general anaesthesia by an ophthalmologist.
- Scans such as ultrasound, MRI, CAT or bone scan.
- Tests of the spinal fluid and bone marrow are also important, to look for metastasis (secondary tumours).

## Treatment

- The type of treatment depends on the number, site and size of the tumours.
- Cryotherapy (a freezing treatment) and photocoagulation (laser-light treatment) can be used to treat small primary tumours or new tumours appearing after radiation therapy.
- Sometimes, if the tumour is too large, other treatments are not working or vision in the eye has been lost, it is usually necessary to remove the eye surgically (enucleation). An artificial eye will be fitted 4-6 weeks after the operation.

# Common childhood cancers

- Radiotherapy may be needed for larger or multiple tumours and for tumours at the back of the eye or near the optic nerve.
- Brachytherapy is the use of implanted radioactive 'seeds' to deliver localised radiation to the eye and is used for small or solitary tumours. This type of radiation can prevent exposure of the eye socket to radiation. The cure rate for patients with localised tumours is as high as 90%.

In most cases, Retinoblastoma responds well to chemotherapy.

## Commonly used chemotherapy drugs

Carboplatin, Etoposide, Vincristine, Doxorubicin, Cyclophosphamide.

## Rhabdomyosarcoma

Rhabdomyosarcoma is the most common of a group of tumours known as 'Soft Tissue Sarcomas'. There are several slightly different types of these tumours, which grow in muscles or sinews, or in the fibrous tissues around the muscles. They are most common in children between birth and five years of age, but it can occur at any age.

### Most common symptoms

Symptoms vary according to the primary site of the tumour. The first sign is usually a swelling, but the child will be well at the time of diagnosis unless the tumour has spread to distant sites in the body.

- If the tumour is in the eye socket, the most common sign is protrusion of the eye.
- Tumours in the sinus cause a blocked nose and bloody nasal discharge.
- Tumours that affect the nerves in the face and head cause paralysis of the facial muscles or abnormal movements of the eyes or eyelids. Other symptoms can include headache, vomiting and high blood pressure.
- Tumours in the bladder and prostate cause blood in the urine or difficulty in passing urine. Other symptoms include a mass in the pelvis or constipation.
- Girls who have a tumour of the cervix or vagina will have extrusion of tissue from within the vagina or a bloody or mucinous discharge.
- Boys with a tumour in the testicle will have enlarged lymph nodes or a lump in the scrotum.
- If the tumour is in a limb (arm or leg) the child will have pain at the site and an obvious lump. The lymph nodes under the arm or in the groin may be swollen.
- A tumour in the chest usually only causes symptoms when the tumour has grown large enough to cause compression on the airway or other structures, which may cause coughing, chest pain and rapid breathing.

### Diagnosis and tests

A combination of CAT, MRI or ultrasound scans are carried out to determine the site and size of the tumour. A CAT scan of the chest, bone scan and bone marrow examination will determine if the tumour has spread to other sites. Various blood tests and analysis of the urine will also be done and a biopsy of the tumour taken.

### Treatment

Usually it is not possible to remove the tumour at first, so it is shrunk with chemotherapy. This is followed by surgery and/or radiotherapy. Treatment lasts between one to two years.

If the tumour has spread to other parts of the body (metastasis) at the time of diagnosis, treatment starts with a combination of chemotherapy drugs given at high doses.

If these control the tumour, further high-dose chemotherapy is given. A bone marrow transplant may be necessary in some cases.

Cure rates vary depending on the type of tumour and the site and degree to which the tumour has spread, but average between 60-65%.

## Commonly used chemotherapy drugs

Vincristine, Actinomycin D, Cyclophosphamide, Ifosfamide, Etoposide, Doxorubicin.

## Osteosarcoma

This is the most common type of bone cancer in children. Most patients are between 10 and 20 years old. It is more common in boys and mostly affects the long bones. The most common site is the leg, with the femur (upper leg) the most commonly affected. The next most common sites are the tibia (lower leg) and the humerus (upper arm). The growth plates (sites of bone growth) at the ends of the long bones are often affected.

Osteosarcoma can also be a complication of radiation therapy for another type of cancer, such as retinoblastoma and can occur between 7 and 15 years after radiation treatment.

## Most common symptoms

- Pain in the affected body part.
- Limited movement of the limb.
- A lump and swollen lymph nodes in the affected area.
- Tenderness and increased heat in the area.
- Trauma does not cause osteosarcoma but often just brings it to medical attention; for example, as a result of a fracture through the tumour.

## Diagnosis and tests

- X-rays will usually show the tumour clearly.
- MRI scans will show the size of the tumour and how the surrounding soft tissue is affected.
- Bone scans using radioactive material will help to see if the tumour has spread to other bones.
- Chest x-ray and a CAT scan of the lungs are used to look for cancer spread in the lungs.
- A biopsy of the tumour and surrounding soft tissue is also important to rule out other bone conditions and make a precise and definite diagnosis of osteosarcoma.

## Treatment

Treatment depends on the age of the patient, the site and size of the tumour and whether it has spread. A few courses of chemotherapy are given for 6 to 12 weeks, to shrink the tumour before it is surgically removed. If at all possible, the limb is not amputated and only the affected part of the bone is removed; this will be replaced with a metal prosthesis. Sometimes doctors have no other choice but to amputate the limb, especially if the cancer has spread. Surgery is usually followed by a few more courses of chemotherapy. Radiation therapy is also used in some cases for local control of the tumour and for pain relief when the cancer has spread. Survival rates for patients with osteosarcoma have improved dramatically over the years.

# Common childhood cancers

## Commonly used chemotherapy drugs

The first drugs used to effectively treat osteosarcoma were Methotrexate and Doxorubicin. Today drugs used are Cisplatinum, Doxorubicin and Ifosfamide. Various combinations of all of these drugs are now used.

## Ewing's sarcoma

This is the second most common type of bone cancer in children and young adults. The Ewing's sarcoma family of tumours is part of a group of tumours that share certain characteristics.

There are two separate types:

- Ewing's sarcoma, which involves the bones;
- Primitive neuroectodermal tumour (PNET) and Peripheral neuroepithelioma, which involves bone and soft tissue.

These tumours can occur in any part of the body, but the most common sites are the pelvis, arms and legs and the ribs.

## Most common symptoms

- Pain at the site of the primary tumour.
- Some patients might have fever or experience weight loss.
- If the tumour is near the spinal cord, symptoms include weakness in the legs and loss of bladder control.
- Sometimes Ewing's sarcoma can be confused with an infection of the bone (osteomyelitis) and this can cause a delay in diagnosis.

## Diagnosis and tests

- A biopsy is done to take out a small piece of tissue from the tumour. Under the microscope the pathologist can look for cells typical to Ewing's family of tumours.
- It is also important to know how big the tumour is and whether it has spread. To find this out various tests are done, including blood and urine tests.
- MRI scans will show the size of the tumour and how the surrounding soft tissue is affected by it.
- X-rays of the bones are taken to look for fractures and to see how much bone has been destroyed by the tumour.
- Bone scans using radioactive material will help to see if the tumour has spread to other bones.
- A CAT scan of the chest will determine whether there is cancer in the lungs.
- A bone marrow aspiration and biopsy are done to see if the cancer has spread into the bone marrow cavity.

## Treatment

Treatment depends on the site and size of the tumour and whether it has spread. A few courses of chemotherapy are given for 9 to 12 weeks, to shrink the tumour. If the tumour is small and in a bone that can be removed completely, surgery alone will be enough to control the tumour. In most cases it is necessary to give radiotherapy, along with chemotherapy, to control the tumour locally. Radiotherapy may last up to six weeks and chemotherapy is given for a total of 30 to 48 weeks, to prevent the tumour from coming back.

Cure rates have improved dramatically over the years and now almost 70% of patients with Ewing's sarcoma can be cured. Unfortunately, if the disease has already spread at the time of diagnosis, only 20-30% of patients are cured.

## Commonly used chemotherapy drugs

Vincristine, Actinomycin, Cyclophosphamide, Adriamycin, Ifosfamide and Etoposide. To lessen the side effects of the chemotherapy, most patients will also need growth factors such as G-CSF. Mesna is commonly used with Cyclophosphamide or Ifosfamide to prevent bladder inflammation, which can cause bloody urine.

## Hepatoblastoma

Cancer of the liver is quite rare in children, accounting for only 1-2% of childhood cancers. Many other childhood cancers can spread to the liver, but these are very different from primary liver cancer.

Hepatoblastoma is the most common type of liver cancer in children younger than three years. Another type of liver cancer, hepatocellular carcinoma, is more common in children aged 12 to 15 years and may be associated with Hepatitis B infection.

## Most common symptoms

The first sign is usually a lump (mass) in the right upper side of the abdomen. Other symptoms may be present for many months before a diagnosis is made and include:

- a vague feeling of fullness in the abdomen;
- pain in the abdomen;
- vomiting;
- diarrhoea;
- fever;
- abnormal weight loss;
- jaundice (yellow appearance of the skin and whites of the eye);
- general itching.

## Diagnosis and tests

Several types of imaging methods can be used to determine the size and exact site of the tumour, whether it has spread, to monitor its growth and to assess how well the treatment is working. These include x-rays, ultrasound, CAT scan and MRI scan.

## Treatment

The best chance for cure of liver cancer is to completely remove the tumour by surgery. Because of the capacity of the liver to regenerate and grow new cells, three-quarters of the liver can be safely removed. Sometimes, when the tumour is too big or involves major blood vessels that supply the liver, it can be impossible to remove the tumour completely. In such cases three to four courses of chemotherapy is given to shrink the tumour. If the tumour has then become small enough, it is surgically removed.

Another procedure, called Chemoembolization, may be carried out. This cuts off the blood supply to the tumour.

Hepatoblastoma responds well to chemotherapy, but hepatocellular carcinoma does not respond well to any known chemotherapy drugs. However, new chemotherapy drugs are being developed all the time.

## Commonly used chemotherapy drugs

The best drugs today are Cisplatin and Doxorubicin.

## Germ cell tumours

Germ cells are the cells that develop into an embryo and then continue growing into a baby in the womb. Some of these cells remain in the child's body and may grow into malignant or benign tumours. The most common places these types of tumour appear are the testes, ovaries, at the bottom of the spine (sacrococcygeal area) and the middle of the brain, chest and abdomen. The different names of these tumours usually refer to the place where they start. This type of cancer is very rare.

### Most common symptoms

Symptoms vary depending on where the tumour is, but usually a lump can be seen and felt in the affected area.

### Diagnosis and tests

Initially, a biopsy of the tumour is done. Germ cell tumours release certain proteins in the blood, like alphafetoprotein (AFP) and human chorionic gonadotrophin (HCG). A blood sample will be taken to measure how high the levels of these proteins are.

Other tests to look for metastases include a chest x-ray, bone scan, CAT or MRI scan and sometimes a bone marrow aspiration.

### Treatment

Usually the tumour is surgically removed and if the tumour is benign this is the only treatment required. If the tumour is malignant but has not spread, surgery will also be the only treatment required. It is sometimes necessary to remove the entire ovary or testicle if the tumour appears in these areas. If there are metastases, surgery will be followed by chemotherapy for a few months.

### Commonly used chemotherapy drugs

The drugs used in most Germ cell tumours are a combination of Cisplatinum, Vinblastine, Bleomycin and Etoposide (VP 16). Germ cell tumours of the central nervous system are usually treated with Ifosfamide, Etoposide and Carboplatinum.

# Treatment of childhood cancers

Whilst cancer in children is a treatable disease and up to 70% of children can be cured, it remains a complex disease. Treating childhood cancer can be an extremely difficult and trying process, both for the child and the parents.

The major portion of your child's treatment will take place in the hospital. Your child's treatment plan (protocol) will be explained to you in more detail by your doctor. Please ask if there is anything that you do not understand. We believe that knowledge of both the disease and its treatment is crucial. By learning all you can, fear is eased, hope is heightened and you can play an active role in your child's treatment.



**The most important decision you as a parent must make in regard to your child's treatment, is to ensure that your child is treated by a qualified and registered Paediatric Oncologist at a specialised Paediatric Oncology Unit.**

The treatment of childhood cancers is significantly different from those in adults and requires specialist knowledge. The Paediatric Oncologist specialises in the diagnosis and treatment of children's cancers. Your child should be looked after by a multidisciplinary team headed by the Paediatrician and treatment should only be practiced in a unit attached to or affiliated with an Academic Hospital.

### Goals of treatment

The goal of treatment is to cure your child of cancer and return them to a 'normal' life. There is also a scientific goal to treatment: to learn more about childhood cancers and to develop treatments that cure more children, with fewer side effects. To achieve these scientific goals, some children (with the parent's consent) are asked to participate in clinical trials. Clinical trials are designed to gain useful information about new drugs or new treatment schedules (protocols). Your child will never be entered into a trial without your consent and only after the trial has been explained to you in detail.

### Diagnosis and tests

Treatment begins with a specific and accurate diagnosis, by doing various tests and examinations. These may vary according to the type of cancer, but will be explained to you in detail by your doctor and other members of the team. Tests are done on all children to make sure that the child's major organs (heart, lungs and kidneys, etc.) are healthy, and the results are usually normal.

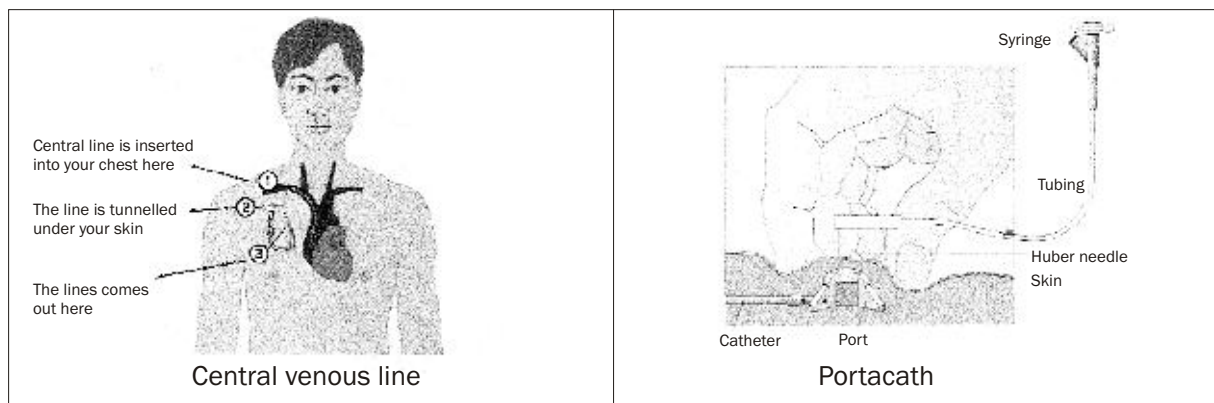
# Treatment of childhood cancers

## Central venous lines

A central venous line (a long, thin catheter-like tube) is put in under general anesthesia by a paediatric surgeon. This helps to make the whole experience of treatment and hospitalisation a little easier for you and your child because no needles are involved.

The central venous line can stay in your child for many months. It is used to administer fluids and chemotherapy, and to take blood samples to and from the child. You may be taught how to clean and take care of the line at home. Don't let this scare you because all the parents who have been there before you have managed just fine. You will too!

Different types of lines are used, the most common ones being a central line and a Portacath.



*These diagrams are with acknowledgement to: [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)*

## Different treatments

Each type of cancer is different and therefore treated differently. Children's cancers are treated by surgery, radiotherapy, chemotherapy, bone marrow transplant and immunotherapy. Almost all childhood cancers require chemotherapy as part of treatment.



**Remember that cancers vary considerably and treatment will vary accordingly.**

## Surgery

This is the most direct way of dealing with a tumour and is the main treatment for localised, solid tumours. Surgery is often followed by chemotherapy and/or radiotherapy, to destroy any remaining cancer cells. Sometimes it is necessary to also remove surrounding tissue or nearby lymph nodes. Depending on the size and location of the tumour, the surgeon will try to remove the whole tumour. If an operation would be dangerous or disabling for the child, chemotherapy or radiation is given first, until the tumour has shrunk. This will ensure that surgery is as safe and effective as possible.

## Radiotherapy

Radiation is a treatment given by high energy x-rays that kill cancer cells in their path. This is also a treatment for a local, solid tumour. The number of treatments will vary depending on the diagnosis, but radiotherapy is usually given for a few minutes every day from Monday to Friday, with a rest period over the weekend. Your doctor and the team of radiologists and radiotherapists will explain every aspect of the treatment to you in detail.

Before treatment begins, the radiologists make a careful plan of the area to be treated. Semi-permanent markings (tattoos) are then made on the skin, to mark the area that is to be radiated. To protect nearby organs and tissue, special shields or moulds are sometimes made.

Radiotherapy treatment is completely painless, but the child must lie completely still to ensure the treatment is given accurately. The child must also be left alone in the treatment room for a few minutes. This can be quite frightening, especially to a very young child, so it is important to explain beforehand that you will be looking at your child on a TV monitor. Try to be calm and reassure your child before the treatment. It might also help if you visit the radiation unit beforehand, so that your child can meet the therapist and have a look around. Encourage your child to keep a favourite soft toy in the room.

It is quite safe to be with your child immediately after treatment. Most children cope very well through radiotherapy, although there may be some side effects depending on the area being treated and the dose of radiation required.

The treatment team will explain in detail how to handle side effects and take special care of the skin in the area that is treated, which becomes very sensitive. To protect the sensitive skin areas there are two important rules you must follow.

- Do not wash the skin in that area with soap and water.
- Do not use any skin creams or ointments, unless prescribed by the doctor.

## **Chemotherapy**

Chemotherapy is treatment with drugs. Drugs may be given orally (by mouth), by injection or intravenously (in the vein), either through a drip or the central venous line (if your child has one).

Chemotherapy drugs circulate through the body destroying cancer cells which are rapidly dividing. However, they also damage healthy dividing cells. Usually chemotherapy lasts a few months. For solid tumours, after each course of drugs, lasting from one to several days, there follows a rest period of 1-4 weeks, to give the body a chance to recover from the effects the drugs have on normal cells.

Many different chemotherapy drugs are available, but every type of cancer is treated with a specific drug or combination of drugs. The drugs used for children's cancers are the same as those used to treat cancer in adults, although given in smaller doses (since dosage is determined by the patient's bodyweight).

Chemotherapy drugs have many potential side effects and these will be explained to you by your doctor. A glossary of commonly used chemotherapy drugs and their side effects appears on pages 77-82.

