



Back to School



Prepared by and obtainable from:

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This publication is intended to support educators dealing with children that have cancer.

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Introduction

A diagnosis of cancer in a learner is a very traumatic time for the school as there is often ignorance and misconception surrounding the illness. It is therefore, important that educators understand their own emotions and the nature of the illness to adequately support the child and family. The only way to conquer fear is through knowledge. This publication is therefore, intended to support educators dealing with children with childhood cancer.

CHOC Childhood Cancer Foundation

CHOC Childhood Cancer Foundation SA is the only organisation in South Africa that provides comprehensive countrywide support for children with cancer and other life-threatening blood disorders, and their families. CHOC has a head office in Johannesburg, six regional offices, two branches, and 12 accommodation facilities close to treatment centres. CHOC relies on corporate sponsors, donations from groups or individuals wanting to make a difference in the lives of these little ones.

Their comprehensive support improves the welfare and quality of care to children with cancer and offers families a wide range of psychosocial services and practical support such as counselling, free accommodation close to treatment centres, free transport and transport fund to ensure that no child abandons treatment due to the family not affording transport costs, food parcels as they recognise the financial difficulties families often face and parent to parent support groups. CHOC plays a leading advocacy role through cancer awareness campaigns and lobbying. They also train and educate healthcare professional, homebased care workers and

traditional practitioners on the early warning signs of childhood cancer to promote early detection.

What is Cancer?

Cancer is the uncontrolled growth of cells in a particular organ of the body causing a growth or tumour. These cancer cells can then spread to other parts of the body. If cancer cells are not stopped, the disease will eventually lead to the death of the child.

The most common childhood cancers are Leukaemia (cancer of the bone marrow and blood cells), followed by brain tumours, lymphomas (cancer of glands), kidney cancer and Retinoblastoma (cancer of the retina of the eye).

Facts about childhood cancer

Worldwide 150 children per million are diagnosed with cancer every year. In South Africa it is estimated that only 70-80 children per million are diagnosed annually. Unfortunately about 50% of the diagnosed children do not survive due to late diagnoses and lack of specialised treatment. The good news is that if diagnosed early and treated correctly, the majority of children can be cured.

The cancers that occur in childhood are generally, different to those of adults and most of them occur in developing cells, like bone marrow, blood, kidneys and tissues of the nervous system. The most common childhood cancer is leukaemia, followed by tumours of the brain, and by a wide variety of other tumours. Generally, childhood cancer is treated with chemotherapy, surgery or radiation, and in some cases a combination of these treatments are used. In certain situations, bone marrow or stem cell transplantation is done. Life-threatening blood disorders include: aplastic anaemia, thalassaemia and Immune Thrombocytopenic Purpura (ITP).

SAINT SILUAN'S EARLY WARNING SIGNS OF CHILDHOOD CANCER



[SEEK] medical help early for persistent symptoms (not all symptoms are cancer – the emphasis is on persistent or out of the ordinary)



[EYE] Be aware if you see a white spot, new eye squint, new blindness or a bulging eyeball.



[LUMP] If there is a lump in the abdomen and pelvis, head and neck, limbs, testes or glands.



[UNEXPLAINED] fever for 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 or an enlarging head.

The Medical Aspects of Childhood Cancer

How childhood cancer is treated

Cancer in children is best treated in an established Paediatric Oncology Unit by a multidisciplinary team of doctors headed by a Paediatrician Oncologist who is a specialist in children's cancer. Cancer in children is treated by a combination of:

- Chemotherapy
- Radiation Therapy
- Surgery
- Bone Marrow Transplants
- Stem Cells Transplants



The side-effects of Childhood Cancer

Chemotherapy affects cells that are rapidly dividing.

- It affects the bone marrow cells which lead to anaemia (red blood cells), bleeding (platelets) and decreased Immunity (white blood cells) with increased chance of infection.
- It affects the mucous membranes which causes mouth ulcers.
- It affects the hair follicles which causes hair loss.
- It affects the stomach and intestinal mucosa which causes diarrhoea stomach ulcers.
- Nausea and vomiting.
- Fatigue and Drowsiness.
- Decreased appetite.
- Headache.
- Emotional effects.
- Surgery may lead to scarring and sometimes deformities.



The emotional impact of childhood cancer on the learner, family and friends

It is important to know that when a child is diagnosed with cancer the impact is not only on the child, but on the entire family and friends. The roles within a family often change when a child is diagnosed as usually one parent has to be in the hospital with the child as he/she receives treatment.

