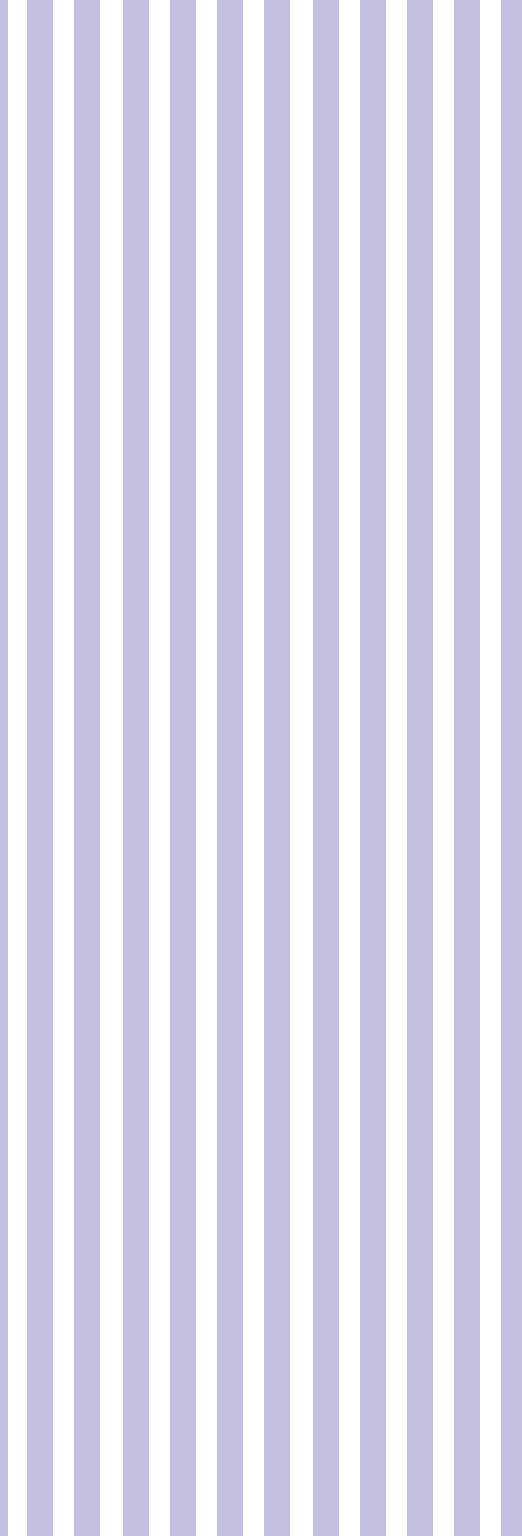


A PARENT'S GUIDE TO CHILDHOOD CANCER



**THE PEDIATRIC ONCOLOGY DEPARTMENT TATA MEMORIAL CENTRE
AND ST. JUDE INDIA CHILDCARE CENTRES**

A series of vertical stripes in shades of purple and white, located on the left side of the page.

**THE GOOD NEWS IS
THAT CHILDHOOD
CANCERS ARE
CURABLE - IF
DETECTED EARLY
AND TREATED
APPROPRIATELY.**

FOREWORD

Dear Parents,

Having a child diagnosed with cancer is one of the most traumatic events that can happen to a family and may cause a significant emotional and financial burden. However, most pediatric cancers are curable if treated early and appropriately. We understand the fear, frustration and panic felt by families who have been told that their child has cancer. During this difficult ordeal, you are not alone and our Pediatric Oncology team comprising of doctors, nurses, social workers, counsellors and dieticians and volunteers would ensure that you get the best care and support on a regular basis.

When a child is diagnosed with cancer, the family faces an array of new medical terms and challenges. It is vital that parents understand the many aspects of the illness and treatment, as well as the experiences they may face and have to cope with during the treatment process. As you and your child embark on this journey, this guidebook has been created to equip you with as much information and as many tools as possible to help you to understand and manage the issues that lie ahead. 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. We would sincerely welcome your suggestions to make this book even better suited to needs of families dealing with childhood cancers.