Your doctor will decide on the best treatment plan (protocol) for your child's specific type of cancer after an accurate diagnosis has been made. International bodies provide guidelines and basic protocols for various cancer treatments, which are up to date with the latest findings in research and drug development. You can therefore be sure that your doctor is not working alone but has access to knowledge gained from around the world.

## **Bone marrow transplant (BMT)**

Some children with leukaemia, certain other forms of cancer, diseases of the bone marrow that are not truly cancerous and some genetic diseases, require a bone marrow transplant as part of their treatment. This

# Treatment of childhood cancers

treatment option is only given to patients for whom BMT offers the best or the only chance of cure, since it is a far more intensive form of treatment than chemotherapy.

BMT is the transplanting of stem cells from the bone marrow of a healthy donor to the patient (See chapter 6 for more information on stem cells). The patient's unhealthy bone marrow cells are destroyed and then healthy bone marrow cells are infused into the patient, almost like a blood transfusion. There are different kinds of BMT and there are many factors to consider when deciding which type of transplant should be used for a particular patient. Your doctor will discuss all of these options with you.

Types of bone marrow transplant include:

- *Autologous transplant*: the child's own bone marrow is used. Bone marrow is taken from the patient, stored in a special freezer and given back to the patient at a later stage.
- *Allogeneic transplant*: a family member or another unrelated person donates bone marrow to the child.
- *Syngeneic transplant*: the child's identical twin is the donor.
- *Stem cell transplant*: stem cells from the circulating blood in the body or from a placenta (after birth) can be used instead of bone marrow.

The first step in preparing for BMT is to destroy the patient's unhealthy bone marrow. This is done by giving the patient high-dose chemotherapy and sometimes a form of radiation therapy called Total Body Irradiation. The purpose of this is to kill all the cancer cells in the body and the abnormal parts of the bone marrow. However, this treatment also destroys the white blood cells that protect the body against infections, making the patient very susceptible to all kinds of infection. It can take 6 to 12 months after the transplant before the patient's immune system recovers.

BMT is really intensive and tough on the patient's body and requires a long stay in hospital of 6 weeks or longer.

## Immune Therapy

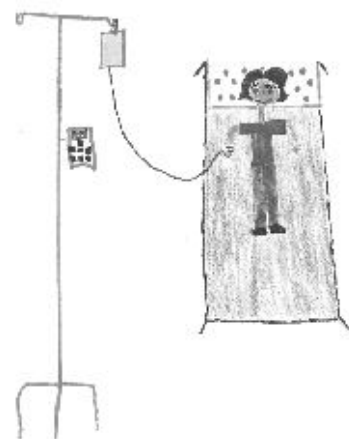
The body's immune system is made up of white blood cells called lymphocytes. These circulate through the body to protect it and fight against infections.

There are two types of cells that work together to protect the body against viral infection:

- B-lymphocytes produce antibodies which bind to a virus, thereby preventing it from infecting healthy cells;
- T-lymphocytes (cytotoxic T-cells) destroy infected cells.

Patients who have had a bone marrow transplant do not have enough T-cells. It is possible to take T-cells from a bone marrow donor and give these to the patient. However, this can cause the patient's body to reject the donor marrow because the foreign T-cells 'attack' the patient's body.

Scientists are now testing ways to give T-cells to a patient without causing this attack and rejection reaction. They are also looking into the possibility of the patient's own immune system fighting the tumor cells. Some tumors are caused by viral infections and in this case the T-cells must be able to recognise and kill the tumor cells. Experiments are now in progress to find new ways of using T-cells to fight and destroy tumours.



*In hospital, by Nakita Dos Reis, 11 years old.*

# Stem cells and stem cell treatment

Stem cell technology is a fascinating, evolving science in medical circles. Much research is being done worldwide to find cures for many diseases where drug therapy has not been successful.

### What are stem cells?

Stem cells are the original building blocks of life, the body's founder cells which differentiate into all the specialised cells that make up the human body (skin, blood cells, muscle, bones, nerves etc). These occur in the embryo during early life and growth. In addition, in many tissues they serve as an internal repair system, dividing to replenish other cells.

### Where are stem cells found?

- **Embryo**

The richest and most abundant source of stem cells is found in an embryo. When the egg and sperm join together, they form one cell that then divides into a group of cells (embryo). From this group of cells, all the body's organs are made, hence the name stem cells. The proposed use of stem cells from this source is what has made stem cells so controversial, as it involves the termination of a potential life.

- **Umbilical Cord**

Stem cells are abundant in the umbilical cord and placenta. However these are committed haemopoietic stem cells, which will only replenish the bone marrow cells. An advantage of umbilical cord stem cells is that the cells have not yet developed immune competence, so there is less chance of rejection when used.

- **Adult**

Stem cells are also found in adults including bone marrow, peripheral blood, neural tissue, adipose (fat) tissue, skin and liver. These stem cells are active in repairing and maintaining our tissues and organs throughout our lives. They are however, small in number and very difficult to isolate. The only adult stem cells used in therapy are those from the bone marrow and peripheral blood that are used in bone marrow or stem cell transplants.

### How are umbilical cord blood stem cells collected?

The umbilical cord stem cells have to be collected at the birth of the child. Once the baby is delivered from the uterus, the cord is cut and the baby is handed to mother or the attending nurse. The placenta remains in the uterus. The Obstetrician or midwife will then place a needle into the vein of the umbilical cord that is still attached to the placenta and drain the blood into a blood bag. About 100-200 ml of blood is collected. The mother will not feel any pain during this procedure which is only about three minutes long. The placenta is then delivered. The blood bag is then packaged and couriered to the laboratory. In the laboratory, the stem cells are separated out of the cord blood and cryopreserved (frozen) at minus 196 degrees Celsius. These cells can then be stored indefinitely.

# Stem cell and stem cell treatment

## How are haemopoietic stem cells collected after birth?

There are two ways in which haemopoietic stem cells may be collected from a person after birth.

1. Directly from the bone marrow via bone marrow aspiration from the hip bone.
2. Peripheral blood stem cells. Stem cells from the bone marrow are stimulated to come out of the bone marrow into the blood with white cell growth factor injections e.g. Neupogen® (G-CSF). The stem cells are then collected in a way similar to a person donating platelets via a vein and a special machine.

## Current applications of stem cells

Haematopoietic stem cells are cells which have the ability to evolve into all the specific cell types in the blood and immune system. Thus, peripheral blood, umbilical cord blood or bone marrow haemopoietic stem cells are used to treat blood and blood-related diseases. Examples of these diseases are:

- blood disorders (inherited or acquired), e.g. Thalassaemia, Fanconi's anaemia, Sickle cell disease, Pure Red Cell Aplasia (Diamond-Blackfan Anaemia), Acquired Aplastic Anaemia;
- malignancies – Leukaemia and bone marrow malignancies, lymphoma, other cancers;
- inherited metabolic diseases;
- inherited immune diseases.

In all the above, except lymphomas or solid tumour cancers, the child's own stem cells (autologous stem cells) cannot be used. These conditions require stem cells from an HLA-matched donor (allogeneic stem cells). The best donors are siblings from the same mother and father. There is a 1 in 4 chance that a sibling is a match.

## Reasons to consider storing your baby's stem cells

- Family history of certain illnesses especially haematological (blood) cancers, inherited blood disorders and inherited immune deficiencies. However, prior genetic counseling and sometimes antenatal testing is essential to ensure the baby does not have the disease.
- Sibling with a disease that is potentially treatable by bone marrow or stem cell transplant.
- Families of African origin and mixed-race marriages, as it is extremely difficult to find suitable donors, as they are seriously under-represented in stem cell and tissue banks.

## Future applications

The future holds huge potential for the use of stem cells. In 2006, scientists identified conditions that would allow adult blood forming stem cells to be 'reprogrammed' into stem cells which can produce other cells of the body. These are called induced pluripotent stem cells (iPSC's). There are human trials underway all over the world, but these are still highly experimental. Examples of diseases for these experimental stem cell therapies are: heart disease, diabetes type 1, cartilage replacement for arthritis, bone production in non-union fractures, blindness, stroke patients, cerebral palsy, spinal cord injury, Alzheimer's and Multiple Sclerosis. As the technology advances, the need for stem cell therapies will increase.

## A parent's guide to cord blood

This website was written by Dr Frances Verter, in memory of her daughter Shai, who died from Leukaemia. This website contains medical facts and opinions about stem cells, useful information about private cord blood banks around the world and what questions you should be asking.

<http://parentsguidecordblood.org/>



*Big person,  
by Sharon*

# The side effects of treatment and how to deal with them

Chemotherapy, radiotherapy and surgery all have various effects on the body. The severity of these side effects depends on various factors such as the type and location of the cancer, the intensity of the treatment and the child's age. Children seem to cope far better with the physical side effects of cancer treatment than adults do.

However, school-age children and teenagers will find it difficult to cope emotionally with some of the side effects like hair loss. It is very important to discuss the possible side effects with your child. Encourage your child to talk about their feelings, listen empathetically to them and provide constant reassurance.



**Many different drugs are used in chemotherapy and their effects differ significantly. A list of the possible side effects of the various chemotherapy drugs is provided on page 79-82.**

## **Common side effects of different cancer treatments**

Patients respond differently to drugs and treatments, yet many of the side effects are well known. Most side-effects can be treated or dealt with very successfully. In this section we will be giving you some tips (tried and tested) on how to deal most effectively with the side effects of different cancer treatments.

### **Bone marrow suppression**

Bone marrow is the soft spongy centre of bones, where most of the blood cells are formed. As the blood cells mature they are released into the bloodstream. Because these cells are fast-growing, bone marrow is very sensitive to chemotherapy and radiotherapy. With bone marrow suppression this naturally leads to reduced functioning of the blood cells in the bloodstream.

Red blood cells carry oxygen from the lungs to the rest of the body. If the red blood cell count becomes low, as a result of bone marrow suppression, the child will develop anaemia. The symptoms of anaemia are paleness, dizziness, weakness and lack of energy, headache and irritability.

**Dealing with it:** Red blood cell transfusions are given to treat this condition.

### **Thrombocytopenia (low platelet count)**

Platelets help to prevent bleeding by causing the blood to clot. When the platelet count is very low it causes bleeding and easy bruising. The signs of a low platelet count are tiny red spots under the skin (petechiae), bleeding from the mouth and gums, nosebleeds, pink or red urine and stools that are red or tarry and black.

**Dealing with it:** A platelet transfusion is given when the platelet count is very low.

# The side effects and how to treat them

## Neutropenia (low neutrophil count)

Neutrophils are a type of white blood cell and the body's main defence against infections. If the neutrophil count is low, the child will be very susceptible to infections. Signs that a child has an infection somewhere in the body include fever, chills, rash, diarrhoea and any area in the body that is red, painful or very warm to the touch. If any of these signs are present, you must immediately contact your child's doctor. Never take any signs or symptoms of a possible infection lightly and take action immediately. Any type of infection can prove fatal in a child who is receiving cancer treatment and has a low white cell count.

### Dealing with it

- Always use a thermometer to determine your child's temperature.
- If your child has a temperature greater than 38°C – even if the temperature responds to medication, contact the doctor without delay.
- Use only drugs containing paracetamol, with or without codeine. These include Panado, Calpol, Tylenol, Stilpane and Stopayne.
- Avoid drugs containing salicylates (i.e. aspirin), mefenamic acid, ibuprofen, diclofenic sodium and indomethacin. These include Aspirin, Disprin, Brufen, Voltaren, Ponstan, Indocid and Lotem.
- Antibiotics will be given when there are signs of infection.
- The two most important ways to prevent infections are:
  - frequent and thorough hand washing;
  - avoiding contact with people who have contagious illnesses, such as colds and flu and all childhood diseases, such as measles and chicken pox.
- Prolonged low blood cell counts can be life-threatening in children receiving cancer treatment. To shorten the duration of bone marrow suppression, certain drugs called Haematopoietic Growth Factors can be given. These drugs help the blood cells to mature quickly so that they can be released into the bloodstream sooner than normal. The growth factor used is Neupogen (G-CSF). This can be given as an injection under the skin or as an intravenous infusion (IV).



**Severe or prolonged vomiting can lead to dehydration.  
For tips on how to prevent dehydration or diarrhoea  
read the section on page 30.**

## Nausea and vomiting

Chemotherapy directly affects the brain's vomiting centre and the stomach's nerve cells. Chemotherapy, therefore, may make your child feel nauseous and can cause vomiting. The nausea and vomiting occurs soon after the chemotherapy drugs have been given and can last for some hours. Different chemotherapy drugs have different effects on the vomiting centre and some are more severe than others. Radiotherapy can also affect the vomiting centre, depending on the site of radiation.

### Dealing with it

- Anti-sickness drugs (anti-emetics) are usually successful, especially when given a few hours before the treatment. These should be continued for at least 24-48 hours after the chemotherapy.
- If your child is vomiting:
  - do not give any liquids or food until the vomiting is under control;
  - keep the room cool and well-ventilated; older children may prefer a dark, quiet environment;
  - try to keep your child as comfortable as possible, in a restful position with the head slightly raised;
  - gently wipe your child's face with a cool cloth;
  - let your child rinse their mouth with cool water or a mild mouthwash, to remove nasty tastes.

## The side effects and how to treat them

- Do not force your child to eat and avoid heavy meals for several hours. Instead, give small and frequent amounts of clear liquids, such as water or non-fizzy drinks.
- As soon as your child feels better, offer small amounts of plain, bland foods, such as vegetables, fruit, low-fat yogurt, custard, jelly, plain meat like chicken, cereal, rice, pasta, mashed or baked potatoes, soup, crackers or toast. Avoid spicy, heavy, fatty and fried foods.
- If food smells bother your child:
  - use cold or room-temperature foods;
  - use a cup with a lid;
  - encourage your child to avoid areas where food is cooking.
- Don't offer solid food and liquids (especially fizzy drinks) at the same time, as this can cause nausea by making your child feel too full. Have them eat solid food for meals and snacks and give liquids 30 to 60 minutes before or after eating.

### Diarrhoea

Children undergoing chemotherapy or radiotherapy treatment develop diarrhoea because the mucosal cells lining the intestines become irritated and damaged. Diarrhoea caused by chemotherapy or radiotherapy can start within hours of receiving the treatment and last for several days, usually until the mucosal cells start to heal.

In some cases, the damage to the mucosal cells results in sores. When this happens, the intestine cannot absorb nutrient or fluids. The child then has frequent loose, runny or watery stools.



**In children, diarrhoea can easily lead to dehydration.  
Prevent dehydration by giving your child  
lots of fluid to drink.**

### Dealing with it

- Prevent dehydration by increasing the amount of liquid given to your child. In some cases the only way to prevent dehydration is by giving fluids intravenously through a drip.
- If stomach cramps or pain occur, drugs to relieve the pain and discomfort can be given. Bed rest may also help to reduce cramps.
- Medications to stop diarrhoea are usually not effective because the intestine must heal before the diarrhoea will improve. They are also dangerous for small children.
- Babies and young children may develop a skin irritation around the rectum (anus) or in the diaper area. Wash the skin with a mild soap after every stool and keep it clean and dry. Use a protective barrier cream for sensitive skin.
- Don't force the child to eat. Instead, give a clear liquid diet for at least 12 hours to allow the bowel to rest while essential fluids are replaced.
- As soon as the child improves offer:
  - full liquids like soup;
  - light meals of soft foods which are low in bulk, such as white bread, fish, chicken, eggs, puréed vegetables and canned or cooked fruit.
- Avoid milk products, fatty, greasy and fried foods, citrus juices, fizzy drinks and raw vegetables or fruit.

# The side effects and how to treat them

## Constipation

Constipation is the infrequent passing of hard, dry stools. This is caused by some chemotherapy drugs, radiation therapy, pain medication and a diet that lacks adequate fluids and/or bulk. When a child has to stay in bed for a prolonged period of time, a lack of exercise may also cause constipation.

### Dealing with it

- When your child is given medicines that are known to cause constipation, a laxative or stool softener will be given at the same time to prevent severe constipation and discomfort.
- Encourage your child to drink plenty of liquids. A special glass and mug with pictures of a favourite cartoon character can work magic with younger children, to encourage them to drink.
- A hot drink in the morning and evening may stimulate a bowel movement, especially drinks containing caffeine such as tea, coffee or cocoa.
- Give your child foods high in fibre, such as:
  - whole-wheat bread and crackers;
  - high-fibre breakfast cereals, for example, All Bran Flakes, Weetabix, whole-wheat Pro-Nutro, muesli and oats;
  - whole-wheat pasta and brown rice;
  - fresh fruit and vegetables;
  - dried fruit or steamed prunes.
- Encourage your child to get some exercise if possible, even if just a gentle walk.



**Do not give a laxative or any other medication before consulting your doctor. Some laxatives may make the problem worse.**

## Mouth sores, sore throat and dry mouth

The mucosal cells lining the mouth, throat and oesophagus are all fast-growing cells, which are very sensitive to chemotherapy drugs and radiation therapy. When these cells are damaged this is called oral mucositis. It usually starts in the mouth 7 to 10 days after receiving treatment. The first signs are red and swollen gums followed by sores in the mouth and throat. Unfortunately this condition cannot be prevented.

### Dealing with it

- Good mouth care and oral hygiene can help to decrease the severity, prevent infections and speed recovery.
- Good mouth care means keeping the mouth clean and moist by brushing and rinsing at least four times a day until all the sores are healed.
- Brushing with a soft toothbrush and toothpaste is very important. Rinsing with a mild mouthwash or even a weak salt solution will help keep the mouth moist.
- There are several medications and solutions available to help healing, prevent infections and decrease pain in the mouth. Ask your doctor to prescribe what your child needs.
- If your child's mouth is too painful for eating, offer a liquid diet and soft, puréed foods.

# The side effects and how to treat them

## Poor appetite and weight loss

Chemotherapy and radiotherapy may make your child feel nauseous and sick because the mucosal cells lining the intestines become irritated and damaged. In addition, some chemotherapy drugs cause a metallic or foul taste in the mouth while the drugs are administered. This will cause the child to lose their appetite and experience weight loss. Excessive weight loss can affect the self-esteem of older children and teenagers. Try to reassure your child and remind them that weight usually returns to normal once treatment is over.

### Dealing with it

- Offer small, appetising meals four or more times a day, consisting of your child's favourite foods, drinks and snacks.
- Give 'power packed' food that is, food with high nutritional value. Consult a dietician to help you create a healthy eating plan for your child.
- Give special food shakes or meal replacement drinks, such as Nutriment-T, Paediasure and Ensure.
- Present your child's food attractively and use special colourful plates, cutlery and napkins, to make mealtimes more fun.
- For smaller children, cut food such as bread, cheese and cold meat into fun shapes and arrange the food to form a 'food picture' on the plate.