The emotional impact on the learner who is diagnosed varies in intensity. When a child who has received treatment for cancer returns to school, very

often their hair will not yet have grown back. This may cause anxiety for the child as they fear being teased and labelled. On their return, they may feel that they no longer 'fit in' and that they are different to other children. It is important to acknowledge these possibilities so that the child does not become isolated and withdrawn.

Children who are diagnosed with cancer and receive treatment usually have to 'grow up' quickly and therefore mature through the experience. They often view life differently to their peers as a result. Although the child may be excited to return to school, reintegration can be a difficult process. A child may be worried that since they have lost out on schooling they will not be able to perform as they previously did. Therefore, they will need encouragement. When a child has returned to school they may also experience a sense of loss as they become even more aware of what they have missed. This may cause feelings of anger and resentment towards their peers and even their siblings.

If the diagnosed child has brothers or sisters, the impact that the changes and diagnosis of their sibling has on them must not be underestimated. The siblings often experience a feeling of being left out or rejected as their ill sibling will be getting all the attention. In some instances mom or dad may not be home as often as they usually are and perhaps not performing their usual duties, like lifts to and from school. The siblings of an ill child often experience feelings of anger and resentment and may start to either act out or withdraw from their school environment. It is important for educators to focus on the siblings while they are at school and acknowledge their feelings. Their environment needs to remain as 'normal' as possible and their routine maintained when and where possible.

Each child, whether the patient or the sibling, will display their emotions differently and should any changes in behaviour be of concern, it should be discussed with the parents so that they can contact a member of the learner's treatment team for guidance on how to handle the situation.

Education

How the school can help ease the transition from hospital back to school for the child with cancer.

The role of the hospital school is to provide continuity in the child's education while hospitalised so that the transition back to mainstream schooling is eased.

Guidelines to assist in this transition:

	Hospital school	Mainstream school
Communication	The ward informs the hospital school of new admissions.	The principal of the hospital school informs the mainstream school that the learner has been admitted to the hospital school for education while on treatment.
	The hospital school requests a status report from the mainstream school.	The hospital school sends an exit report to the main stream school on the child's return.
	The hospital school develops an Independent Educational Support Programme (IESP) for learner.	The main stream school uses the IESP to develop a remedial programme to assist the learner in areas of difficulty.
	It is very important to keep regular contact with the parents to discuss information regarding the child's progress at home and at school.	
Organisation	Subjects that are not offered at the hospital school should be provided by the mainstream school.	The mainstream school should provide the hospital school with work sheets to keep the learner on par with the schedule.

	<p>The purpose is to facilitate re-entry to mainstream school without the loss of the educational programme. Work assignments and meaningful activities for the child should be planned in consultation with the hospital educator.</p>	
	<p>A member of the hospital school should attend ward rounds to discuss the learner's physical problems</p>	<p>On request, a member from the paediatric oncology treatment team can visit the mainstream school to brief them regarding the impact of childhood cancer on the learner.</p>
	<p>The educators should identify problems the child may be confronted with as far as mobility, fatigue, lack of concentration; side effects of medication and treatment are concerned.</p>	
Emotional problems	<p>Should any physical, emotional and behavioural changes be detected in the learner, the educator should contact the parents immediately for discussion with the treatment team.</p>	

The staff from the mainstream school should liaise with the hospital school staff for a briefing session regarding the learner



"South African Schools Act, 1996 (Act No 84 of 1996)

The right to education and the financial responsibility of the state:

13) The Bill of Rights in the Constitution of the Republic of South Africa, 1996 (No. 108 of 1996) establishes the right to education in these terms:

"Everyone has the right:-

- a) to basic education, including adult basic education; and*
 - b) to further education, which the state, through reasonable measures' must make progressively available and accessible*
- "(Section 29(1))."***

List of hospitals schools linked to Paediatric Oncology Units in South Africa.

Paediatric Oncology Unit	Hospital School	Contact Details of Hospital School
Gauteng Charlotte Maxeke Johannesburg Academic Hospital	Johannesburg Hospital School	Tel: 011 484 3082/2429 Fax: 011 484 5554 ronel@autjhb.co.za
Gauteng Chris Hani Baragwanath Academic Hospital	Chris Hani Baragwanath Academic Hospital Bara School	Tel: 011 933 8248 Fax: 011 933 4559
Western Cape Tygerberg Children's Hospital	Tygerberg Hospital School	Tel: 021 938 5261 Fax: 021 938 5261 tbhskool@sun.ac.za
Western Cape Red Cross War Memorial Children's Hospital	Red Cross War Memorial Children's Hospital School	Tel: 021 658 5042 Fax: 021 658 5042 primaryredcross@gmail.com