I sincerely hope that you and your child win the war on childhood cancer and join thousands of other victors of childhood cancers who are living happy, healthy, productive lives and have become role models for others in our society and across the world.

Best wishes,

Dr Shripad Banavali, MD
Head, Department of Medical & Pediatric Oncology
Tata Memorial Centre, Mumbai.

CONTENTS

Remaining Positive And Hopeful	4
Childhood Cancer	6
Types Of Cancer	7
When The Child Is Diagnosed	8
The Treatment Of Cancer	9
Possible Side Effects Of Cancer Treatment	10
Day-To-Day Concerns	12
Effects On The Family	13
Looking After A Child With Cancer	14
Preventing Infections	16
Diet	20
Dietary Recommendations	22
Problem Solving- Common Complaints	26
After Discharge Care	30
Social Support	31
Accommodation	32
Bibliography	33
When To Contact The Doctor Immediately	37

REMAINING POSITIVE AND HOPEFUL

The best thing you can do for a child who has been diagnosed with cancer is to remain positive and hopeful.

1 Be normal

Do not discuss the child's illness and your worries all the time—it passes on anxiety to the child.

2 Talk

If the child is old enough to understand, it is good to tell the child about the illness, and that the treatment will make the child better. Let the child ask questions and be ready to answer them or get the treating doctor to answer them. Ask the doctor what to tell the child. They will guide you depending on the age of the child.

If you need to talk, ask questions or simply need reassurance, please talk to the doctors or our trained counselors. Do not hide your anxiety.



3 Keep the mind active:

Make use of free time, by involving the child in activities. If kept busy, the child's mind will remain positive. Encourage the child to use this time away from school to acquire new skills, read, sing, draw, play games, and solve puzzles. All this will keep the child's brain stimulated and active.

4 Keep the body active:

If the child is feeling well, let the child play outdoors in a clean, un-crowded and dust-free environment and get some fresh air.



6 Show Affection

Be affectionate - it shows the child that you care. Children need reassurance when faced with a new and difficult situation.



5 Be flexible

During treatment, on some days, the child will not feel well and may not want to eat or perform routine activities. Offer and encourage small, frequent meals that the child likes. Allow the child to rest or play.



7 Pray/Sing

Often it helps to maintain positive energy and release stress if you pray or sing together as a family.

8 Stay in touch

Continue to keep in touch with the rest of the family, especially other children back home. They need your time too.

CHILDHOOD CANCER

Cancer in childhood is uncommon. It can affect any part of the body - the most commonly affected are blood, muscles, bones and organs.

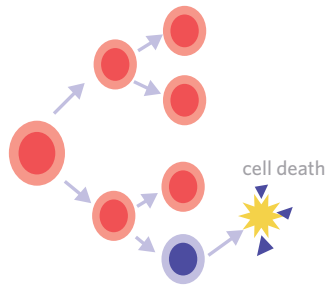
Children's cancers do not always act like, get treated like, or respond like adult cancers. Do not compare adult cancer to cancer in children.



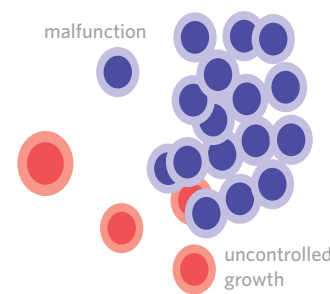
CANCER IS NOT CONTAGIOUS. IT DOES NOT PASS BY CONTACT OR FROM PERSON TO PERSON.