## Weight gain

Excessive weight gain and a round 'moon' face are common side effects of treatment with steroid drugs. Older children and teenagers find this very difficult to cope with and it can dramatically affect their self-esteem.

### Dealing with it

- Lots of patience and tender, loving care (TLC).
- Talk to your child and explain this possible side effect before the treatment is started, so that your child knows what to expect.
- Encourage your child to talk about how they are feeling and you must really listen. Constantly reassure your child that their weight and appearance will return to normal as soon as the treatment is over.
- Avoid salt and salty foods.

## Hair loss (alopecia)

Hair loss or alopecia caused by chemotherapy and radiotherapy usually does not bother small children. Older children of school age and teenagers can find this devastating.

### Dealing with it

- Lots of patience and TLC.
- Talk to your child and explain this possible side effect before the treatment is started, so that your child knows what to expect. Then decide on a plan of action: wigs, hats or bandanas.
- If your child decides on a wig, take them to choose one before their hair falls out, so that it will be as close as possible to your child's natural hair colour and style.
- Buy some fun hats or colourful bandanas to cover up your child's bald head.
- If your child's hair is long, it may be better to cut it shorter as soon it starts falling out, to help it appear less messy.
- Reassure your child that the hair will grow back as soon as the treatment is over. In most cases the hair grows back thicker and more beautiful than before.
- Maybe the child's Dad, sibling or other family members will be willing to shave their hair off to show support.

# The side effects and how to treat them

## Fatigue (tiredness)

Children can experience fatigue during any stage of their cancer treatment even after the treatment is over. Intensive chemotherapy, radiotherapy and recovery from surgery often cause physical and emotional tiredness and weakness. Side effects such as nausea, vomiting, diarrhoea, pain and poor nutrition can all cause feelings of weakness and fatigue. Once again, fatigue seems to affect older children and teenagers more than it does younger children and can interfere with their quality of life.

## Dealing with it

- Try to plan ahead so that your child can have adequate rest periods after their daily activities.
- Try to deal effectively with other side effects that can contribute to fatigue.
- Ensure that your child sleeps well at night by making the sleeping environment comfortable, dark and quiet.

## Pain

What many parents fear most is to see their child in pain. You may have heard horror stories of how painful cancer is and that nothing can be done to relieve the pain, fortunately, this is not true.



### IMPORTANT

- **Not all cancers are painful.**
- **Not all pain experienced by a cancer patient is from the cancer.**  
**Every new pain your child has does not mean that the cancer has come back.**
- **Pain can be controlled very effectively. No child needs to suffer unnecessary pain.**

## Pain from cancer

Pain is caused by the following:

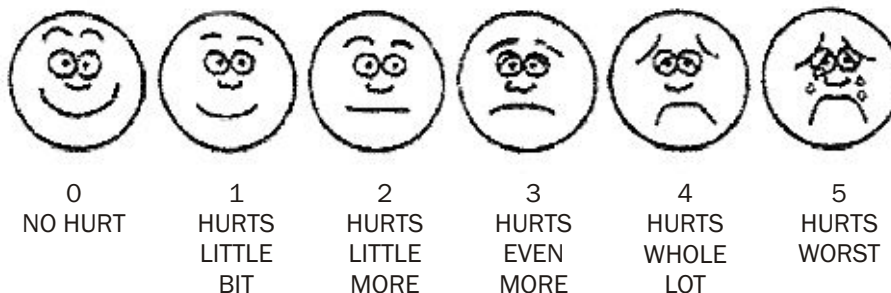
- The tumour pressing on bone, nerves or body organs. As soon as the tumour is removed, the pain often lessens or disappears.
- The procedures – most procedures involve needles and for children this is a dreaded part of cancer treatment. By having a central venous line put in, the use of needles can be significantly reduced.
- The side effects of treating cancer – this can include pain after surgery, mouth sores, stomach ache or nerve damage. There are medications available that effectively control the various types of pain.

## Dealing with it

- Encourage your child to speak up about pain as soon as they start feeling it. This is very important because it is much easier to control pain in its early stages, before it becomes too severe.
- Reassure your child that you believe them when they tell you that they are in pain. Tell your child that they do not have to hide their pain. Hiding the pain and not telling you makes controlling the pain more difficult.
- Discuss your child's pain management plan with your doctor and the other staff members involved. This plan may include medications, radiotherapy or nerve blocks.
- One way of getting the child to indicate the level of pain they are feeling is by way of a pain chart. This could be in the form of 'smiley faces' for example the chart on page 34.

## The side effects and how to treat them

### Wong Baker Faces Pain Rating Scale



Explain to the person that each face is for a person who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 1 hurts just a little bit. Face 2 hurts a little more. Face 3 hurts even more. Face 4 hurt a whole lot. Face 5 hurts as much as you can imagine, although you don't have to be crying to feel this bad. Ask the person to choose the face that best describes how he is feeling. Rating scale is recommended for persons age 3 years and older.

Brief wording instructions: Point to each face using the words to describe the pain intensity. Ask the child to choose the face that best describes his own pain and record the appropriate number.

*From: Wong DL, Hockenberry-Eaton M, Wilson D, Winkelstein ML, Schwartz P: Wong's Essential of Pediatric Nursing, 6/3, St. Louis, 2001, P. 1301. Copyrighted by Mosby, Inc. Reprinted by permission.*

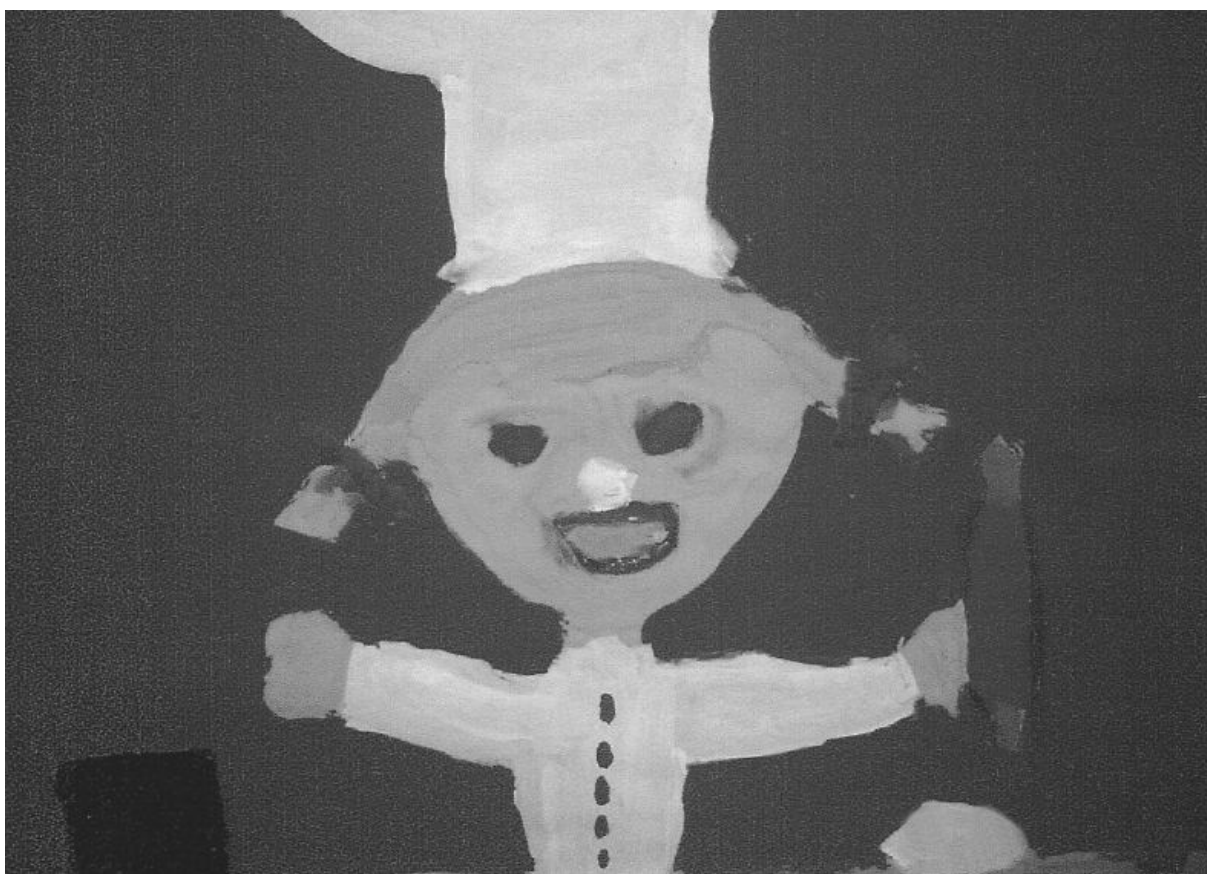
- Many pain medications may cause constipation. Take steps to prevent this (see notes on preventing constipation on page 31).
- Other ways of reducing pain include using a hot or cold pack and giving massages. But do check with your doctor before using any of these methods.
- A psychologist or play therapist can help you and your child by teaching you more about pain control and helping to lessen your child's fear of pain.
- Give brief and honest explanations about what is happening to your child on a level that suits your child's age, intellectual abilities and personality. Not being truthful or honest and not telling a child that a procedure will be painful, can break down your child's trust in you.
- You are your child's greatest source of strength. If you are confident that your child's pain can be controlled, your child will be too.
- If possible, stay with your child during the procedure. It will make your child feel safer and calmer.
- Give some control back to the child. This can be as simple as saying, "You know this is going to hurt, but if you take a deep breath and blow out slowly, it may hurt less." Praise your child for every effort to co-operate and be brave. For instance, you could say, "You were really still during the lumbar puncture. That was very good." Offer some form of reward to show your child that you recognise their efforts.
- Anxiety and tension make pain worse, so lessen your child's anxiety and tension by encouraging activities to promote relaxation. Let your child's age guide you in choosing suitable activities, for example:
  - for infants, stroking, swaddling and rocking, or giving a pacifier;
  - for toddlers and young children, singing songs or nursery rhymes or telling stories, to distract them during painful procedures;
  - older children and teenagers can use music or imagery (for example, thinking of being at a favourite and pleasant place such as the beach) to help them relax.

## The side effects and how to treat them



### IMPORTANT

- Tension, anxiety and fear make pain worse.
- **ALWAYS** be honest and truthful with your child. Explain procedures and what to expect and give reassurance.
- Learn ways to lessen anxiety and use these to help your child relax. Teach older children ways to relax and lessen anxiety.



*Doing an activity, such as painting or baking, can sometimes help a child to take his or her mind off mild pain*

# Non-malignant haematological conditions of childhood

## Chapter 8

### Aplastic anaemia

The central portion of bones is filled with a spongy red tissue called bone marrow. Bone marrow is the 'factory' of blood cells. When the bone marrow fails to produce blood cells, then the condition is called aplastic anaemia or Bone Marrow Failure. This lack of cells results in a pancytopenia i.e. all three blood cell types are decreased.

- Anaemia is due to a lack of red blood cells. This causes weakness, tiredness, breathlessness and a pale appearance. This is measured as the haemoglobin level.
- Low platelets lead to easy bruising, nose and gum bleeds and can sometimes cause serious internal bleeding. The most serious internal bleed is in the brain.
- Low white blood cells mean that the body cannot fight infections and unexplained fevers may occur.

Without blood cells, we cannot survive.

To make a diagnosis of aplastic anaemia a bone marrow aspiration and bone marrow biopsy must be done.

There are two main categories of aplastic anaemia: Acquired and Inherited, also known as Fanconi aplastic anaemia.

#### Acquired aplastic anaemia

The causes of acquired aplastic anaemia may be exposure to excessive radiation, toxic chemicals, certain drugs or infections. In most cases of acquired aplastic anaemia, the specific cause is never discovered. These cases are known as 'idiopathic aplastic anaemia'. There is often a defect in the body's immune system caused by an unknown agent. This leads to the bone marrow cells being destroyed by our own immune cells.

The treatment is either a bone marrow (stem cell) transplant from an identically matched brother or sister, or immune therapy (anti T-cell). Both have an identical recovery rate in children of around 80%. Patients will also require many blood and platelet transfusions as recovery usually takes several months. In addition, the patient having a stem cell transplant will have to be on anti-rejection medication.

#### Fanconi aplastic anaemia (FA)

This is the inherited or genetic form of aplastic anaemia. Both parents must be carriers of the abnormal gene. There is then a 1 in 4 chance that the baby will have Fanconi anaemia. In South Africa, Fanconi anaemia occurs mostly in people of Afrikaner descent or Black African descent. It also occurs rarely in people of Ashkenazi Jewish descent. Each group has their own specific gene.

# Non-malignant haematological conditions

Children may have a variety of noticeable birth defects, some minor, some serious: shortness in height, abnormalities of the thumb and arm, kidney problems of shape and structure, skin spots and discolourations, small head and eyes, heart defects and learning disabilities. Bone marrow failure occurs at around 4-6 years of age and is usually progressive and fatal. However a small percentage of patients will only have mild bone marrow problems. In addition, Fanconi anaemia patients have a high incidence of leukaemia (18-20%) and a much higher incidence of other cancers than the general population.

## Treatment consists of several options

- Transfusion therapy, antibiotics and hospital care may be effective in the short term, but is not a cure.
- Drug therapy: about 50-75% of FA patients respond to androgen therapy. These are artificial male hormones which can prolong the lives of FA anaemia patients for many years. However it is not a cure and there are many undesirable side effects.
- Stem cell or bone marrow transplant can 'cure' the aplastic anaemia or leukaemia. However transplants in FA patients are more difficult than non-FA patients and have more complications. It does not reverse the birth defects and the patients are still at high risk for developing other cancers especially head and neck carcinomas.

## ITP – Idiopathic Thrombocytopenic Purpura

This is one of the most common acquired bleeding disorders in children. It is a low platelet count due to increased destruction of platelets by the scavenging cells of the spleen, as a consequence of the body making antibodies against the platelets after a viral infection. The platelets are innocent bystanders. The child is usually well except for easy bruising and bleeding and the other blood cells are normal. A bone marrow test is needed if treatment such as cortisone (steroids) is to be used or if there are atypical features.

Most cases of ITP are acute and will either get better by themselves or respond to treatment such as cortisone or high dose intravenous gamma-globulin (e.g. Polygam) within 6-8 weeks. The aim of treatment is to get a rapid increase in the platelet count so as to prevent life-threatening bleeds especially in the brain.

A small percentage of patients will develop chronic or recurrent ITP (more than six months duration). These are more problematic to treat and an operation to remove the spleen may be required. There are many other treatments which have been tried, but each child will respond differently.

## β-Thalassaemia

Beta Thalassaemia is an inherited blood disorder where normal haemoglobin (in red blood cells) is unable to be made due to a gene defect. This results in severe anaemia. It occurs in people of Mediterranean, Middle Eastern and Indian origin. Untreated, most children would die by 1-3 years of age. In addition the liver and spleen become swollen and the bones of the face and head become deformed. Chronic, regular blood transfusions are required to sustain life. If the haemoglobin is kept in the normal range, then children can lead "normal lives". However the result of many transfusions is the over-accumulation of iron in the organs of the body. This leads to heart failure, liver cirrhosis and diabetes. Iron can be eliminated from the body by a certain drug called Desferrioxamine. Unfortunately this must be given by injection under the skin as a continuous infusion with the help of a syringe-driver 'pump'. Recently new oral drugs have been developed which are effective and safe and can be given by mouth. However they are very expensive. If the iron level in the body is

kept low, then patients can live for more than 50 years. Other possible treatments include stem cell transplant and in the future, gene therapy.

### **Sickle cell anaemia**

Sickle cell anaemia is an inherited blood disorder where an abnormal haemoglobin, sickle haemoglobin is produced in the red blood cells. It occurs in people of Central and West African origin. The sickle haemoglobin causes the red blood cells to become deformed into a sickle shape. This results in 'sticky' red blood cells which block small blood vessels and cause painful 'crises' in the bones, tummy and chest. More seriously, a stroke may occur when the brain is affected.

The red blood cells also get stuck in the spleen which results in the spleen not being able to perform its immune function. This results in severe infections especially in young children. The patients are moderately anaemic and also have jaundice. Crises may be prevented by drinking plenty of fluids, treating fevers promptly and avoiding becoming too hot or too cold. Because the spleen is not functioning, children should be immunised against two bacteria; Pneumococcus and Hemophilus. They should also take Penicillin as prevention. More recently, a drug called Hydroxyurea can be taken to increase foetal haemoglobin and thus decrease crises. sickle cell anaemia can be cured by a bone marrow transplant but only from an unaffected matched brother or sister.

### **Hereditary spherocytosis**

This is an inherited disorder where the red blood cell membrane or covering is abnormal. This results in small, round red blood cells which are rigid and non-deformable and are easily destroyed by the spleen. The disorder varies from being mild with only mild jaundice (yellow eyes), to severe anaemia requiring blood transfusions. Almost all patients have an enlarged spleen. A vitamin called Folic Acid should be taken so that the bone marrow can work better to produce more red blood cells. Treatment consists of removing the spleen so that the red blood cells are not destroyed. This should only be done after the age of 6 years when the body's immunity is fully developed. The child should receive a pneumococcal vaccine prior to the splenectomy and should take the antibiotic Penicillin for life as a prevention against infection.

# Diet and nutrition

Diet and nutrition are very important in childhood because children are growing and developing. Good nutrition is particularly important when a child has cancer because the child's growing body also has to cope with the various treatments and their side effects. The focus should be on preventing or treating cancer-related malnutrition, as prevention is always better than cure.

Not all children react to cancer treatment in the same way. Many children have no problem with nutrition – they are able to eat enough and have the strength and energy to maintain their normal levels of activity. However, some children lose weight, grow more slowly, frequently feel tired or irritable and get infections more easily. These can all be signs of poor nutrition.

### The benefits of good nutrition

- Normal growth in height, weight gain and development, both physically and mentally.
- Enough energy and strength to continue with normal activities and have a good quality of life.
- A healthy immune system that helps the body to fight infections.
- A general sense of well-being that makes the child feel more relaxed and helps them cope better with their treatment.

### What is good nutrition?

For good nutrition, your child must consume sufficient amounts of calories, protein and other nutrients, such as vitamins and minerals. The goal is that your child continues to grow in height, gain weight and otherwise develop normally.

On some cancer treatments your child may lose weight simply because they are not taking in enough protein and calories. Reasons for this include loss of appetite, nausea, vomiting, diarrhoea or constipation, sore mouth and throat or any other side effect of the treatment.

### Calories

A calorie is the amount of energy the body gets from food. All food contains calories but the amount varies. For example, foods high in fat and sugar, such as cakes and chocolates, are high in calories, while fruit and vegetables have the least number of calories.