Western Cape Groote Schuur Hospital	Groote Schuur Hospital School	Tel: 021 404 5012 Fax: 021 9454725 grooteschuur.hospitalschool@gmail.com
Eastern Cape Frere Hospital	No Hospital School – CHOC Interactive Play & Education Programme	
Bloemfontein Universitas Academic Hospital Netcare Universitas Private Hospital	Universitas Hospital Primary School	Tel: 051 405 3645/1423 Fax: 051 444 3230
Pretoria Dr George Mukhari Academic Hospital	George Mukhari Hospital School	Tel: 012 529 3725/96 Fax: 012 560 0717 tw240721@webmail.co.za
Pretoria Steve Biko	Hospital School Pretoria	Tel: 012 329 1560/73 Fax: 012 329 1280 Email: hospitalschoolpretoria@gmail.com
Polokwane Provincial Hospital	No Hospital School	
Port Elizabeth Provincial Hospital	No Hospital School	
Kwa Zulu Natal Durban Inkosi Albert Luthuli Central Hospital	No Hospital School – CHOC Interactive Play & Education Programme	
Kwa Zulu Natal Pietermaritzburg Pietermaritzburg Metro Complex	No Hospital School	

Learner Profile

The following Learner profile can be added as an addendum to the medical history of the Learner's School Profile;

Name of Learner: _____

Grade: _____

Name of the hospital school: _____

Contact person at school: _____

Physical Address: _____

Postal Address: _____

Contact Details: T: _____

F: _____

Email: _____

Website: _____

Name of the Learner's Main Stream School: _____

Contact person at school: _____

Physical Address: _____

Postal Address: _____

Contact Details: T: _____

F: _____

Email: _____

Website: _____

General Information:

Description of illness and the proposed treatment:

Factors that may cause absence:

Visits to out-patients: how regularly and for what purpose

Hospitalisation: Periods of time

Factors that may affect social interaction

Changes in physical appearance due to surgery, chemotherapy and radiation:

- ❑ Loss of limb (amputation).
- ❑ Weight loss or weight gain.
- ❑ Hair loss.
- ❑ Indwelling catheter.
- ❑ Mood swings.
- ❑ Loss of appetite or increased appetite.
- ❑ Urge to urinate frequently.

Factors that may affect learning:

- ❑ Neuropsychological side-effects of the treatment
- ❑ Changes in fine/ gross motor co-ordination.
- ❑ Audio-visual impairment.
- ❑ Limitations in physical activities.
- ❑ Fatigue.
- ❑ Nausea and vomiting.
- ❑ Emotional stress.

Factors that may have negative impact on treatment:

- ❑ Medication that must be avoided.
- ❑ Problems with catheters.
- ❑ Exposure to infectious diseases e.g. chickenpox, measles, mumps.

The parent or treatment team should be informed immediately when the school detects the following:

- ❑ Fever;
- ❑ Persistent fatigue or inactivity;
- ❑ Pallor;
- ❑ Nose-bleeding;
- ❑ Vomiting;
- ❑ Excessive or easy bruising;

Guide-lines for Educators:

Learner with Cancer in the Hospital	
Does	Don'ts
Phone or visit – call the ward in advance.	Groups or children under 12 years are not allowed in the wards.
Send cards, phone or visit the parents.	
Motivate the learner.	
Give special attention to the siblings.	
Encourage the child, even during prolonged hospitalisation and when critically ill, to have a goal to which to aspire.	



Learner with Cancer back at school

Does	Don'ts
Be aware of the effects that the treatment may have on the learner's educational progress.	Show fear of having sick learners in the class.
Modify lessons and assignments to accommodate the learner who may get tired quickly.	Pity the learner.
Motivate the learner.	Share important information about the learner's appearance, needs and behaviour with colleagues or role players who are not actively involved with the learner.
Be sensitive to the needs of the learner to obey the doctor's instructions, e.g. use of toilet, eating habits, wearing a hat, etc.	Have expectations of the learner beyond what they are able to do.
Know what the side-effects of the treatment are e.g. slurred speech, falling asleep in the class, mood-swings, failure to submit to discipline, moon face, etc.	Create the impression that the learner cannot do certain things.
Prepare class-mates for physical and emotional changes in the learner due to long-term	Underestimate the learner when it comes to homework and assignments.

treatment and suggest ways of helping the learner.	
Treat the learner as normally as possible, taking into account limitations due to the illness.	
Maintain interest in the learner's treatment.	
Involve the learner in as many class activities as possible.	
Give special attention to the siblings.	
Manage the class-mates' reactions to the sick learner for example, teasing, mockery, manhandling and name-calling.	
Encourage the learner to act independently.	
Stimulate the child's intellect to compensate for the child's physical limitations.	
Encourage regular school attendance.	