● Healthy cell ● Injured cell

NORMAL CELL DIVISION



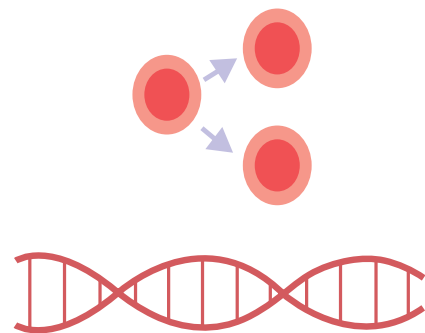
CANCER CELL DIVISION



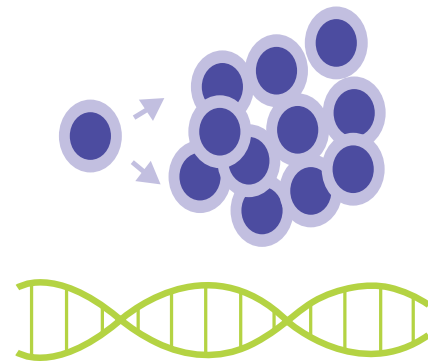
What is cancer?

The human body is made up of millions of tiny parts called cells. These cells divide to form new cells which replace the old cells. This normal cell division allows the different organs in the body to function and is guided by the genetic code or the DNA of each cell. Cancer is a term used for a group of diseases where cells divide abnormally without any control due to a defective genetic code. When too many abnormal cells are made in an organ, it interferes with that organ and other parts of the body from working properly. Cancer cells can invade other parts of the body through the blood and lymph systems. When cancerous cells are made and accumulate in one place, a lump or tumour may be formed.

NORMAL CELLS



CANCER CELLS



What causes cancer?



While in some adult cancers the cause is known—e.g. smoking causes lung cancer or tobacco chewing causes oral cancer, most childhood cancers have no known cause. Diet and child rearing practices are not related to the development of cancer. Childhood cancer may occur suddenly and without early symptoms.



CANCER IS NO ONE'S FAULT, SO PARENTS SHOULD NOT FEEL GUILTY

TYPES OF CANCER



There are two main types of cancer

1 Blood cancer

Leukemia is a type of blood cancer where the white blood cells in the bone marrow divide too quickly. The bone marrow is the soft part in the centre of our long and flat bones. In Leukemia the bone marrow gets so clogged up with unhealthy blood cells that there's no room for healthy blood cells to grow.



BONE MARROW

BONE MARROW WITH HEALTHY CELLS



BONE MARROW CLOGGED WITH CANCEROUS CELLS



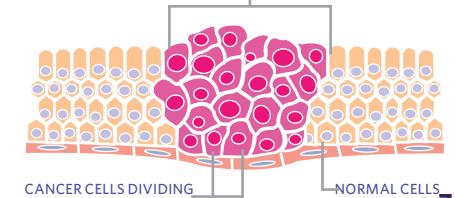
this is dangerous. Cells in these tumors are abnormal and divide without control or order.

Tumours can also be non cancerous and are called **benign**. They can often be removed and, in most cases, they do not come back. Cells from benign tumors do not spread to other parts of the body. Most importantly, benign tumors are rarely life threatening.

2 Solid tumours

When cancerous cells clump together they form a tumour. Tumours can grow in any part of the body. They tend to destroy the surrounding healthy organs and

A TUMOUR IS FORMING



WHEN THE CHILD IS DIAGNOSED

Staging of cancer

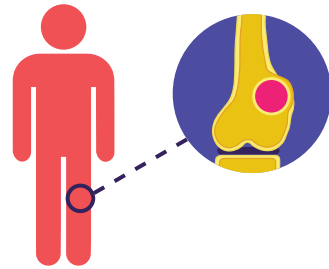
After the child's cancer has been diagnosed, a few tests are done to help identify the specific type of cancer. This is called **confirmatory testing**. After this, a series of tests are done to determine the burden of cancer in the body and where it is located. This is called **staging**.

To stage solid tumors, the doctor looks at the size of the tumor, the lymph nodes affected, and where it has spread.

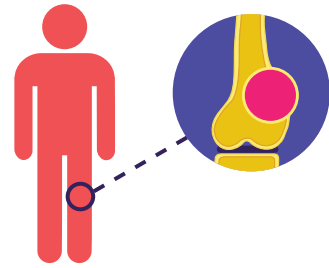
To stage lymphoma, the doctor checks the lymph nodes, bone marrow, liver, spleen, lung, and the rest of the body around the cancer site. Some special tests such as genetic testing of tumours may also be carried out to assess the curability of the cancer.