When a child eats more calories than the body needs, the extra calories are stored as fat. If a child does not eat enough calories, the body does not get enough energy from food, so the body starts to use its own fat and muscle stores for energy.

## **A balanced diet**

A healthy, balanced diet must include foods from each of the main food groups daily. The main food groups are:

- grains (bread, rice, pap and pastas);
- vegetables and fruit;
- proteins (such as meat, chicken, fish, eggs, dried beans, nuts and milk);
- fats and sugar.

## **Grains**

Bread, cereals, pap, rice, pasta, wheat and corn are all sources of carbohydrates (starches). Carbohydrates supply quick energy, vitamins, minerals and fibre and should form 50-60% of the daily food intake. Most of these should be complex carbohydrates, such as whole-wheat bread and pastas, brown rice and cereals. These also provide fibre, which is important for proper digestion and helps to prevent constipation.

*Daily needs: 6 - 11 servings of bread, crackers, potatoes, rice, pasta, porridge or cereals, etc.*

## **Fruit and vegetables**

Always make sure that fruit and vegetables are as fresh as possible and wash them very well before eating.

Fruit contains simple carbohydrates that provide the quickest energy to the body. Fruit is also rich in vitamins, minerals and fibre.

*Daily needs: 2 - 4 servings of fresh fruit, dried fruit, canned fruit or 100% pure fruit juice.*

Vegetables contain complex carbohydrates that supply fibre, vitamins and minerals and energy at a slower rate. They can be served fresh and raw, as in salads or lightly cooked or steamed. When cooked for too long and in too much water, most of the vitamins and minerals are lost.

*Daily needs: 3 - 5 servings of raw or cooked vegetables, vegetable soup or vegetable juices.*

## **Protein**

Proteins are needed to build healthy muscles and organs and are very important in healing and rebuilding damaged tissues in the body. Children with cancer should therefore eat plenty of protein.

Good sources of protein include: meat, fish, chicken, eggs, dried beans and peas, nuts and dairy foods such as milk, cheese and yogurt. Soya products are also an excellent source of protein.

*Daily needs: 2 - 3 servings of meat, fish, chicken, eggs, etc. 3 - 4 servings of milk, cheese, yogurt, custard, etc.*

## **Fats and sugars**

Fat is a good supply of energy and is essential for many of the body's functions. It is not a good idea to limit the intake of fat and cholesterol in children younger than 2 years because they get almost half their energy from fat and need it for growth and development. Children older than 2 years should have the same amount of fat as adults, which is no more than 30% of the total daily calories. Adding fat to a child's food can be a good way of adding calories to the diet and helping an underweight child to gain weight.

Saturated fats which come from animal sources (meat, eggs, milk, etc.) and coconut and palm oil are less healthy than fats from most plant sources, such as seeds, nuts and olive or canola oil.

Sugar is found in most sweets, cakes, desserts and fizzy drinks. Sugar is high in calories but its intake should be limited because:

- it does not contain any nutrients, therefore it provides 'empty calories';
- too much sugar in the diet can cause dental decay and weaken the immune system.

## Fluids

Fluids are an important part of a healthy diet and almost 70% of the human body is water. To maintain a healthy balance and for the body's organs to function properly, we need to drink enough fluids to prevent dehydration. Drinking enough water also helps the body to flush out toxins, which can be harmful to health.

Fluid intake is very important when your child has cancer and is receiving chemotherapy. Depending on age and size, your child should drink at least 1–2 litres of fluids per day while receiving chemotherapy drugs. When your child is vomiting or has diarrhoea, drinking enough fluids is important to prevent dehydration.



*Chef preparing dinner*

## Tips for parents

### When your child does not eat

Most of the common side effects of cancer treatment, such as nausea, vomiting, mouth sores, diarrhoea or constipation, poor appetite, altered sense of taste, dislike of hospital food, disruption of normal routines and fatigue, will inevitably affect your child's nutrition. At times, due to the side effects of treatment, your child will simply be unable to eat or will not feel like eating.

We understand that this situation may cause you, as parents, to worry about your child. However, try not to put pressure on your child to eat. This will only cause everybody more anxiety and unnecessary stress. Remember that children of all ages learn very quickly to manipulate worried parents by not eating.



- **Remember, your child's inability to eat at certain times is not a behavioural problem. Your child's eating pattern will return to normal eventually.**
- **Talk to your doctor and dietician about your concerns.**
- **Do not force your child to eat.**
- **Be patient with your child and give them lots of love and emotional support.**

On the days that your child is eating, try to make sure that everything they eat is high in calories and nourishment, to help make up for those periods when your child does not eat. As the basis of a balanced diet, include fish, meat, chicken, eggs, milk, cheese, fruit, vegetables, breads and cereals.

Here are a few examples of 'power packed' foods:

- soups and sauces made with milk instead of water;
- vegetables with added butter;
- whole-wheat bread with cheese or peanut butter and banana;
- fresh, canned or stewed dried fruit with custard.

Nutritional supplements can be useful when your child refuses food because they provide many nutrients in a small volume. Supplements usually come in the form of beverages that can be given as a snack or meal replacement, but they are also available as candy bars or puddings. *Do not give any supplements before discussing it with your doctor and dietician.*

### **Adapting to your child's changing tastes**

Children often develop food 'fads' during treatment for various reasons (see above). You may find that your child loves certain foods and absolutely hates others, even though they did not have such tastes before. Time carefully when you give your child their current favourite foods. If given on days of treatment or when your child is feeling nauseous, this may put your child off that food in future.

It may be better to offer small amounts of food regularly instead of three large meals at set times. Try to make mealtimes more fun by presenting the food in an appetising way on a neatly laid tray or table. Young children can sometimes be tempted with a colourful plate, glass or mug, and by food that is cut into fun shapes. Encourage friends and relatives to bring your child's favourite nourishing foods when they come to visit.

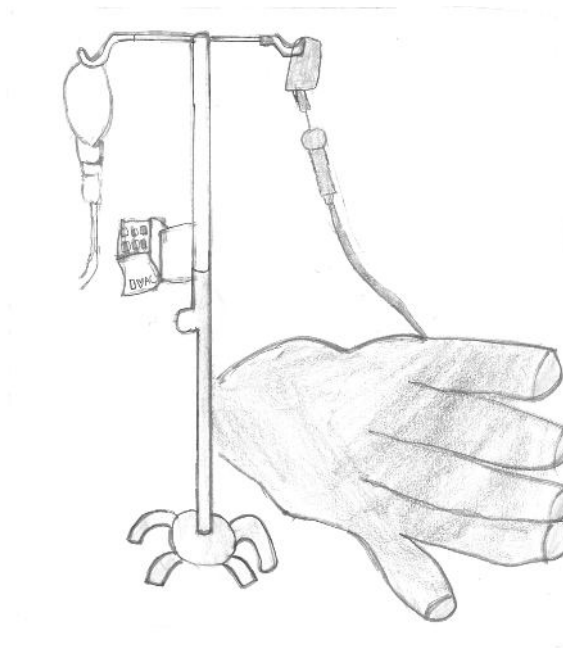
### **Tube feeding**

Some children may need a helping hand to maintain their nutritional status in the form of tube feeding. When a child is too ill to eat and drink sufficient daily amounts, they will start to lose weight and will have a poor nutritional status. This will make it even more difficult for your child to recover from the illness and build up strength. A child who is malnourished may also be unable to complete their cancer treatment since their body will be too weak to tolerate the treatment. The tube feeding will be stopped as soon as your child is able to eat normally again on their own.

Try to be positive about tube feeding because it is helping your child. Your child looks to you for support and if you have a positive attitude about it, they will too.



- **Your child's height and weight should be measured regularly and compared to standard growth charts.**
- **Your doctor should inform you if a certain drug or treatment will affect your child's growth.**
- **Never hesitate to speak to your doctor and dietician about your child's diet and nutrition. They are the best people to ask for advice and help if you have any worries or problems.**



*Getting an IV*

# Hospital and ward life

Most of your child's treatment will take place in hospital. Hospital stays can vary from several days to several weeks at a time. This will depend on: the type of cancer; the type of treatment; how your child responds to treatment; and your child's general condition. It is wise to be prepared for long stays in hospital and to make the necessary arrangements with your employer and for the care of family members at home. The ward and your child's room there will become like a second home to you for the duration of your child's illness and treatment. You will get to know the staff on the ward very well and they will become a valuable source of support for you and your family.

## **Ward facilities**

Facilities for parents vary from one hospital to another, but all wards welcome parents and are happy for them to spend as much time as possible with their child. Some hospitals may even provide facilities that allow one parent to stay and sleep with the child at night. If possible, it is recommended that a parent or care-giver stay with the child for the duration of admission. You will be given a tour of the ward where your child is treated and receive more information from the staff about the ward's routine, visiting hours and rules, etc.

Most of the children's oncology units in South Africa make every effort to provide a child-friendly environment, with colorful interior decorating of the wards and rooms, with toys, books, TV sets, video machines, games and other comforts to make your child's stay as comfortable as possible. You are welcome to bring any of your child's favourite toys, books or videos, etc. to the hospital with you. However, all toys must be fully washable to prevent the spread of infections.

Most oncology units have a small kitchenette in the ward for use by the parents. It is usually equipped with a kettle, toaster, microwave oven, fridge/freezer and basic cutlery and crockery. Some units also have a washing machine and tumble dryer for personal laundry.

## **Hospital stays**

You are welcome to stay with your child and participate in their normal day-to-day care as much as possible. This will not only help to lighten the burden of the nursing staff, giving them time to give proper medical care and attention to each patient, it will also make you feel useful and reassure your child. You may bathe and dress your child yourself, feed your child at mealtimes, take your child for walks around the ward or outside (if permitted), and accompany them to other departments for tests or treatments, such as the x-ray department.

Remember, knowledge is power! Learn as much as you can about your child's illness and its treatment because then you can play an active role in the treatment.

It is not necessary for your child to wear pyjamas all of the time. On days when your child feels well enough, your child can be dressed in normal day clothes. These should be comfortable and loose fitting, such as tracksuits or t-shirts and shorts or pants.

A sick child may become spoiled easily by too much attention and gifts showered on them by well-meaning parents, relatives and friends. Be careful not to forget about your other children – they need attention too. Make your relatives and friends aware of this fact.

### **Time for a break**

You will spend a lot of time in the hospital ward with your child, which can be very tiring and the stresses and strains of having a sick child will also take its toll on you. It is therefore very important that you take regular short breaks, for example, to visit the hospital cafeteria for a cup of tea or coffee, for a short walk in the fresh air, or to visit a nearby shopping centre where you can treat yourself with a visit to the hairdresser or just browse through the shops. A break from the hospital will often raise flagging spirits. Ask a friend or relative to stay with your child for a few hours and take your partner to lunch or a movie (or both!). At most of the units, volunteers also offer babysitting services, to give you a much needed break.

If you cannot stay with your child all the time because of work and family obligations, don't feel guilty about this. If possible, ask a friend or relative to stay with your child when you can't be there. Younger children especially may feel calmer and more relaxed if someone they know and trust is with them all the time.

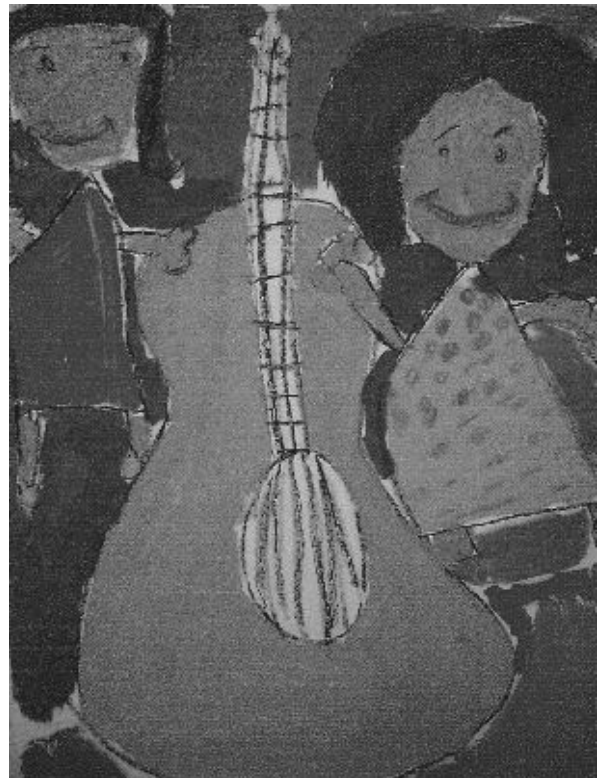
It is also quite normal for your child to get upset when you arrive or when you have to leave. Always say goodbye to your child before your leave, tell her where you are going and when you will be back. Don't just disappear as this will make her feel unsure and unsafe. Also tell the ward sister that you are leaving, where you can be contacted and what time to expect you back.

### **Visitors**

Family and friends are welcome to visit and visits from healthy school friends can be very good for a child's morale. Find out what the rules of the ward are regarding visitors and visiting hours.

You will need to inform all visitors that no sick persons or anybody with a fever will be allowed to visit your child either in hospital or at home. You have to protect your child from getting infections from other people, especially when their blood count is low and their immune system is not functioning properly. At such times your child will be particularly vulnerable to infections that could make them very ill.

Too many visitors at the same time may be tiring and frightening for a sick child. Ask family and friends to arrange a schedule for visiting among themselves, to avoid overcrowding at the hospital.



*It is important to take some time out to do some of the activities that you love*

## **CHOC volunteers**

CHOC volunteers visit the wards on a regular basis. Many of them are parents who have been in the situation you now face. They therefore understand your fears, anger, grief and all the many other emotions parents in your situation normally experience. CHOC volunteers are there to offer a helping hand through practical help, such as babysitting and moral support through listening to you with great empathy. The volunteers may not be trained counsellors but they are willing and understanding listeners.

## **CHOC houses**

In some of the provinces, CHOC provides special facilities where parents and siblings can stay free of charge. CHOC Houses are a 'home away from home' for the family of a child who is receiving cancer treatment. Your local treatment centre or CHOC division will be able to give you more information.

## **Useful articles to take for your stay in hospital**

Below is a list of articles that other parents and children have found useful during their long stays in hospital. Remember, it helps to make your stay more comfortable and 'homely', so feel free to change the list to suit your own needs.

- Cell phone, Telkom phone card or enough change for the public telephone.
- Notebook with the phone numbers of all your friends and family.
- Notebook and pen to write down all the questions you want to ask the doctor because it is easy to forget or not to think of something while the doctor is on their daily rounds.
- Own bedding, for example, your child's duvet and pillows.
- Towels.
- Comfortable loose-fitting clothes for your child.
- Your child's favourite games, books, videos and music, etc.
- A radio/CD/cassette player (earphones are a good idea).
- A portable TV and video machine (and TV games too if you like) if the ward does not provide these.
- Your child's favourite cup, glass and plate, to make mealtimes more fun.
- Coffee, tea, sugar, powdered milk, cup-a-soup, rusks, salty biscuits (e.g. Provitas) for a quick snack.
- You and your child's favourite snack foods.
- Something to keep yourself busy – books, magazines or handwork.
- Dishwashing liquid and dish towels.
- Washing powder and fabric softener if you are going to do your own laundry in the ward.
- Cleaning materials for cleaning the bathroom after use, such as Handy Andy, thick Jik, air freshener and a cloth.

## Chapter 11

# How to cope with your child's cancer

Most parents will turn to this section of the guide first. As parents who have been through the situation you now face, we understand that your greatest fears are probably that your child might die and that you will not be able to cope. We also know that eventually you will learn to cope and that you will get through this, because we have been able to do it before you. You are not alone!

When the doctor tells you that your child has cancer your whole world starts caving in. The first reaction is normally feelings of shock, disbelief, fear and numbness. "Why us?" is a common question, to which there is no answer. Feelings of guilt are also common. Parents wonder if they could have prevented the cancer. It is reassuring to know that nothing we did or did not do as parents caused our child's cancer.

You will have to cope with many changes in your life. You will experience very strong emotions, increase your knowledge in areas previously completely unknown to you, develop new skills, change your life plans, re-evaluate your goals and dreams, deal with a loss of control and learn to cope with many unknowns.

### Coping strategies for parents

No two families are the same. Each couple and their family will have to work out their own strategies for coping with cancer. Below are a few guidelines and suggestions that you might find helpful.

- Most parents find it is best to tell close relatives and friends the truth about their child's illness. If you do not tell the truth, you will have to maintain a lie for many months. It might also hurt their feelings if you deny them the opportunity to help and support you. The support of your relatives and friends will be invaluable and it will also be a relief to talk to them.
- Work together as a couple – share the burden on a practical level but also emotionally. You need one another and your child needs both of you.
- It is important that both parents fully understand all the implications of their child's disease and its treatment. Try to attend important discussions with the doctors together, if possible.



### Live one day at a time.

- Effective communication is vital! Talk to the doctors and hospital staff openly and ask them to explain until you understand, even if you have to ask over and over again. You may find it helpful to write down your questions in a notebook as they arise, because these questions are easily forgotten when you see the doctor.
- Always be truthful with your child and explain things in a way that is appropriate for your child's age and level of understanding. If your child understands what is happening they will be less anxious about what is going to happen next.

# How to cope with your child's cancer

- Try not to make your sick child the centre of your world. This will be hard, but try to stick to normal routines and family activities as much as possible, to keep the family secure.
- Take good care of yourself physically! This means adequate rest and sleep, a healthy diet, time to relax and regular exercise. This will lay a strong foundation that gives you the emotional strength to cope and the ability to be optimistic and hopeful.
- Respect your own needs and the needs of others. Learn to communicate your needs by expressing your thoughts, feelings and questions as openly, clearly and truthfully as possible, with your family, the medical staff, your social worker or other counsellors. It is important that you spend time by yourself, with your partner and with your other children.



**You can only give to others what you have received!  
Taking care of your physical and emotional needs helps you  
be a better caregiver.**

- Try to maintain a positive attitude, although there will be times when this is easier than others. Remember that your child looks to you for support and will also be positive and more relaxed when you are.
- Differentiate between things you can and cannot control. This will help you to be realistic in setting goals and solving problems.
- Ask for help from relatives, friends, hospital staff and any other persons willing to lend a helping hand. Don't try to cope all on your own. There are many people willing to help and support you in any way they can.
- Accept offers of help with household tasks or the care of other children.
- Talking to other parents and families who are going through the same experience and feel similar kinds of pain, fear and anxiety, can be very helpful to yourself, your child who has cancer and your other children.
- The unit your child is treated in may have the services of CHOC volunteers who visit the ward on a regular basis. Talk to them. They are often parents whose child has also had cancer. They have been where you are now and therefore they understand your fears, anger, grief and all the many other emotions parents in your situation normally experience. They may not be trained counsellors but they are willing and understanding listeners.