Possible Risks to Academic Performance:

- A diagnosis of Brain Tumour or Leukaemia.
- Disease, surgery, chemotherapy or radiation of the central nervous system (brain).
- Cancer diagnosed before mastery of basic academic skills.
- Persistent fatigue or a lack of energy.

- High rate of school absence.

Negative Educational effects of children who are treated for cancer of the central nervous system

- The rate and quality of cognitive information processing.
- Attention and concentration.
- Memory and retrieval of information.
- Abstract and visual-spatial abilities.
- Planning and organisational skills.
- Limited stamina.

Treating cancer of the central nervous system can result in brain damage and/or long-term changes in the basic cognitive processes

- It may develop over a number of years after treatment.
- It may interfere with learning and expected school achievements.
- Damage may not always be visible.
- May result in poor educational performance.
- May cause educational disability.
- The child may require special educational services.
- Neurological losses may manifest as emotional or psychological problems.

Letter of communication from the school to all parents

LETTERHEAD OF SCHOOL

Dear Parent/Guardian,

Re.: Infectious Diseases

We kindly request your co-operation in this important matter.

One of our learners is receiving medical treatment for Cancer which puts him/her at risk if he/she is exposed to infectious diseases such as measles, chicken-pox, shingles, mumps, etc.

The majority of children is already immunised against most infectious diseases (or should it be illness), but should your child have one of the aforementioned diseases or is suspected of having it, we kindly request you to immediately bring it to the attention of the class educator.

The health and well-being of our learners depends on your co-operation.

Yours sincerely

HEADMASTER

DATE

Terminology

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	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.
CNS Central Nervous System	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.
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 pinprick 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.)
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	The giving of nutrients intravenously when a child cannot take food in

Total Parenteral Nutrition	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

Useful Websites

www.choc.org.za

www.icccpo.org?

www.saccsg.co.za

www.acco.org

www.ped-onc

www.aspho.com

www.onconurse.com/factsheets/child_can_school.html

www.ncbi.nlm.nih.gov

www.jpepsy.oxfordjournals.org

www.ehow.com/search.html?s=video+on+childhood+cancer&skin=health&t=all

www.cure4kids.org

www.naccpo.org.uk

www.saaled.org.za

www.cancerhelp.org.uk

www.cancerresearchuk.org

Resources

Back to School: School reintegration after childhood cancer / van Roosmalen, Tanja; Assman-Hulsmans, Claire. ICCCP, 2000 (*Journal article*)

Educational Issues in Childhood Cancer / Armston, F Daniel; Horn, Marianna. 1995 (*Journal article*)

Emotional Aspects of Childhood Leukaemia: A Handbook for Parents / Deasy-Spinetta, Patricia et al. (*Book*)

Guidelines for School / Education / SIOP Working Committee on Psychosocial issues in Paediatric Oncology. 1995. (*Journal article*)

Guidelines to support education for children with cancer / Children's Cancer Association of Japan. ICCCP, 2003 (*Journal article*)

Hairballs on my Pillow / CARTI. (*Manual, Journal – Academic Publication*)

Improving The Quality of Life for Children with Cancer: Commission of the European Communities "Europe against cancer" Programme – European School of Oncology Report / **Jankovic, M;** Jenney, M E M et al (*Research Report*)

Long Term Follow Up / Eiser, C. November 2003 (*Lecture Handout – Medical*)

Long Term Follow Up / Eiser, Christine. ICCCP, 2003 (*Journal Article*)

Organising school education for children with cancer in Finland / Vasankari-Vayrynen, Leena. ICCCP, 2001 (*Journal Article*)

Returning to school – A Teacher's Guide for Students with Brain Tumor / Petersen-Broyd, Bette. ICCCP, 2005 (*Journal Article*)

The School Program of the Dutch Childhood Cancer Parent Organisation / Naafs-Wilstra, Marianna C. ICCCP, 2002 (*Journal Article*)

School Re-Entry Resource Manual / Candle lighters Childhood Cancer Foundation Canada. 1992. (*Manual, Book*)

School shouldn't be a bad memory / Wicks, Beth. ICCCP, 2003. (*Journal Article*)