DEVELOPMENT OF CANCEROUS CELLS IN AN ORGAN

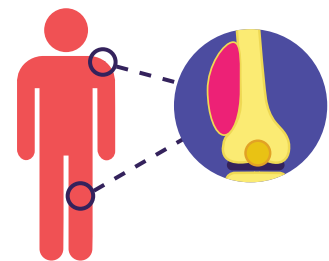
THE CANCER IS SMALL AND ONLY IN ONE PLACE IN THE BODY.



THE CANCER HAS SPREAD INTO PARTS OF THE BODY CLOSE TO WHERE IT STARTED.



THE CANCER IS LARGE OR MAY HAVE SPREAD TO OTHER PARTS OF THE BODY.



Primary and Secondary cancer

The **primary** cancer is where the cancer started. If some of the cancer cells break away from the primary cancer site and settle in another part of the body this cancer is then called a **secondary** cancer or metastases. The cancer cells can spread locally, by entering the bloodstream or the lymphatic system. Secondary cancers are made up of the same type of cells as the primary cancer.

Cancer that has spread is called metastatic cancer.

THE TREATMENT OF CANCER

There are 3 main types of treatment for cancer - Surgery, Chemotherapy and Radiation Therapy.

The type or combination of treatment used depends on the type of cancer the child has. The doctor will advise you on which treatment is the best option.

The 3 main types of cancer treatment:

1 Surgery

The tumour is physically removed by an operation.



2 Chemotherapy

Medical drugs are used to slow or stop the growth of cancer cells.

These drugs are given by:

- **Intravenous (IV) (drip):** injection into a vein
- **Oral, (PO or O):** as tablets or capsules
- **Intramuscular (IM):** injection into muscle
- **Subcutaneous (SC):** injection just under the skin
- **Intrathecal (IT):** by lumbar puncture

These chemotherapy drugs travel through the bloodstream. As the drugs are carried in the blood, they reach and destroy cancer cells all over the body. Therefore, chemotherapy is very useful in treating cancers that are generalized e.g. blood cancers or those that have spread to other parts of the body. The chemotherapy drugs destroy the cancer cells permanently but also affect the healthy cells. The healthy cells affected by the drugs repair themselves over a period of time. However, the healthy cells need time to recover, so chemotherapy is given as a series

of treatments called cycles/phases, which are separated by a few weeks.

Chemotherapy drugs can cause side effects. Since every child is different, children may react to chemotherapy differently, and may have very variable but usually mild side effects.

3 Radiation therapy

High doses of radiation are applied to stop the cancer cells from growing.

Radiation is an invisible treatment where high-energy rays from a machine are used to destroy the cancer cells in one particular area of the body. This treatment is given in daily sessions at the hospital. Each session takes about 10 to 15 minutes. The overall length of time of the treatment depends on the type of tumour and may be from 2 to 6 weeks.

Unfortunately, radiation kills some healthy cells as well as cancer cells, and this causes some side effects like fatigue, skin change and loss of appetite.

POSSIBLE SIDE EFFECTS OF CANCER TREATMENT

Nausea and vomiting

These may start immediately after chemotherapy or occur several days later. These effects last for a variable period of time (hours to weeks). Medications (called anti-emetics) will be given to decrease the nausea and vomiting after chemotherapy.

Diarrhea

This may develop at any time after the start of chemotherapy and is usually due to one of two reasons. First, the chemotherapy drug may affect the intestines. Second, it may be due to unhygienic food consumed during the period of chemotherapy. (e.g. fast foods, fruit juices & coconut water from road-side vendors).



Sores and ulcers in the mouth and throat

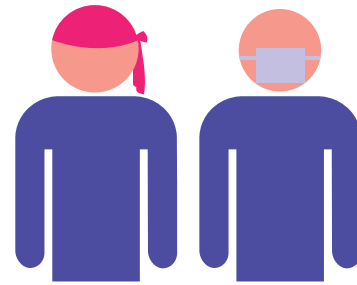
These effects typically start few days after the start of chemotherapy. The child should maintain good oral hygiene. Please inform the doctor immediately if the child develops sores or ulcers in the mouth.