**Knowledge is Power!  
By learning all you can about your child's disease  
and its treatment, fear is eased, hope is heightened and  
you can play an active role in your child's treatment.**

## Coping strategies for siblings

Your sick child's siblings are also experiencing many feelings and emotions about the patient, the illness and the attention the sick child is receiving. It is quite normal for children to feel resentment and jealousy because they believe they are being neglected, even though they also feel sorry for the sick child.

# How to cope with your child's cancer

- Try to create an open atmosphere in the family, since it will be more likely that the whole family will understand and share the burden of the new situation.
  - Be honest and explain things in a way that is appropriate for your children's different ages and levels of understanding. It is always better for your children to hear the truth from you than from rumours going around. Ask for the help of a social worker if you are not sure how to explain the situation to your children.
  - Reassure your children that, whatever emotions and feelings they may experience, these reactions are normal. Give them your loving and understanding support.
  - Some children may bottle up their feelings because they do not want to burden their parents further. When this happens the child will become withdrawn and difficult. Spend time alone with each child and encourage them to talk about their feelings. Really listen before reacting and always reassure them of your love.
- Younger children may not be able to talk about their fears and feelings, but may express them by different or difficult behaviour. For example, the child may become withdrawn or may begin bed wetting again. Be gentle and loving and give them reassurance and a little extra time to adjust to the new circumstances.
  - Include your children in the illness and its treatment in any way possible. Children who feel needed will rise to the challenge of sharing in the new situation.
  - Think of ways to make things more cheerful around the house for everybody.
  - Contact the teachers of your sick child's siblings and inform them that there is cancer in the family. This may help the teachers to understand any behavioural changes at school and to deal with them sensitively. Refer your child to a social worker or psychologist for professional intervention, if necessary.



*Being with my brothers*

## Your spiritual needs

Many humans feel a spiritual need to be connected to a 'Power' or 'Being' greater than themselves. (For the purposes of this booklet, we will refer to this 'Power/Being' as God.) Many people who do not consider themselves religious and do not belong to a religion or actively take part in religious activities, may admit to being 'spiritual'.



**For most people, faith and spirituality play a major role in coping with cancer.**

In times of great difficulty (like the time you are experiencing now), it is normal to feel a greater need for a connection with God. Indeed, one of your first reactions might have been: "Why me God? Why did You let this happen?"

## A crisis of faith

It is not uncommon to experience a crisis of faith in times of grief. Faith is like a lens through which you view the world, including the cancer you now have to face. The grief you experience because of your child's cancer can also act as a lens through which you view the world. When faith and grief meet, a crisis of faith can often arise. For example, you may find it difficult to understand how a loving, caring God can inflict such pain and suffering on an 'innocent' child.

Many people through the ages have experienced similar crises of faith. One Jewish Rabbi, Harold S. Kushner, wrote a book about his struggle when his son was diagnosed with a terminal illness. This book is called *When bad things happen to good people* (see the suggested reading list below). Does Kushner have an answer for the "Why me, God?" question? Even this 'man of God' did not find an easy, simple answer but had to admit that God's ways are often beyond our comprehension; that we sometimes have to accept there are no simple answers or even no answer at all for some questions. However, Kushner's book and many other similar stories can give people hope in their relationship with God.

No matter how great your faith, you cannot go into the fight against cancer without feeling some sense of grief and despair. Your child is precious to you and yet you cannot protect them from the pain or suffering of their illness and its treatment. That is why you are grieving now. It will help you to learn what to expect in the months to come and begin to work through your grief. Taking control and deciding to actively do something will increase your sense of spiritual wellbeing and enable you to be a greater source of support for your child.



**Remember: You can only give what you have received!**

## Challenging 'spiritual myths'

In coming to terms with your child's cancer it is not uncommon to have thoughts that challenge your beliefs and your faith. We will call these thoughts 'spiritual myths'. Some common examples are listed below:

### Spiritual myths

1. God has chosen me, my child, my family to have cancer.
2. This cancer is punishment for a sin someone in our family has committed.
3. God has abandoned me and He does not hear my prayers.
4. It is wrong to feel anger towards God.
5. God will not give me more than I can handle.
6. If my faith were stronger I would not be grieving so deeply.
7. My child's cure depends on my faith; therefore I have to be strong.
8. If I had greater faith my child would not need medical treatment.

Sometimes these are not only thoughts in your head but comments from people trying to make you feel better. You should not try to dispel these thoughts but rather to understand them. Remember, they are a normal part of grief. Talking to a religious leader or a dear friend and reading relevant books can help in your search for understanding.

Below, we have shared some of our thoughts on each of the eight myths described above and hope you find these useful.

# How to cope with your child's cancer

## **1. God has chosen me, my child, my family to have cancer**

"Why me, God?" is a very common question in any grieving process. Since the beginning of time people have struggled with the question "Why does God allow suffering?" Many books have been written on the subject you may find reading some of them helpful, but the fact is that no one knows the answer. God's ways of thinking and acting are beyond our comprehension and we simply have to accept this fact. What we do know is that illness, suffering and tragedy have existed since the beginning of creation and are inevitably part of human life. So the answer to "Why me?" may simply be "Because you are human and you live in this world."

Living a good moral life does not shelter you from suffering and pain. However, God can be with you in your pain and suffering, to help make it bearable. Talk to Him about it, tell Him your feelings and your burden will become more manageable.

## **2. This cancer is punishment for a sin someone in our family has committed**

God does not look for people on whom to inflict pain and suffering as a punishment, and He certainly does not get some form of sadistic pleasure from your grief. God constantly offers love and forgiveness. Allow Him to love you and accept His forgiveness.

Please be aware that there is a certain danger in thinking of illness as a punishment for sins. This belief may cause you to dig up old issues and cause conflict and great pain in your family.

## **3. God has abandoned me and He does not hear my prayers**

This is a normal reaction to the shock of knowing that your child has cancer. It does not reflect a lack of faith or spirituality. God is with us always and He will never abandon you. He is with you and your family through this difficult time, regardless of what or how you may feel.

## **4. It is wrong to feel anger towards God**

Anger is a natural expression of grief and everybody feels it at some time in their lives. It is hard to avoid and you need not feel guilt or shame for being human. In the writings of most faiths are examples of people who were faithful followers of God but who raised questions and felt anger at the unfairness of life. It is okay to talk to God about your anger – He understands and still loves you. But you do have to deal with your anger and work through it, and this can be done with the help of a therapist or your religious leader.

## **5. God will not give me more than I can handle**

Often well-meaning people say this to make you feel better. The truth is that there will be times when you feel that the load you bear is too heavy to carry any further. A comment like this could therefore make you feel guilty at not being able to cope, or that you are failing or disappointing God. Please remember that it is normal under the circumstances to feel overwhelmed at times and that God did not give your child the illness or situation to see how much you can withstand. God is not asking you to prove your loyalty or faith to Him, or your ability to suffer adversity. God wants to help you carry your load and to lighten your burden, because He is a loving God.

## **6. If my faith were stronger I would not be grieving so deeply**

God is not asking you to prove your faith because He already knows what is in your heart. In your situation grief is normal and is impossible to ignore. Keeping all your grief inside will only cause greater pain and suffering for you. It will make you feel more alone and exhausted, because you will waste precious energy on hiding your feelings. Talk about your grief with someone you trust and talk about it to God. He understands and wants to help you work through it.

## 7. My child's cure depends on my faith, therefore I have to be strong

You must remember that you are only human. If you believe this myth, you will burden yourself with an impossible task.

Naturally you feel a responsibility to protect your child and will go to any lengths to do so. When your child was diagnosed with cancer you probably realised that you have limited control and are no longer able to protect them from pain, you can only participate in their healing. Do not be afraid to cry out to God in your most sincere prayers, hoping to receive relief and a cure for your child and your family. God will hear your prayers and He needs no persuasion because He desires only the best for His people.

All that faith requires from you is that you offer your child the emotional, physical and spiritual support they need, every day to the best of your abilities. Remember that you do not have control over everything in this world. Just do your best and leave the rest to God.

## 8. If I had greater faith my child would not need medical treatment



**Some religious groups have objections to some forms of medical treatment. If you have any religious objections to medical treatment you should discuss these with the doctor before treatment begins.**

Faith and medical science work very well together. You may find that an active spiritual life makes going through cancer treatment much easier and that receiving the best medical treatments for your child strengthens your faith (when you see how it helps your child's condition to improve).

Nourish your spiritual life through regular prayer, spending quiet time alone with God and reading and studying religious texts, books or other material. Try to attend religious services where possible. If this is difficult for you, you could listen to religious services and readings on the radio or a CD/tape, or you could watch services on the TV or video. If possible, talk regularly with people who share your religious faith.

### Suggested reading list

A few spiritually-enriching books are listed below, but you should also ask your religious leader for suggestions or visit your library.

- *When Bad Things Happen To Good People*, Harold S. Kushner
- *When God Doesn't Make Sense*, Dr. James Dobson
- *The Power of Suffering*, John MacArthur
- *Recovering from the Losses of Life*, H. Norman Wright
- *Man's Search for Meaning*, Victor Frankl
- *Tuesdays with Morrie*, Mitch Albom
- *Life Lessons*, Elizabeth Kubler-Ross & David Kessler
- *The Shack*, William P. Young
- *Where is God when it hurts?* Philip Yancey

# How will your child cope?

Your child's age and ability to understand what is happening will determine what you tell them and how they cope with the cancer and its treatment. We know it is hard to tell your child the truth about the illness and its treatment, but it is far better that you do this.



**It is very important that you are as honest as possible with your child at all times. Your child looks to you for support and has trusted you. Do not destroy that trust by lying to them.**

Children are individuals with their own personalities and therefore not all children respond in the same way to any given situation. You know and understand your child best and that makes you your child's greatest source of strength and support. If anything in your child's behaviour worries you, talk about it to the doctor and/or the child psychologist, play therapist or social worker.

You should explain the basic facts of the illness to your child in a way that they can understand. This will help them to understand that the treatment is necessary. Even a very young child will be able to understand an explanation about 'good cells' and 'bad cells', and that the treatment will kill the 'bad cells'. You can ask a child psychologist, play therapist or social worker for advice on how to talk to your child in a way best suited to their age.

Children of school age and teenagers may find it very helpful to talk to other children who have completed cancer treatment and their parents.



**Let your child know that nothing they or anybody else has said, done or thought has caused their cancer.**

We understand that you feel sorry for your child but resist the temptation to give in to their every whim and demand. Children who have to spend time in hospital are often difficult and demanding both in hospital and at home. Spoiling your child will only cause behavioural problems and make them unhappy and unpopular. It may be a good idea to ask relatives and friends not to bring your sick child too many gifts and to include any siblings when handing out gifts and attention.

Try to maintain the old discipline as much as possible. Every child needs limits to help maintain a sense of security and this also applies to your sick child. It is best for your child if you maintain a normal environment and

loving family, and apply normal house rules. This will prevent future problems with unhappy siblings and your sick child once they have recovered.

Helping your child cope with their feelings and emotions can be particularly difficult for you. No parent wants to see their child suffering and unhappy. You will be better able to help your child cope with these emotions if you understand your own feelings and are dealing with them in a positive way. Talking about your feelings to a therapist, a religious leader or a trusted friend or relative can be very helpful. A sympathetic ear will help you to deal with your emotions and relieve the tension and stress of what you are going through.



*Art can help children to express their feelings*

### **Toddlers and young children**

A very young child may not understand what is happening or why they have to go to hospital and have certain treatments. They may find it hard to cope with the situation, refuse to come to hospital and refuse to have a treatment that they find unpleasant. The doctors and hospital staff understand this situation well.

The best approach to this problem is loving firmness. Let your child know that they have to have the treatment in a firm, but loving and encouraging way, and do not get involved in long arguments about it.

### **Making treatments and hospital stays easier**

- Bringing a favourite toy, blanket or other prized possession to hospital may be just the moral support your child needs. It may even help if Teddy or Dolly gets the injection (or test) first, because sharing unpleasant experiences can be comforting.
- Try to distract your child by talking about things that really interest them. You can give medical staff cues – they will quickly pick up on these and help to distract your child's attention. Stay with your child and hold their hand or touch them in some way and encourage them all the time. As soon as it is practically possible, cuddle your child and praise them for their brave effort. Tell your child how wonderful they are, how proud you are of them and how much you love them.
- Even though we advise against spoiling a child, we do believe in rewarding bravery. A treat at the end of a treatment will give your child something to look forward to. It can be something really simple like reading a favourite story, watching a favourite video together (don't forget the popcorn!) or playing a special game.

## How will your child cope?

- Try to make hospital stays easier by bringing, from home, some favourite toys, games and books and a favourite blanket or duvet. Younger children may also find hospital stays easier if someone they know and trust stays with them all the time. If possible, arrange with a relative or friend to stay with your child when you or your partner cannot be with them.

### **Handling the effects of treatment**

Young children may not always be able to talk about their feelings and fears, but you will notice changes in their behaviour and moods. They may become withdrawn, revert to baby-like or childish behaviour, behave differently or become difficult or start bed-wetting after recently being potty trained. What they need from you is a little time to adjust and lots of patience, love, understanding and reassurance.

Young children may benefit from play therapy to help them cope with everything that is happening to them. Ask your social worker, doctor or psychologist to recommend a suitable therapist if the hospital does not have a play therapist on staff.

Usually young children are not really bothered by hair loss but it is best to gently tell your child that they will probably lose their hair. If your child has very long hair, it may be best to cut it shorter before it starts falling out. Most young children find wigs uncomfortable and prefer to wear hats, baseball caps, knitted caps or leave their heads uncovered. What is important is that your child feels comfortable and happy. It can be helpful to prepare your child for the stares and comments they may encounter in public, and to encourage them to talk about their experiences with their friends.

If your child has been given permission by their doctor to mix with other children and to return to school, encourage them to do so. Your child will benefit from the social interaction and the feeling that they are still like other children.

### **Older children and teenagers**

Older children and especially teenagers face particular difficulties and stresses when they are diagnosed with cancer and while going through treatment. Teenagers are in a stage of their development where they are longing for independence and are trying to find their own place in the world. They may find it very difficult to reconcile this with the increased dependence and lack of privacy they experience as a result of their illness.

Once again, it is very important to be honest and explain to your child about their illness and treatment in a way that is appropriate for their age. Never lie to your child or tell half-truths. Answer their questions truthfully and allow them to share their feelings openly. Also involve your child in decision making whenever possible.

Encourage your child to talk about their feelings and fears and really listen to them before you say anything. Sometimes children will hold back because they do not want to cause their parents more pain and anguish. Let your child know that they do not have to 'spare' you but also don't be afraid to show your own emotions. Your child may be better able to cope with their own feelings if they see that you also experience similar feelings and are not afraid to show them.

In other words, you don't have to hide in the bathroom every time you want to cry, but it is also not wise to share every worry and fear in detail with your child. You know your child and what they can handle; let that and your child's age and level of understanding, be your guide.



**Remember: understand your own feelings and emotions and get them under control, then you can better help your child deal with their feelings and emotions.**

If it is too hard for your child to talk openly with you, it may be wise to get a therapist or social worker to talk with them, someone they can trust and feel safe with. It can also be very helpful for your child to talk with other patients and children who have finished treatment. Seeing and talking to children who are experiencing similar pain and fears can help your child to feel that they are not alone.

Coping with physical changes such as hair loss, weight gain or loss or losing a limb through amputation, can be devastating for children. Your child may react in a number of ways: withdrawing, becoming depressed, or becoming very hostile and aggressive. The help of a therapist or psychologist may be needed to help your child deal with these difficult issues.

Remember, it takes time to come to terms with any loss. All you can do is be there for your child encourage them to talk, listen to them, be loving, caring and keep reassuring them of your love and support. You will have to be very patient and give them all the time they may need.

### **Your child's spiritual needs**

Even though children may not be aware of themselves as spiritual beings, they still have spiritual needs. The younger the child, the more it is the parent's responsibility to take care of these needs and to prepare the way for the child. To do this you have to take care of your own spiritual needs first and develop a clear sense of the elements on which your spiritual life is built.

If your child is very young, you can read stories and sing songs to them which carry a spiritual message. Concentrate on stories telling of how much God loves us and cares for us every day.

It is important to pray with your child, and you could do this out loud together every day. In your prayers ask God to heal your child and to keep them safe. When your child hears you talking to God in a natural way, telling Him of your day-to-day needs, they will learn to trust in Him in the same way as you do. Let your child pray their own prayer but do not force them or make them feel guilty if they do not want to pray out loud.

It may be more difficult dealing with the spiritual needs of older children and especially teenagers. Outwardly they may not want to participate in prayers nor listen to readings. Do not let this stop you reading from a religious text and praying aloud with them, since it could be a source of spiritual strength for them even if they do not admit this to you. You could also get your child some spiritual books or other reading material suitable for their age. Reading these might help to strengthen their faith and offer answers to some of their questions.

Teenagers may struggle with the same questions that you have. The sections on *Your spiritual needs* and *spiritual myths* may give you some guidelines on how to answer your child's questions on matters of faith.

Once again, be as truthful as possible and don't be afraid to admit that you do not have all the answers. You can ask your religious leader for help or, if your child is a member of a religious youth group, you can ask the leaders of the group for help and support.

# Going home

### Going home between treatments

Most parents fear going home for the first time after a lengthy stay in the hospital. Parents often feel safe in the hospital where they are surrounded by professionals who know exactly how to take care of their sick child.

Most parents feel unsure about their own ability to cope with their sick child at home. However, you can take comfort in the fact that the doctor will not discharge your child if he is not sure that you and your child will be able to cope at home.

- You will be allowed to go home after a treatment as soon as the doctor is satisfied with your child's overall conditions.
- If your child has a central line, you will be shown by the doctor and nursing staff in the ward how to clean and take care of the line while you are at home. You will be given the necessary sterile packs and everything that is needed to clean the line at home. Make sure you have written step-by-step instructions telling you how to clean the line. Some units in South Africa have a video demonstrating the whole process available for you to take home.
- If your child has to take medication at home, make sure you have enough of it or a prescription from your child's doctor.
- Also make sure you know: how the medication should be taken (e.g. orally or injection); the correct dosage; how often; before or after meals; how the medication must be stored (for example in the fridge); or any other special precautions you need to take.
- Do not give any medications or other treatment without first consulting the child's doctor at the treatment centre!
- Your GP must also be informed about your child's condition and treatment, so that he can assist you appropriately when necessary. You can ask your child's doctor to write a short report to your GP. This is very important if you live in another town far from the treatment unit. Now you will also see the value of your own knowledge. The more you know and understand about your child's illness and treatment, the more confident you will feel in taking care of your child at home.
- Most children will be allowed to continue with most of their normal daily activities. However you should avoid places with crowds, such as cinemas or shopping malls.
- If you feel unsure about anything, check with your doctor, because activities like contact sports may not be allowed.
- It is important for the whole family to keep things at home as normal as possible. Continue with your normal family routines and activities as far as possible. These give a much needed sense of security to your sick child and your other children and keep the family secure.