Constipation

This is usually a side effect of anti-emetics prescribed with the chemotherapy drugs. However it may also be due to the chemotherapy drugs themselves. Please inform the doctor if the child experiences constipation. It may seem to be unimportant but constipation may have significant repercussions on the treatment by causing other complications.

Hair loss

The child might have partial or complete hair loss during treatment. There is no proven effective measure to prevent this side-effect. Most children will regain the hair within 4-6 months of completion of chemotherapy.

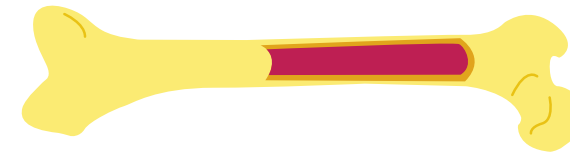


Low white blood cell counts (leukopenia) with or without infection

This complication usually starts about 6 to 7 days after start of chemotherapy and lasts for a variable period of time (usually few days). Low WBC counts may or may not be associated with infection. The first sign of infection is usually fever ($\geq 100^{\circ}\text{F}$) although some patients can develop severe infection without fever. Please inform the doctor immediately if the child has fever or you see other signs of infection. Refer to the section; SIGNS OF INFECTION.

Extravasation

A small leakage of the chemotherapeutic drug can cause pain, swelling and ulceration at the site of injection. Please inform the doctor if this happens.



1

RED BLOOD CELLS



2

WHITE BLOOD CELLS



lymphocyte



eosinophil



neutrophil



basophil



monocyte

3

PLATELETS



COMPOSITION OF BONE MARROW

Low platelet counts

This can develop at a variable time after the administration of chemotherapy (usually in the 2nd week) and last from a few days to several weeks. Platelet count is important because the chance of spontaneous bleeding (for e.g. from nose, gums, skin, or with vomiting or stools) increases with low platelet count particularly when it falls below 20000/mm³ or when accompanied by fever.

The most worrisome but rare site of bleeding is the brain, which can lead to altered consciousness. During low platelet counts, you should not give the child any medications without asking the doctor, prevent cuts and any kind of injury and also avoid strenuous physical activity.

Platelet transfusions may be required (as decided by the doctor) in some patients. Please understand that transfusions may be arranged by the hospital subject to availability. It is advisable to keep blood and platelet donors ready in case of an emergency. Please talk to the doctor about this.

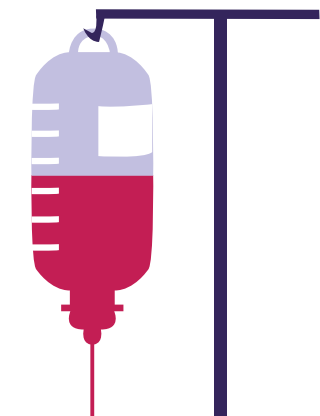


Anemia

This refers to low hemoglobin levels in the blood and is a well-documented side effect of many chemotherapy drugs. This usually occurs after several cycles of chemotherapy. There are several other factors that may contribute to the development of anemia, e.g. bleeding, heavy or prolonged menses, pre-existing malnutrition, poor food intake etc.

The symptoms of anemia are weakness, fatigue, palpitations, shortness of breath, poor concentration etc. The doctor may decide to give the child blood transfusions to treat this condition or the child may require iron supplements and other vitamins.

FOR TIPS ON HOW TO COPE WITH THESE SIDE EFFECTS, PLEASE REFER TO THE SECTION ON PROBLEM SOLVING AND DIET.



BLOOD TRANSFUSION

DAY-TO-DAY CONCERNS



Talking with your child

Your first question may be, “Should I tell my child about the cancer?” You may want to protect the child, but children usually know when something is wrong. The child may not be feeling well, may be seeing the doctor often, and may have already had some tests. The child may notice that you are afraid. No matter how hard you try to keep information about the illness and treatment from the child, others - such as family, friends, clinic or hospital staff—may inadvertently say things that let the child know about the diagnosis. In addition, it will upset the child to find out that you were not telling the truth; the child depends on you for honest answers.

Telling children about their cancer is a personal matter, and family, cultural, or religious beliefs will come into play. It is important to be open and honest with the child because children who are not told about their illness often imagine things that are not true. For example, a child may think that they have cancer as a punishment for doing something wrong. Health professionals generally agree that telling children the truth about their illness leads to less stress and

guilt. Children who know the truth about their illness are more likely to co-operate with treatment. You may share the information about the illness based on the child’s age after discussing it with the child psychologist at the hospital.

WHEN YOU SHARE THE INFORMATION WITH THE CHILD, REMEMBER TO REASSURE THE CHILD THAT CANCER IS CURABLE AND THAT ONCE IT IS CURED, THE CHILD WILL LEAD A NORMAL LIFE.

Finally, talking about cancer often helps to bring the family closer together and makes dealing with the cancer a little easier for everyone.

Schooling

The child may not be able to attend school due to hospital stays, side effects from treatment or general weakness. At times, they may miss a whole school year.

As the child’s health improves and treatment allows, going back to school can be either a relief or a challenge. It depends from child to child - some children view school as a refuge where they can forget all their troubles and feel ‘normal’ again, while others dread going back because they look different and worry that their friends and

teachers will act differently with them.

To make sure that children do not have problems in school (whether they are emotional, physical or about schoolwork), it is important to talk to the teachers. If the problems are about schoolwork, you can help by making sure they do their homework regularly, and help them understand what they have missed out.

For toddlers with cancer, who have not started school as yet, a question arises on whether you should send the child to school (with the risk of infection), or whether you should delay sending the child to school (with the risk of limited social growth and development).

There is no “right” decision—this is a very personal choice. If you are confused, the doctors will help you to decide the “right time” to send the child to school.



EFFECTS ON THE FAMILY



It can be overwhelming to deal with a child who has cancer, but remember that help is available to help you cope.

Feelings and emotions

These feeling and emotions are difficult to deal with, but remember they are NORMAL reactions to the situation:

- **Acceptance of diagnosis:** of the disease. You may refuse to believe that your child is suffering from cancer.
- **Fear:** about the fate of the child.
- **Sadness:** about the difficult times you and the child are facing.
- **Guilt:** about the fact that the child has cancer and that you may have made some mistakes.
- **Anger and uncertainty:** with doctors, hospital staff, family, friends, and even the child.
- **Financial stress:** worries about the cost of medical treatment and how it will affect your family’s financial situation.

Information and support

Information and support are key to feeling more sure and ready to help the child get better. The more you know about cancer, the less confused or unprepared you will feel. Information and support are available from doctors, hospital staff and booklets like these that are available at cancer hospitals.

Looking after yourself

It is very important to take care of your own needs. You must keep yourself physically and mentally fit. Eating well, sleeping well and taking care of your own health issues and talking about your feelings to friends or family are all important for this.

Only if you are well, can you look after the needs of the child who is unwell.

Dealing with other members of the family

Close family relatives and friends
The adults of the family may experience the same feelings and emotions that you are feeling. They should be given accurate information about exactly what is happening, and should be asked for their help and support.

Brothers and sisters of the child
The siblings of the child may feel all the same things you feel, however, since they may be young and separated from you, their feelings may be intensified. The confusion and separation from you and their ill sibling may lead to disruptions in

their daily routines. Also, they may feel left out and angry towards the ill child because of the lack of your attention.

- It is common for siblings to:
- Withdraw and become quiet
 - Cry easily
 - Become frustrated and angry
 - Become disruptive in school
 - Miss school
 - Get lower grades
 - Fight/ argue with their friends
 - Be rebellious towards authority

It is important to not completely overlook your other children. Arranging to spend some time alone with them may help to make them feel less anxious and irritable. Asking for teachers and other members of the family to help and support them may also be a good idea. It is essential that you keep your other children as informed and as engaged as possible.