- The treatment centre will advise you when the child can return to school. The school must also be informed about your child's condition.
- Your child should not be given any immunisations while on treatment for cancer.
- See chapter 14 for more details about school and infectious diseases.
- Make sure you have the contact numbers for the doctor, the ward and the oncology clinic, so that you can contact them if you have questions or feel unsure about anything.
- Please feel free to contact your child's doctor, the ward or the clinic anytime you have a problem.
- If you are using, or plan to use, any homeopathic or alternative medicines or treatments for your child, you must discuss this with your treatment centre before going home.

### **When to contact the doctor**

Contact your doctor immediately if:

- your child shows any of the symptoms as described on page 29 under the heading 'Neutropenia';
- any persistent vomiting / nausea or any other symptom (complaint) that you cannot explain occurs;
- your child comes into contact with any children with a childhood disease such as chicken pox, measles, mumps, etc;
- your child is put on any medication by another doctor for whatever reason.

If you are unsure as to whether you should contact the doctor, then you should do so. How to contact the doctor will depend on the treatment centre, so make sure you know how to do this before you go home.



*Getting back to normal*

# School: infectious disease, vaccinations and inoculations

## School

CHOC has a *Back to School Pack*, which is a guide to teachers offering information about the child's illness, how to support the child and what to tell other pupils. Ask your CHOC volunteer for a copy and visit the child's school as soon as possible to discuss the situation with the teacher(s).

Your child should continue to attend school as much as possible if their physical condition allows for it. The teachers should be made fully aware of your child's condition and the possible side effects of treatment, such as hair loss, lack of energy and stamina, weight loss or weight gain etc. If your child has a central venous line, their teachers also need to know about it and how it may affect your child's ability to participate in certain activities, such as sport. Most schools are very understanding and will do everything possible to support your child.

If your child does not have the stamina or energy to attend a full day of school, special arrangements can be made for them to attend for a half-day. To help your child keep up with their school work, you will need to work closely with your child's principal and class teachers. The teachers should be willing to help by giving you the planned programme of school work and the necessary study materials and notes. You can also arrange for private tutoring or home schooling if necessary, as and when your child's condition requires.

Most importantly, support and encourage your child as much as you can without putting them under unnecessary pressure. Remember, they have enough to cope with without feeling that you are worried because they are missing school. Repeating a school year is not the end of the world; your child's health and happiness is far more important.

## Infectious diseases

### Chickenpox and measles

These are potentially life-threatening diseases for a child with cancer because chemotherapy and radiation therapy lower the child's immunity. Contact with chickenpox (or shingles) and measles should therefore be avoided at all costs both during treatment and for 6 – 12 months after treatment has ended.



**Ask the teacher(s) to tell you immediately if there is a case of chickenpox or measles in your child's school. Parents of children in your child's class should also be informed of the risk to your child's health.**

## School: infectious diseases, vaccinations and inoculations

If your child is exposed to either of these diseases you must inform your doctor immediately. Do not take your child to the doctor's office, the clinic or the hospital because this will put the other cancer patients at risk too.

Exposure means that your child has spent an hour or more in the same room with someone who is contagious. Chickenpox is contagious from 24 to 36 hours before the first spots appear and remains so until all the spots have disappeared (usually after several days).

- If your child was exposed to chickenpox or shingles an injection of Varicella/Zoster Immune Globulin (VIG) can prevent your child from developing chickenpox, but it must be given within 96 hours (4 days) of exposure. If your child does develop chickenpox while on cancer treatment, it will probably be necessary to treat it with an anti-viral agent.
- If your child was exposed to measles, an injection of antibodies may be given to reduce the risk of their developing measles.

It is best for your child to avoid all contact with children who have a fever or any other visible signs of infections or illness.

### Vaccinations and inoculations

Make sure that all your children have had their vaccinations. It is important to check with your GP or nurse at the clinic that all your children have had MMR (Measles, Mumps, Rubella) and the other normal childhood vaccinations.

Children on chemotherapy cannot be given live vaccines like polio vaccine, B.C.G. and MMR while they are on treatment and for about a year after treatment. Diphtheria and tetanus may be given. Always check with your child's oncologist if you are unsure.

If your child's normal vaccination schedule has been disrupted by the cancer, wait at least 12 months after cancer treatment is finished to continue with their vaccinations. It is not necessary to start the vaccination schedule all over again; it can simply be resumed from the point where it was interrupted.

Children who have had a bone marrow transplant should be evaluated individually before deciding to continue with vaccinations.



**Speak to your child's oncologist and your GP before giving any vaccinations to a child who has or had cancer.**

# After-cancer therapy

Completing cancer therapy is an important milestone in the life of any child with cancer and their family. As their parent, you may feel enormous relief emotionally and psychologically. The end of treatment also offers the promise of the end of the physical problems related to cancer treatment.



**Having a child with cancer and going through cancer treatment with them is a life-changing event that will impose a new reality on you and your family.**

Getting back to living life the way it was before cancer is not something that simply happens over night. Change of any kind is stressful, so be prepared: it takes time, patience and even some work. It is also true that some things will never be the same again perhaps because the experience has changed your whole outlook on life and what you consider important.

### Emotional and psychological reactions

- Your first reaction might be joy and relief when the treatment is finally over.
- You may be surprised to find that you actually miss the support of the staff on the ward, the doctors and the other parents.
- Quite often it is only at this stage that the full enormity of what has happened really hits you.
- The most common fear parents experience is that the cancer will come back now that it is not being actively treated. This fear will eventually lessen as time goes on and your child's health continues to improve.

Over the months of your child's treatment, you have become accustomed to a hectic routine and way of life that was centered on the sick child. Easing back into a quieter, less demanding routine will take a while. You no longer need to plan your life around treatment schedules and time spent in hospital. You can begin to plan a more regular schedule and the amount of time spent at home, at work, at school and in leisure activities instead of at hospital, can increase.

For many months your sick child was the centre of the whole family's attention. Now you consciously need to ease out of this level of attention and shift your focus to your other children and the family as a whole again. This may be a good time to reaffirm your relationship with your other children.

You will have to be patient with yourself and all members of your family – it will take time to get back to a regular routine but eventually it will happen. Even though you have gone through the experience together, every member of your family experienced it in their own way. It is important that you talk about this with them and really listen to each other. If you find this transition difficult to cope with, seek counselling for yourself and your family.

### Physical care

About 4 – 6 weeks after their last treatment, your child will undergo a series of tests to make sure there is no trace of cancer in their body. After this your child will return to the clinic as an out-patient for regular check-ups, which will become less and less frequent as time goes on. Your doctor will discuss the schedule for check-ups with you in detail. If your child has a central venous line, it will usually be removed 1 – 2 months after their last treatment. Your doctor will also discuss this with you.

It is important to explain to your child's school principal and teachers, and your employer, the planned schedule for your child's medical follow-up. You will also have to explain your need for ongoing emotional support to your family and friends, because they will probably not be aware of your needs.

It is possible that your child's blood count will remain below normal for some time after treatment has finished. The degree of this will vary depending on the type of cancer and treatment that your child has had. Remember that low white cell counts mean that your child's immune system is not strong enough to fight infections. In this case you will need to take the necessary steps to protect them from exposure to anybody with a fever, signs of a cold or flu, or any other contagious illnesses. Contact with chickenpox (or shingles) and measles should be avoided for 6 – 12 months after treatment has ended (see notes on infectious diseases on pages 59 - 60).

As your child gets stronger and their general health improves, they will want to return to their old activities and sports, or try new ones. It is a good idea to first discuss all planned activities with your child's oncologist. Also make sure that their teachers are aware of your child's medical history.

If your child is injured and has to go to casualty or receive emergency care, always mention their medical history to the doctors and medical staff. Also make sure that your GP, dentist and any doctor your child visits, are aware of your child's medical history.

### Skin cancer awareness

Although skin cancers are not specifically a childhood cancer, they do occasionally occur in children and there are general dangers to children who are over-exposed to the sun.

**Malignant melanoma:** There is an increased risk if there is a family history of melanoma, a large number of dysplastic moles (flat dark moles) or previous primary melanoma. General risk factors include a very fair skin which never tans and episodes of severe sunburn. Although there are no set rules on when and how to monitor there have been known cases of malignant melanoma in children as young as 10 years. If there are increased risk factors then one should probably monitor yearly from the age of 10 years.

**Danger to cancer patients:** When a person has chemotherapy, the immune system weakens. This causes the normal surveillance cells in the skin to be decreased in numbers and function. If there are cells damaged by sunburn with abnormal precancerous changes, then these are allowed to flourish while the immune system is depressed. Skin cancers such as malignant melanoma can then grow. The best treatment is prevention. Sunblock and sun avoidance helps to decrease damage to the skin and subsequent cancers of the skin. "From 11 to 3, stay under a tree."

# Financial matters

The diagnosis of cancer in a child is likely to have a dramatic impact on your family's finances. Medical care today is extremely expensive and the costs of treatment continue to rise. Even if you are a member of a medical aid or insurance scheme, it is likely that they will not cover all the costs of your child's treatment. Money matters can be easily neglected because parents spend all their time and energy on caring for their sick child. It is a good idea if one of the child's parents takes control of the family's finances right from the start and keeps proper records of expenditure.

### The 'hidden costs' of treatment

There are many 'hidden costs' of treatment, which you might not think of initially. The following are a few examples.

- Travelling to a hospital far from your home, which includes the costs of petrol and wear and tear on your car, or paying for public transport.
- The value of your car may decrease drastically due to high mileage when you have to drive far (and often) to the hospital.
- Accommodation and meals for parents while the child is in hospital.
- Needing to make more telephone calls than usual you may find that a mobile or cell phone suddenly becomes a necessity.
- Nappies – a sick child will use more nappies, for example, when they have diarrhoea.
- The special dietary needs of your sick child.
- You may need to take unpaid leave at work when your regular leave is used up by long periods of hospitalisation.

Though your medical aid might pay for most of your child's treatment and hospitalisation, it will not cover any of these 'hidden costs'. You will be amazed at how quickly money disappears when you have a sick child, don't let this catch you unaware.

### Record keeping

It is very important to keep proper records of all medical expenses and hidden costs, right from the start. Even though this calls for some effort and time, it will be worth your while because it will help you to keep your finances under control. Either you or your partner should decide to take on this responsibility.

Keep a separate folder in which you file:

- all medical bills and statements;
- details of payments made;
- records of hidden costs (see above);
- any other receipts and cash slips for expenses regarding your child's illness.

Proper record keeping will ensure that your bills get paid in time. Your child's wellbeing depends on medical service providers, so you do not want to compromise your child's treatment by not paying bills on time and getting involved in legal proceedings. If you have financial difficulties or cash flow problems, talk to the service provider involved in your child's treatment and try to come to an agreement about payments of account. You could also ask your child's doctor for a letter explaining your child's condition, if this will help the service provider to better understand your situation. If you talk openly to the service provider and explain your situation, you may find that most institutions are quite understanding and willing to help in any way they can.

### **Income tax claims**

Costs not covered by your medical aid could be deducted from your income tax; however, you will need proper records and proof of these expenses. You will need to motivate every claim with full explanations and proof provided in the form of account statements, receipts, cash slips and letters from doctors, etc. If you want to claim transport costs, keep all petrol slips or other receipts and confirm journeys made with letters from doctors and the hospital to prove dates. There are people at the Receiver of Revenue's offices who will be able to help and advise you in this regard. If you are not registered for income tax, you can still claim medical expenses by completing an IB 12SE form. This form is available at the Receiver of Revenue's offices. It is important to attach all medical bills and receipts when claiming.

### **Your medical aid**

If you are a member of a medical aid you will need to notify your medical aid/insurance company as soon as you receive your child's diagnosis. Most medical aid providers will have a representative who will come and visit you in the hospital soon after your child's first admission. They may be able to give you advice on how to handle claims. This visit may also be a very good time to familiarise yourself with the rules and claim procedures of your medical aid. You must know exactly what benefits you have and what medical aid you will be paid and when.

Most medical aid companies require that you get special authorisation from them for hospitalisation and certain procedures, such as MRI or CAT scans and surgery. Make sure that you are given an authorisation number, which will need to appear on all relevant statements and bills sent to the medical aid provider. This will ensure that the claiming procedure runs smoothly, without unnecessary delays or misunderstandings. Make sure that you keep a copy of every medical bill and record of payment. Then you will know exactly how much you are responsible for paying and can do your financial planning accordingly. You should know exactly when you will not have any benefits left under the medical aid and have to pay everything yourself.

Medical aid providers have strict rules regarding benefits but it is possible to get extra benefits (ex gratia) in special circumstances. It may be worth asking your medical aid representative for extra benefits to cover your child's treatment costs. It is important to get all the financial help you can get, so don't let pride or fear stand in your way.

### **State and university hospitals**

Usually medical services at these hospitals are much cheaper than at private hospitals because the state subsidises most of the costs. In fact, many Paediatric Oncologists in South Africa work at Children's Oncology Treatment Units in these hospitals, providing excellent medical care to the highest standards. No child will be refused treatment because their parents cannot pay. At these hospitals all children with cancer will receive only the best medical care available. Discuss your financial position with your child's oncologist and the social worker at the hospital. They will be able to advise you on how to handle any financial problems with regard to your child's treatment.

# CHOC and other sources of support

### **About CHOC Childhood Cancer Foundation South Africa**

CHOC is an organisation started and run by parents who have had a child diagnosed with cancer or a life-threatening blood disorder. It began in 1979 with a group of parents in Johannesburg and in 2000 became a country-wide organisation, with parent groups now functioning in Pretoria, Free State, Western Cape, Eastern Cape, Kwa-Zulu Natal, as well as in Johannesburg.

CHOC's primary aim is to provide a wide range of support for both the children and their families, throughout the long period of treatment. The areas of this support are described in more detail below.

In addition, we have found that it is necessary to address other areas which improve the treatment and care of the children and to try to ensure that all children in the country are diagnosed and treated effectively.

### **Support programmes of CHOC**

A very important part of our support is in the psychosocial area – to assist parents and families to cope with the many new demands on the whole family and to provide relevant information to assist them. This support is provided by: other parents, social workers, social auxiliary workers and groups of dedicated volunteers.

Successful treatment of the children requires that they come into the specialised treatment centres many times over a period of up to three or more years. For many families, this obviously imposes a large financial burden. An important part of our support is funding for transport, to ensure that children are brought back on schedule for the whole of the course of treatment and that the programme is not abandoned because of family financial constraints.

Any hospital is a daunting place and especially so for children. CHOC has helped to make the clinics more 'child friendly' places, by the provision of: decorations, curtains, duvets, etc; furniture and laundry facilities; and TVs, toys and games.

One of CHOC's most visible support programmes are their CHOC Houses. See the section below for more details.

Because budgets at tertiary hospitals are often under considerable pressure, not all of the medical equipment is readily available in the ideal quantities. To supplement this, CHOC has provided much-needed medical equipment to specialised treatment centres.

To ensure that specialised medical expertise in childhood cancer is maintained, CHOC supports doctors and nurses to attend conferences and training courses.

## CHOC Houses

CHOC runs several houses for parents and children from out of town to stay at, when the child is in the clinic for treatment. These have proved to be a very valuable service to the families and take a great deal of the strain off parents who have to travel long distances to bring their child for treatment.

### All of the houses provide accommodation and meals for caregivers and children

These houses are attached to the childhood cancer treatment centres in the following hospitals:

Charlotte Maxeke Johannesburg Academic; Chris Hani Baragwanath (Soweto); Universitas (Bloemfontein); Tygerberg (Cape Town); Red Cross (Cape Town); Nkosi Albert Luthuli (Durban); Frere (East London) and Steve Biko Pretoria Academic.

There are various rules for who may stay at the houses, which are:

- Only doctors from the treatment centre (or their designated social worker) may request accommodation for a newly diagnosed family.
- The admission of the child to a CHOC House for a specific period shall be recommended by the staff at the treatment centre for the times when the child is required to attend the centre for more than one consecutive day.
- Normally only one caregiver will be allowed to stay with the child.
- No child may stay at the house without a caregiver and the care of the child shall at all times be the responsibility of the caregiver.
- The child and parents must live permanently outside of a 50km radius of the treatment centre.
- Any stay at the house is subject to the signing of acceptance of the rules of the house. All guests at the house are expected to behave with consideration for the other occupants and for CHOC property.

Directions to the CHOC Houses are available at the treatment centres and also on the CHOC website ([www.choc.org.za](http://www.choc.org.za)).

Families will be advised of all the rules when they are at the treatment centre.

## How to contact CHOC

CHOC has a presence in all of the main treatment centres in South Africa and you will probably have met some of the volunteers or parents who visit the wards. Please feel free to contact your local CHOC office; their details are on the back cover of this guide.

## Other organisations

There are other organisations who work closely with CHOC, to provide different types of support for children and families. These include:

- **Reach for a Dream:** they aim to make the lives of children with any life-threatening illness better, by fulfilling a dream that the child has, whether this is meeting a celebrity, going on an outing or sponsoring something special that the child really wants.
- **Just Footprints / Camp Quality:** they run camps for children with life-threatening illnesses, to give the child a chance to experience time away from their normal environment, to have fun and to help to rebuild their confidence.

Both of these organisations have close relationships with many of the treatment centres, but ask your local CHOC office if you want to contact them.

Families have found many other organisations that support them, often within their local community, including woman's groups, churches and other religious groups.

Service organisations such as Rotary, Round Table, and Lions can also be of assistance at times.

### Information available elsewhere, and on the internet

There are many sources of information about childhood cancer available, if you want to delve more deeply into things. Some of this is in medical books, but the internet is probably the most accessible to the majority of people.

You should be aware that, apart from accurate and reliable information, there is also a lot of rubbish on the internet and some of it can be positively dangerous to the health of your child.

Remember that your child's doctor understands your child's specific case and therefore he/she is still in the best position to answer all your questions about your child's disease.

## Very important

Always discuss all information and possible treatments with your child's doctor first.