LOOKING AFTER A CHILD WITH CANCER

Children with cancer may have a low white blood cell count (WBC) for a variety of reasons. Low WBC count may be due to chemotherapy, radiation therapy, or sometimes the cancer itself. One type of white blood cell called neutrophil, is especially important in fighting infections. A shortage of neutrophils in the blood is called **Neutropenia**. Neutropenia makes the patient susceptible to bacterial or fungal infections, which may at times be life-threatening.

Signs of infection

Fever is a sign of infection and the child has to be treated or seen in the hospital by the doctor.

Other Common indicators of Infection:

- Chills, shivering, sweating
- Loose motions
- Sore throat and / or cough
- Burning during urination
- Redness or swelling in the skin or in the genital area
- Unusual vaginal discharge or swelling

Temperature checking

Learn the correct procedure to check the child's temperature.

For a young child take the temperature in the armpit:

1. Use a digital thermometer so that the reading can be understood clearly.
2. First wipe the arm pit with a clean cloth and then put the bulb in the arm pit and have the child hold it there for 2 minutes and then check the temperature.
3. Don't touch the bulb / tip of the thermometer, as this may result in a wrong temperature reading.
4. Keep a daily record of the child's temperature by recording the child's temperature at the same time everyday.

For an older child take the temperature in the mouth:

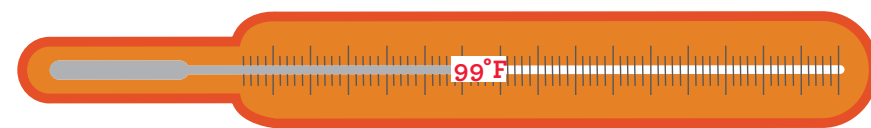
1. Use a digital thermometer so that the reading can be understood clearly.
2. Make sure the child has not eaten or drunk anything for at least 15 minutes before taking the temperature. This can give an incorrect reading.
3. Disinfect the bulb and stem of the thermometer with a Dettol solution. Wipe it dry.

4. Insert the bulb end of the thermometer under the child's tongue, toward the side of the mouth. Tell the child to hold the thermometer gently with lips closed, for 2 minutes.
5. Remove the thermometer from the mouth gently and read the temperature.
6. Don't touch the bulb / tip of the thermometer, as this may result in a wrong temperature reading.
7. Keep a daily record of the child's temperature by recording the child's temperature at the same time everyday

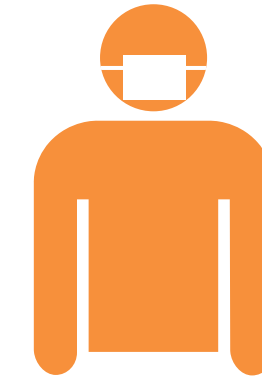
If the fever is more than 99°F, sponge the child with cool tap water. Follow the doctor's instructions and give the correct dosage of the fever reducing medication and bring the child to the hospital OPD or Casualty Ward.

If you are far away from a hospital give the child the antibiotics prescribed by the doctor and come to the hospital as soon as possible.

If you are outside the city where the hospital is, take your file and go to the local doctor for antibiotics and a CBC check.



BASIC PRECAUTIONS TO TAKE TO PREVENT THE CHILD FROM CONTRACTING AN INFECTION



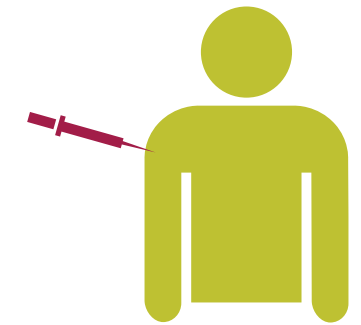
1 WEAR A MASK



2 AVOID CROWDS



3 AVOID PEOPLE WITH COLDS, FLU, BOILS



4 AVOID CHILDREN WHO HAVE BEEN RECENTLY IMMUNIZED

There are several measures that can help to lower the risk of infections. You must follow the instructions regarding hygiene and diet given in the next few pages.