You may want to visit some of the websites listed below.

1. CHOC's website: **[www.choc.org.za](http://www.choc.org.za)**
2. Campaigning for Cancer: this SA site gives general information related to cancer (not specifically childhood cancer) and has relevant information, especially related to personal advocacy **[www.cancerhelp.co.za](http://www.cancerhelp.co.za)**.
3. International Confederation of Childhood Cancer Parent Organisations: **[www.icccpo.org](http://www.icccpo.org)**
4. International Society of Paediatric Oncology (SIOP): **[www.siop.nl](http://www.siop.nl)** – Click on “The Links” for a large number of links to other cancer-related sites
5. Families of Children with Cancer: **[www.fcco.org](http://www.fcco.org)** – Click on “Resources”, you will find a large number of links to other cancer related sites
6. Children's Cancer Web: **[www.cancerindex.org](http://www.cancerindex.org)**
7. Paediatric Oncology Resource Centre: **[www.acor.org](http://www.acor.org)**
8. United Kingdom Children's Cancer Study Group: **[www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)**

# Should/if cancer comes back – relapse

Recurrence (relapse) of cancer is the reappearance of cancer at the same site, near the initial site or in other parts of the body. This can occur during treatment or after what was believed to be successful treatment of the cancer.

Finding out that the cancer has come back may come as a great shock to you and your child, especially when you believed that the cancer was cured. You may begin to doubt that a permanent cure is possible and you (and your child) may experience great fear that your child might die. Children will remember the hard times they had to go through while receiving treatment before and may be very scared about having treatment again. Even you, as parents may become very upset at the thought of going through all the pain and grief again.

It is natural to go through many of the emotions you had when you first learnt that your child had cancer. You and your child may also go through the whole process of grief all over again. What makes it particularly difficult with a relapse is the fact that you know what is ahead and how hard it can be. As a family you may have adapted to a certain routine and lifestyle in order to cope and a relapse changes it all again. It is normal to become overprotective of your sick child and to want to protect him/her against pain, discomfort, worry and anything that can be upsetting.

In a study done at a children's oncology hospital in the USA, 50 parents of children aged 5 to 21 years were interviewed about how they coped with their child's relapse. A large group of children, between 10 and 21 years of age, were interviewed separately. The comments in this chapter are largely based on the answers of these parents and children, as well as on our experiences as CHOC volunteers in hospitals all over South Africa, in helping parents cope.

## **How parents react**

- The first reaction many parents experience when hearing that their child has relapsed is shock and an overwhelming feeling of despair. These emotional reactions may be much stronger than your reaction when the cancer was diagnosed the first time.
- Parents who can overcome the initial shock and despair may be better able to make wise decisions about their child's treatment.
- Knowing what lies ahead sometimes makes going through it so much harder. You may find it more difficult to be, and stay, positive because your expectations of a cure for your child have been taken away by the relapse.
- Parents fear the impact the relapse will have on their family life, work and finances. You could fear the loss of a normal family life and the effect it may have on other family members and your relationships. These fears are mostly based on previous experiences during the first diagnosis and treatment.

## Should/if cancer comes back – relapse

- You may experience a feeling that everything in life is different now that your child's cancer has returned. These differences include changes in relationships with family members, friends and your sick child. Many parents may seek to be emotionally close to their sick child, but are sad and shocked when there is an emotional distance.
- You may experience a profound sense of isolation and distance from everybody around you including family and close friends.
- Most parents feel that other people, including health care providers, interact differently with them after the relapse than before. You may feel that people are uncomfortable in your and your child's presence and do not know how to react.
- Assessing or monitoring the seriousness of the relapse and its impact on your child, both physically and emotionally, may be a longer-lasting reaction. Parents may spend a lot of time and effort getting as much medical information as possible on their child's condition and all possible treatment options.
- Most parents, at some point of treatment after a relapse, have thoughts of ending all treatment and efforts to find a cure for their child's cancer. You might be afraid that the treatment may be too hard on your child. You may feel that you are only willing to fight to a certain point, as yet unknown, but dread the possibility that some time soon you may have to make a decision to stop treatment. A decision that no parent wants to make.
- Many parents experience very uncomfortable, but very natural, thoughts about the cure of their child and the death of their child. One part of you may be fighting hard for your child's cure, while another part of you is 'preparing for loss'. You may feel that you have to prepare yourself 'for the worst' in some way because you don't want to be taken by surprise by your child's death and not be able to cope with it.

### How parents cope

#### Coping with the initial shock and despair

- In most cases the initial shock reaction does not last long. Most parents soon realise that they cannot 'give up' and force themselves out of the shock. Throwing all their efforts into seeking treatment options often helps parents overcome the initial shock.
- Discuss possible treatment options with your child's doctor. If there is an available treatment option, you may find it easier to overcome the shock and panic.
- Once again, learn all you can about your child's illness and treatment by talking to the doctor and other health professionals.



**Knowledge is power. By learning all you can about the disease and treatment fear is eased, hope is heightened and you can play an active role in your child's treatment.**

### **Coping with feelings of isolation, emotional distance and being different from others**

To overcome feelings of isolation and emotional distance you can take three very important steps:

- First: Work harder at and put more effort into your relationships.
- Second: Directly approach health care providers and other people and seek interaction. Most people, even health care providers and close family members and friends, feel sad for you and your child; but they may feel awkward and not know what to say or how to react to your situation. By directly approaching people you can help them feel more at ease.
- Third: Reach out and try to stay involved with others who are going through a similar experience. Talking with other parents and children may help you feel less isolated, distant and different.

### **Coping with medical information about the child's condition and possible treatment options**

#### **The 'selective awareness' approach**

Some parents are very selective (choosy) in their approach to treatment options, choosing only to hear medical information that they want to hear. These parents do not refuse to believe medical information, they simply choose to listen to some information more than other information. When talking to the doctor they will let him/her know that they do not want to hear all the details, just the important facts. By doing this parents can avoid being given potentially negative information and hearing about distressing situations which may force them to face their deepest fears and emotions.

Parents following this approach prefer to interact with parents and patients who are responding well to treatment and are well on their way to recovery. They usually avoid parents whose child is quite ill or has also had a relapse.

This approach does have its benefits. It may help you to be more positive about the situation and the outcome of your child's relapse. It may also make it easier for you to avoid being overwhelmed by your own fears about your child's disease.

#### **The 'watchful and wary' approach**

Other parents are what we call 'watchful and wary'. This means keeping a close eye on the treatment the child receives and the child's response to the treatment. Parents using this approach spend a lot of time looking for medical information and making sure their child receives the best medical care available. They want to ensure the best possible treatment outcome. For example, a 'watchful and wary' parent may question medication dosages, recalculate IV rates and request copies of every test result and laboratory analysis because they want to be certain of accuracy.

This approach may help you to feel in control. Having some control in certain areas is a helpful way of coping.

# Should/if cancer comes back – relapse

## Remember

- Regardless of which approach you choose to follow, you have to tell the members of the health care team which style of monitoring you prefer. You may also find it easier to cope if you allow your physician to give you honest feedback during treatment.
- You may find the whole process of 'keeping an eye' on your child's condition and treatment very tiring and emotionally draining. It is very important to take a break from the treatment situation, seek social interaction with friends and have brief periods free from the responsibility. This will give you time to recover from the emotional and physical tiredness and help to renew your energy.

## How children and teenagers react and cope

The comments below are based on interviews with youngsters between 10 and 20 years. Although members of this age group usually react to their cancer relapse differently from their parents, some of the reactions may be quite similar to your own.

- The first reaction usually is shock and disappointment and they are scared about starting all over with treatment, especially after they believed that it was all over.
- Most children remember the hardest part of the treatment and worry about how they and other family members will cope.
- Older children and teenagers may fear their own death, some may even think of suicide. This is not because they want to die, but because they see it as a way of escaping treatment.
- Teenagers also don't want their families to go through another painful treatment process again and commonly feel very guilty.
- Children of 10 to 12 years are more likely to talk about wanting to disappear, for example, when it is time for a painful procedure.
- Children have doubts about the outcome of treatment and their own, and their family's, ability to cope with another treatment process.
- They may avoid thinking about the relapse or the treatment plan and may choose to focus all their attention on one treatment or one symptom.
- In an attempt to cope with their doubts, fears and emotions many have private talks with themselves. They try to encourage themselves by saying things like:
  - "I have gone through treatment once, I can do it again"
  - "It is not my fault the cancer came back"
  - "I can do nothing to change the situation, but I can help myself by going through treatment one more time"
  - "It is no use worrying because I cannot control how this will end"
  - "I will be fine, the doctors know what they are doing."
- At some point during treatment, when they have dealt successfully with the initial shock, fears and doubts, older children and teenagers may suddenly become very positive. They may even talk about their life plans after completing treatment. During this phase they often talk about part of themselves that they still consider 'normal', something that is typical of them prior to treatment or something that is typical of their friends.
- Most children and teenagers in this phase will refer to a belief in God and miracles. They cling to a firm belief that they will be one of the survivors of cancer and will often say to themselves and others: "I'm going to make it."
- They prefer socialising and joking with their friends. This helps them to avoid thinking about the relapse and treatment. If it helps them cope, support them and respect their efforts to cope with the situation.

# Should/if cancer comes back – relapse

## Advice for parents

- Respect the fact that you and your child are not going to react to a relapse in the same way. You may feel the need to be emotionally close to your child and talk to him/her about the relapse, but instead experience an emotional distance. In part this is due to the different ways parents and patients react to a relapse.
- It is all right to share your own feelings with your child in a way that is appropriate to his/her age and maturity, but only when he/she is ready to hear those feelings.
- Do not force your child to talk if he/she is not ready to. Most teenagers might actually find it easier to talk to someone outside of their immediate family, because they want to spare their parents more pain. Respect this and don't feel threatened or feel that your child is shutting you out.
- Your child must know that you love him/her and that you are there for him/her. Let your child know that he/she can talk to you whenever he/she wants to.
- Try to remember that the younger the child is, the more difficult it will be to explain the situation to him/her. Children who are very young or unable to say how they feel might act or behave in a difficult or different way. It is not uncommon for a young child to express or act in anger towards his/her parents. It is often best to get the help of a professional Child Psychologist, who will work with your child and can advise you on how best to handle the situation.

## Contemplating an end to treatment

- Be prepared. There will be times during the treatment when you might consider stopping the treatment. You may fear that your child cannot tolerate it and you may even feel guilty for allowing the treatment to continue.
- There might come a time when your child's condition and ability to tolerate the treatment forces you to think about what the limits are, as to how long treatment can continue.
- As a parent you only want what is best for your child, and that includes the best chance for a complete cure of his/her cancer. People who care for you and your child know this and will respect the decisions you make about your child's treatment.
- Discuss your fears about a possible end to treatment with your child's doctor and make sure you have all the correct medical facts about your child's condition.
- You may need to start preparing yourself for your child's possible death. Talk to someone you trust about your feelings. These are very difficult feelings to face, but talking about them with a friend or trained counsellor will help you to cope with and understand your feelings.



**Try to accept that the outcome of the disease is beyond your control.**



*By Stella Kunihiro  
11 years old*

# Palliative and end-of-life care

Palliative and end-of-life care are two aspects of childhood cancer that are the most difficult to discuss. Although the cure rate for childhood cancers is at 70%, to a parent the other 30% is a real fear. This is a natural reaction to the very difficult circumstances you are in, where always looking on the bright side is extremely hard and potentially unrealistic. Your worst fears have come true; you are now faced with the knowledge that your child is going to die from cancer and that you will outlive your own child.

This chapter is based on many years of experience of working with dying children and their families who have walked the path of caring for them. Each person and family have their own special way of dealing with palliative and end-of-life care. There is no correct or better way, just the way that makes the most sense to you and your unique family circumstances.

## Palliative care

When it is evident that there is no more curative treatment for your child, palliative care needs to be provided. It entails improving your child's quality of life, not its length, by providing pain relief and helping your child to maintain a sense of dignity. During this time you as a family have very special needs. Consult with the medical team and psychosocial support team where your child was treated to help you make a decision that best suits your own unique family circumstances and resources.

Depending on your family's unique circumstances, your support system and the resources available in the area where you live, palliative care can be provided for your child at the following facilities:

- in the hospital where your child was treated;
- at a hospice;
- at home.

### Hospital

For many families the unit where their child was treated, even though they associate that unit with pain, has become a place where they feel safe, loved and cared for. The thought of caring for their dying child at home may be too stressful and worrisome. They prefer the immediate back up and support of the medical, nursing and psycho-social support staff to guide and support them through this difficult time.

### Hospice

If you do not have the resources to care for your child at home and you feel that the hospital ward or unit where your child was treated has too many painful memories, a hospice may be a suitable option. It is, however, important to make sure the hospice has the resources, including staff who are comfortable with caring for dying

children, to see you and your child through this very hard time. It is helpful to discuss this option first with the social worker in the hospital where your child was treated. They will also be able to give you the names of hospices in, or near to, your area.

### Home

To be cared for at home is almost always the sick child's preference. Your child can be in his or her own room, surrounded by family etc. For you, as a parent, home may be the place where you feel in control and best able to look after your child. However, caring for your child at home can be very stressful and you will need a lot of support and resources. Discuss this option with the medical team and social worker to find out whether home-based care can be arranged and supported.



**Remember:**  
**There is no 'right' or 'wrong' when it comes to deciding on the best place to care for your child at the end of life.**

Always remember your child is part of a family system and that each member of the family system deals with difficult, painful life events in their own special way. Open and honest communication, where each member gets the chance to share their needs, feelings and fears without being judged by others, is very helpful and aids emotional healing later on.

### Your dying child's needs

There are a number of practical ways in which you can help your child. You can discuss these in detail with the medical team caring for your child. There are also a number of other ways to help your child cope with palliative and end-of-life care.

- Your child is a person with a sense of dignity and respect. It is important to treat your child with that respect.
- Open and honest communication is also very important. Include your child in any decisions about care in ways that are appropriate to your child's age and level of understanding. This will help your child not to feel isolated, fearful and anxious. It is also important to remember that your child will continue to need the boundaries that make things feel safe and secure.
- Although it is important to be honest about your own feelings, guard against projecting your own fears and feelings of helplessness onto your child.
- Your child needs appropriate and adequate palliative care and pain control. Pain control is essential to aid the psycho emotional and spiritual process of dying.
- In cognitive terms, children may not always know that they are dying, but they do have a spiritual awareness that this is the case. The younger the child the less 'complicated' this may be. The older the child with more advanced cognitive development, the more difficult things may be because of the perception, thoughts and feelings they have already developed about death and dying. Listen to your child's needs, fears and concerns and respond accordingly. Feelings your child may find difficult or are unable to communicate directly may be expressed through nonverbal (without words) cues or behaviour which can be very revealing. Learning to find ways to 'hear' what your child is communicating is valuable as it helps you to assess when more information or reassurance is needed.

# Palliative and end-of-life care

- Difficult as this may sound, your child needs permission to die. Your child needs to know that you will always love him or her, that it is going to be very hard, but that you will be okay. It is important to make sure that your child does not feel responsible for your wellbeing. It will make it more difficult for your child to let go and may prolong suffering.
- Children should not be left alone, but may choose to die when the parent briefly steps out of the room because they intuitively know how difficult the moment of death will be for the parents.

It is important that you, as a parent, communicate your needs and fears to the people around you to ensure that there is not any 'unfinished business' which may make grieving more difficult. As the parent you are the expert in taking care of your child. You have empowered yourself with knowledge and understanding of your child's illness and now you can empower yourself once again. Trust in your own inner strength to be able to care for your child right to the end and to be able to come through this most painful time with courage and dignity.

## **Your other children's needs**

In a way the emotional needs of your other children are the same as those of your sick child. They need to be kept informed and included all the time, as the process unfolds. Make sure they have the opportunity to say goodbye to their sibling/s and that they are able to express their own fears and sadness. This will aid their healing later on.

## **Friends and peers**

School friends and peers can be of great importance to your sick child. They fulfil needs that family members may not be able to, such as giving them a chance to talk and share thoughts and feelings on an equal basis. It is therefore important that they too are kept in the picture.

## **Grandparents**

Depending on the relationship, grandparents may be a source of great support and strength to you and your family. It is, however, important that you communicate boundaries clearly to ensure that there is no added stress. People can be very well meaning, but not understand your and your family's needs.

## **Community**

Often there are members of your community who would like to help but are not sure how without being intrusive. There will be times when it all feels too much and you feel you can't cope. A close family member or friend can co-ordinate the support from your community by asking them to help by bringing cooked meals, doing school lifts, shopping, etc. However, it is important to set boundaries for people who you feel are 'loading' you with their own unresolved issues around death and dying.

Those who witness the pain that parents suffer at such a time are largely powerless when it comes to offering them any kind of reassurance or relief from doubts and fears. The best that can be done by sympathetic bystanders is to offer some practical guidelines or suggestions which, admittedly, offer small comfort but at least promise to make parts of the road ahead a bit easier.

## **Culture and religion**

Draw from the strength that your culture and/or religion offers you and use what is helpful to you and your family.



**Remember, what is important are your child's and your family's needs, not those of the often well-meaning but ignorant people around you.**

## **Bereavement**

The loss of a child is the most difficult event you may face in your life. Parents who have experienced their child's death know just how true these words are. Nothing can prepare you for it, even if you know that it will eventually happen to your child. No words can describe the intense pain in your heart. Your whole world is changed forever. It is true what is said: "You never get over your child's death – you simply learn to live with it."

By giving yourself the time to mourn and by facing your feelings with courage you can once again find renewed interest in life. Most people have limited knowledge and understanding of the grieving process. Some people feel that courage means denying pain, putting on a brave front and carrying on with life. Real courage means being honest about your feelings and allowing yourself to feel the pain. In time you will feel ready to move forward and resolve your grief.

Unresolved grief can appear later on in different ways: emotional, physical and mental. As soon as unresolved grief is discovered it is important to go back to it and resolve it as fully as possible. There is a lot of literature available that deals with grief and mourning to empower yourself with. Other resources you may have access to are: support groups; counsellors, social workers or psychologists. Support groups offer a safe environment in which to share and draw strength from other people who are trying to understand their feelings around death or who have resolved grief successfully. Also, it is healthy to seek the help of a professionally trained counsellor, social worker or psychologist, with experience in grief work, to support you and your family through the grieving process.

### **Useful reading material for adults:**

*So Will I Comfort You*, Jenny Kander  
*The Courage to Grieve*, Judy Tatelbaum  
*On Grief and Grieving*, Elisabeth Kübler Ross & David Kessler  
*Summer of the Bees*, Andy Sutherland  
*Hannah's Gift*, Maria Housden

### **Useful reading and workbook material for children:**

*When Goodbye is Forever*, A Lions Children Book  
*Talking about Death*, Earl A Grollman  
*Remember the Secret*, Elizabeth Kübler Ross  
*Will I Live Forever*, Carolyn Nystorm  
*Emma Says Goodbye*, Carolyn Nystorm  
*Badger's Parting Gift*, Susan Varley



"Those whom we love and lose are no longer where they were before. They are now wherever we are". (John Chrysosin)



**Commonly used chemotherapy drugs and other supportive drugs**

**Side effects of chemotherapy drugs**

**Glossary of medical terms**

## Commonly used chemotherapy drugs & other support drugs

Generic name & other terms	Trade Name
Actinomycin D / Dactinomycin	Cosmegen
All-trans retinoic acid	Vesanoic
L'asparaginase / Laspar	Laspar
Bleomycin	Blenoxane
Busulphan	Myeleran
Carboplatinum / CBDCA	Paraplatin RTU, P&U Carboplatin
Carmustine / BCNU	BiCNU
Chlorambucil	Leukeran
Cisplatinum / Cisplatin	Platosin, Abiplatin
Co-Trimoxazole	Bactrim / Septran / Purbac etc.
Cyclophosphamide / CTX	Endoxan, Cyclophosphamide, others
Cytarabine / Ara-C / Cytosine / Arabinoside / Cytosar	Alexan, P&U Cytarabine
Dacarbazine / DTIC	DTIC - Dome
Daunorubicin / Daunomycin	Daunoblastine, Cerubidine
Doxorubicin / Adriamycin	Caelyx, others
Epirubicin / 4-Epi Adriamycin	Farmorubicin
Etoposide / VP 16	Vepesid, P&U Etoposide, Etopophos, others
Fludarabine	Fludara
Fluorouracil / 5-Fluorouracil / 5FU	Abic Fluorouracil, Fluroblastin
Hydroxyurea	Hydrea
Ifosofamide / IFOS	Holoxan
Imatinib	Gleevec
Interferon	Roferon-A
Irinotecan	Campto
Kytril/Granisetron	Kytril
Leukovorin	Rescuvinol
Mabthera / Rituximab	Mabthera
Melphalan	Alkeran
Mercaptopurine / 6-Mercaptopurine / 6MP	Purinethol
Mesna	Uromitexan
Methotrexate / MTX	Methotrexate-Lederle, Emthexate, others
Mitoxantrone	Novantrone
Neupogen / Filgrastin	Neupogen
Procarbazine	None at present (was Natulan)
Steroids <ul style="list-style-type: none"> <li>• Predisone / Prednisolone</li> <li>• Dexamethasone / Decadron</li> <li>• Hydrocortisone</li> <li>• Methylprednisolone</li> </ul>	Steroids <ul style="list-style-type: none"> <li>• Meticorten, Meticortilone etc</li> <li>• Decadron</li> <li>• Solu-Cortef</li> <li>• Depo-Medrol</li> </ul>
Temozolamide	Temodal
Teniposide / VM26	Vumon
Thioguanine / 6-Thioguanine / 6TG	Lanvis
Topotecan	Hycamptin
Vincristine / VCR	Oncovin, Vincristine PCH, many others
Vinblastine / VBL	Vinblastine PCH
Zofran / Ondansetron	Zofran

## Side effects of chemotherapy drugs

### Side effects of chemotherapy drugs

The side effects listed below are not all the possible side-effects but the most common ones. The list will give you a general idea of what to expect when your child is receiving chemotherapy. If you note anything unusual, do not hesitate to speak to the nurse or doctor immediately.

Chemotherapy drug	Early side effects	Late/delayed side effects
Actinomycin D	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Diarrhoea</li> <li>• Unexplained fever</li> </ul>	<ul style="list-style-type: none"> <li>• Liver damage</li> </ul>
Amsacrine	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Mouth ulcers</li> </ul>	<ul style="list-style-type: none"> <li>• Heart damage</li> </ul>
Bleomycin	<ul style="list-style-type: none"> <li>• Hair loss</li> <li>• Mouth ulcers</li> <li>• Loss of appetite</li> <li>• Fever (at time of injection)</li> <li>• Allergic reaction</li> </ul>	<ul style="list-style-type: none"> <li>• Lung damage</li> </ul>
Busulphan	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Seizures</li> </ul>	<ul style="list-style-type: none"> <li>• Skin becomes darker</li> <li>• Liver damage</li> <li>• Menstruation stops (amenorrhoea)</li> </ul>
Carboplatin (also known as CARBO, CBDCA)	<ul style="list-style-type: none"> <li>• Tiredness (fatigue)</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Loss of appetite</li> </ul>	<ul style="list-style-type: none"> <li>• Hearing problems (high tone)</li> <li>• Liver/kidney damage</li> <li>• May cause infertility</li> </ul>
Carmustine (also known as BCNU)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression</li> <li>• Pneumonitis</li> </ul>	<ul style="list-style-type: none"> <li>• Liver damage</li> </ul>
Chlorambucil	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> </ul>	<ul style="list-style-type: none"> <li>• May cause infertility and secondary cancer</li> </ul>
Cisplatin	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Diarrhoea</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Loss of appetite</li> <li>• Damage to the vein and tissue if the drug leaks out of the vein</li> </ul>	<ul style="list-style-type: none"> <li>• Hearing problems (high tone)</li> <li>• Kidney damage</li> <li>• May cause sterility</li> <li>• Low levels of magnesium</li> </ul>

## Side effects of chemotherapy drugs

Chemotherapy drug	Early side effects	Late/delayed side effects
Co-Trimaxazole (also known as Septrin, Bactrim)	<ul style="list-style-type: none"> <li>• Nausea and vomiting (mild)</li> <li>• Mouth ulcers (sores)</li> <li>• Bone marrow suppression (low blood counts, mild)</li> <li>• Diarrhoea</li> <li>• Skin rashes</li> </ul>	
Cyclophosphamide (also known as CTX)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Mouth ulcers (sores)</li> <li>• Cystitis (bladder inflammation)</li> <li>• Swelling because of fluid retention</li> <li>• Metallic taste in mouth while the drug is infusing</li> </ul>	<ul style="list-style-type: none"> <li>• Bladder cancer and secondary leukaemia (rare following chronic use)</li> <li>• May cause infertility</li> </ul>
Cytosar (also known as Cytosar-U, Cytarabine, ARA-C, Cytosine Arabinoside)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Diarrhoea</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Mouth ulcers (sores)</li> <li>• Fever</li> <li>• Skin rashes</li> <li>• Irritated eyes</li> <li>• Seizures or liver damage (from high dose treatment)</li> </ul>	<ul style="list-style-type: none"> <li>• May cause infertility</li> <li>• Liver damage</li> </ul>
Adriamycin Daunorubicin Doxorubicin Epirubicin Idarubicin	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Pink urine</li> <li>• Mouth ulcers (sores)</li> <li>• Burns the skin if drug leaks out of the vein</li> </ul>	<ul style="list-style-type: none"> <li>• Skin becomes darker</li> <li>• Heart damage</li> <li>• Deformities of the skin or tendons</li> <li>• Secondary cancer</li> </ul>
Etoposide (also known as VP16) Tenoposide (also known as VM26)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Diarrhoea</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Mouth ulcers (sores)</li> <li>• Allergic reactions (wheezing, difficulty breathing, skin rashes, swollen lip)</li> <li>• Low blood pressure</li> <li>• Metallic taste in the mouth while the drug is infusing</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary leukaemia (rare)</li> </ul>

## Side effects of chemotherapy drugs

Chemotherapy drug	Early side effects	Late/delayed side effects
5-Fluorouracil	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Mouth ulcers (sores)</li> <li>• Hair loss</li> <li>• Bone marrow suppression (low blood counts)</li> </ul>	
Hydroxyurea	<ul style="list-style-type: none"> <li>• Drowsiness (sleepy)</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Skin is darker in colour</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary cancer</li> </ul>
Ifosfamide (also known as IFOS)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Cystitis (bladder inflammation with blood in urine)</li> <li>• Irritation of the vein</li> <li>• Confusion or hallucinations (seeing and/or hearing things that are not really there)</li> </ul>	<ul style="list-style-type: none"> <li>• Kidney damage</li> <li>• Liver damage</li> <li>• Skin is darker in colour</li> <li>• May cause infertility</li> </ul>
L-Asparaginase (Also known as Laspar)	<ul style="list-style-type: none"> <li>• Loss of appetite</li> <li>• Nausea and vomiting</li> <li>• Fever</li> <li>• Allergic reactions such as rashes or breathing problems</li> <li>• Temporary diabetes</li> <li>• Change in mental status</li> </ul>	<ul style="list-style-type: none"> <li>• Liver damage</li> <li>• Pancreas damage</li> </ul>
Melphelan	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Mouth ulcers (sores)</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Skin rashes</li> <li>• Liver damage</li> </ul>	
Mercaptopurine (also known as 6-MP)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Mouth ulcers (sores)</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Loss of appetite</li> <li>• Skin rashes</li> </ul>	<ul style="list-style-type: none"> <li>• Liver damage</li> </ul>
Methotrexate (also known as MTX)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Mouth ulcers (sores)</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Loss of appetite</li> <li>• Fever</li> <li>• Skin rashes</li> </ul>	<ul style="list-style-type: none"> <li>• Seizures</li> <li>• Kidney and/or liver damage (from high-dose treatment)</li> <li>• Intellectual impairment</li> </ul>

## Side effects of chemotherapy drugs

Chemotherapy drug	Early side effects	Late/delayed side effects
Mitoxantrone (Novantrone)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Urine has a green colour</li> </ul>	<ul style="list-style-type: none"> <li>• Heart damage (dose related)</li> </ul>
Prednisone Prednisolone Dexamethasone Hydrocortisone Methylprednisolone (these are all steroids)	<ul style="list-style-type: none"> <li>• Increased appetite</li> <li>• Weight gain (round "moon face")</li> <li>• Temporary diabetes</li> <li>• Stomach irritation</li> <li>• High blood pressure</li> <li>• Acne</li> <li>• Changes in mood and behaviour</li> <li>• Muscle weakness</li> </ul>	<ul style="list-style-type: none"> <li>• Growth slows down</li> <li>• Bone density decreases</li> <li>• Damage to joints</li> </ul>
Procarbazine	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Flu-like symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• May cause infertility and secondary cancer</li> </ul>
Thioguanine (also known as 6-TG)	<ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Mouth ulcers (sores)</li> <li>• Bone marrow suppression (low blood counts)</li> <li>• Loss of appetite</li> <li>• Liver damage</li> </ul>	<ul style="list-style-type: none"> <li>• Menstruation stops</li> </ul>
Topotecan Irinotecan	<ul style="list-style-type: none"> <li>• Diarrhoea</li> <li>• Bone marrow suppression (low blood counts)</li> </ul>	Unknown
Vincristine (also known as VCR) Vinblastine (also known as VBL)	<ul style="list-style-type: none"> <li>• Thinning of hair/hair loss</li> <li>• Constipation</li> <li>• Seizures</li> <li>• Weakness in legs</li> <li>• Numbness/tingling in hands and feet or loss of reflexes</li> <li>• Jaw pain</li> <li>• Loss of appetite</li> <li>• Skin burns if drugs leak out of the vein</li> </ul>	<ul style="list-style-type: none"> <li>• Deformities of the skin or tendons</li> </ul>
Vindesine	<ul style="list-style-type: none"> <li>• Bone marrow suppression (low blood counts)</li> <li>• Hair loss</li> <li>• Nausea and vomiting</li> <li>• Allergic reactions</li> </ul>	

## Glossary of medical terms

Medical Terms	Meaning
Acute	Occurring suddenly or over a short period of time.
Alopecia	Loss of hair caused by certain chemotherapy drugs and radiotherapy to the head.
Anaesthetic/anaesthesia	Drugs to put a patient to sleep (general anaesthetic) or to numb part of the body (local anaesthetic).
Anaemia	A condition in which blood is deficient in red cells and haemoglobin.
Antibodies	Naturally occurring substances which are created by the body when it is exposed to foreign proteins, e.g. measles, viruses, etc.
Anti-emetic	A drug given to prevent nausea and vomiting. To be most effective the drug must be given a few hours before chemotherapy treatment.
Antigen	A foreign protein, such as a bacteria or virus, that stimulates the production of antibodies.
Benign	A non-cancerous growth.
Biopsy	The removal and examination of a piece of tissue from the body for diagnostic purposes.
Blast cells	An immature stage of cellular development. This term is commonly applied to leukaemia cells seen on examination of a sample of blood or bone marrow.
Blood count	Blood test which assesses the number of different cells contained in a sample of blood.
Bone marrow	The soft spongy centre of the large bones where most blood cells are formed.
Bone marrow aspiration	A procedure whereby a sample of bone marrow is taken from the bone in the hip or leg, usually under general anaesthetic.
Broviac Catheter/ Hickmann Line/ Central venous line	These are different varieties of a long thin tube which is inserted into a large vein in the neck. The tip of the tube lies in the heart. The Hickman line is then burrowed under the skin, and exits on the chest wall. All blood samples can be taken, and medications and transfusions given through these devices. The port is accessed by a special needle through the skin, whereas the Hickman line avoids the use of needles. These devices can be left in place as long as needed. Absolute cleanliness is essential when handling the lines, or dealing with the port, to avoid infections.
Carcinogen	A cancer-causing agent.
CAT / CT scan	X-ray procedure in which a computer is used to generate a 3-dimensional image. It is used in diagnosis to measure the extent of a tumour and during treatment to estimate response to chemotherapy or radiotherapy.
Chemotherapy	Treatment with anti-cancer drugs.

Medical Terms	Meaning
CNS	Central Nervous System, which is the brain and the spinal cord.
Constipation	The infrequent passing of hard, dry stools.
Cyto-	To do with cells.
Dehydration	About 70% of our bodies are water. When large amounts of fluids are lost from the body due to diarrhoea or bleeding, the water content of the body and cells become dangerously low and body cells cannot function properly.
Diuretic	A drug or substance used to help rid the body of extra fluid, by passing more urine.
Dysfunctional	Not working properly.
ECG	Electrocardiogram. A test that records electrical changes in the heart muscle. It is often used to assess the effect (if any) that a particular drug may have on the heart. (Electrical sensors are attached to the body but do not cause any discomfort.)
EEG	Electroencephalogram. A test that records electrical events in the brain and is used to determine brain function. (Electrical sensors are attached to the body but do not cause any discomfort.)
Endocrine	To do with hormones.
G-CSF	Granulocyte Stimulating Factor. A substance which occurs naturally in the body and is occasionally used to stimulate the production of neutrophils.
GFR	Glomerular filtration rate. This test is given to assess how well the kidneys are functioning. Three injections will be given at two hourly intervals.
Haematology	The study of blood and blood-forming organs.
Haemoglobin	The substance that gives the red colour to red blood cells.
Haemorrhage	Bleeding.
Haematopoietic growth factors	Drugs that help the blood cells to mature more quickly so that they can be released into the bloodstream sooner than normal (see also G-CSF).
Immune system	The body's natural defence mechanism against disease and infection.
Immunodeficiency	Lowering the body's defence mechanisms, for example, with chemotherapy.
Intravenous	The administration of fluids or drugs into a vein.
Intravenous infusion	A drip, also called an IV.
IVP	Intravenous pyelogram. An examination of the kidneys. It requires the injection into a vein of a substance that causes the kidneys to be visible on x-ray. Special preparation is needed before the procedure.

## Glossary of medical terms

Medical Terms	Meaning
Isotope scan	A procedure for examining the bones, liver, spleen, thyroid, etc. The child will be given an injection of a radioactive substance.
Lumbar puncture	Referred to as LP. A diagnostic procedure to obtain a specimen of spinal fluid for examination. An anaesthetic agent is given for this procedure.
Lymphoma	Cancer affecting the lymphoid organs, i.e. the lymph nodes, spleen, and thymus.
Lymph nodes	Bean-shaped structures scattered along vessels of the lymphatic system. They may become swollen due to infection or invasion by cancer.
Malignant	Cancerous.
Metastases	Cancer that has spread to another part of the body, also known as secondary tumours. These growths start from cancer cells shed by the primary cancer.
MRI Scan	Magnetic Resonance Imaging Scan. This scan is used to obtain three-dimensional images of a tumour and to assess response to treatment. The images are obtained using a high-powered magnet. No x-rays are involved.
Nausea	A sick feeling; feeling that you want to vomit.
Nephro-	To do with the kidneys.
Neuro-	To do with the nervous system.
Neutropaenic	A patient who has a very low neutrophil count and is therefore at high risk of bacterial infection.
Neutrophil	A type of white blood cell that plays an important role in protecting the body against invasion by foreign organisms that can cause infections.
Oedema	Swelling caused by fluid.
Oesophagus	The "tube" between the throat and the stomach through which food and liquids pass on their way to the stomach after being swallowed.
Oncologist	A doctor who specialises in cancer care.
Ophthalmology	The study of the eyes.
Osteo-	To do with the bones.
Paediatric	Relating to children.
Petechiae	Tiny haemorrhages from small blood vessels just beneath the skin's surface. They appear as little red pinpoint spots on the skin when the blood count (especially the platelets) is low.
Platelet	One of the types of blood cells. It helps blood to clot and control bleeding. (See Petechiae above and Thrombocytopenia below.)

Medical Terms	Meaning
Primary (tumour)	Original site of a tumour.
Prognosis	The long-term expected outlook or outcome of a disease.
Protocol	The treatment plan for a specific type of cancer.
Prosthesis	Artificial replacement of a bone, limb or organ, for example, an eye.
Pulmonary	To do with the lungs.
Radiotherapy	Treatment to destroy cancer cells in the body using high-energy radiation x-ray machines, cobalt, radium and other sources.
Red blood cells	The blood cells that carry oxygen around the body. Haemoglobin is the substance that gives these cells their red colour. (See Anaemia and Haemoglobin.)
Relapse	The return of the symptoms of a disease after a period of good health.
Remission	A period of good health in which there is no detectable evidence of a disease or tumour.
Sarcoma	A tumour which forms in bone or muscles.
Terminal illness	It means that the likely course of the illness will cause the patient to die, because there are no known treatment options available that have been proven to be successful.
TPN	Total Parenteral Nutrition. The giving of nutrients intravenously when a child cannot take food in the normal way.
Thrombocytopenia	Low platelet count, which causes bleeding and easy bruising.
Tumour	An abnormal lump of tissue formed by a collection of cells. It may be benign or malignant (see above).
White blood cells	The blood cells which are involved in the body's defence against infections.