Despite these precautions some patients will develop infection. In the vast majority of patients, infection can be controlled with either oral or injectable antibiotics, if it is diagnosed and treated early. In very few children, infections can be dangerous.

The child must report to the hospital as early as possible if they develop fever or any other signs

of infection after the administration of chemotherapy.

In an emergency, the hospital will never be closed for the child. Hospital emergency departments (casualty) are always open.

The doctor may call the child to check the blood counts after the 1st or subsequent cycles of chemotherapy.



LOW BLOOD COUNTS CANNOT BE ALTERED BY ANY SPECIFIC FOODS.



PREVENTING INFECTIONS

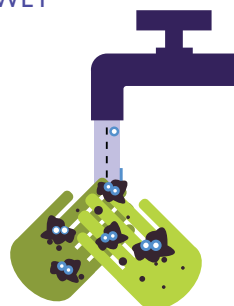
Hand hygiene

Simply washing hands in the correct way can prevent many cross infections.

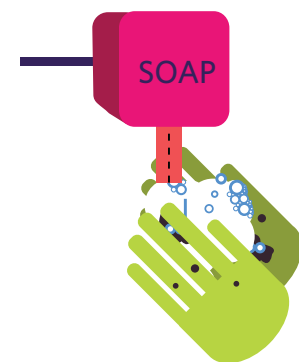
1. Learn to wash hands in the correct way with antiseptic soap, each time, after using the toilet and before eating food.
2. The child and parents must remove finger rings before washing their hands, and dry their hands properly with a clean cloth after hand-washing.
3. If you do not have access to soap and water then use a hand rub Technique—First take hand rub on palm, rub it on palms and the back of hands and allow it to dry completely.
4. Wash the child's hands often during the day, especially when they come from outdoors, before they eat, and before and after they use the toilet.

5. While the child is in hospital, never touch the child without using hand rub or allow any doctor/nurse/relatives to do so.

1. WET



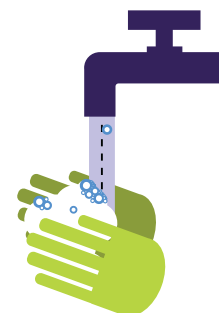
2. SOAP



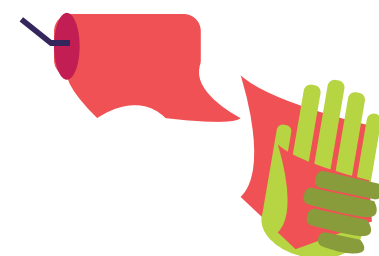
3. WASH FOR 20 SECONDS



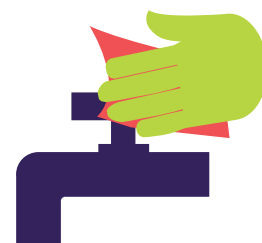
4. RINSE



5. DRY

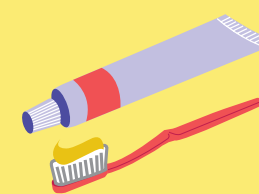


6. TURN OFF WATER WITH PAPER TOWEL



Dental hygiene

1. The child's teeth should be brushed twice a day, once before breakfast and once after dinner. If platelet counts are normal, then the brushing should be done with a soft bristle toothbrush and toothpaste. If the counts are low, brushing should be done with the child's finger to avoid bleeding.
2. The child should gargle with Chlorhexidine mouthwash (ask your doctor or chemist) at least 3-4 times a day, after **every meal** to prevent mouth ulcers and infections. While preparing the mouthwash, mix equal amounts of clean drinking water and mouthwash. The child must hold the solution in the mouth for 30 seconds and then spit it out.
3. If the child is very young and cannot use mouthwash, apply a Candid mouth paint inside the child's mouth. Before applying it, the child's mouth should be cleaned with a clean cloth that is washed with Dettol solution. To make the 'paint' more effective, the child must not eat or drink anything for half an hour after the 'paint' is applied.
4. A Clotrimazole (Clogen) tablet (ask the doctor) should be slowly



dissolved in the child's mouth thrice a day to prevent fungal infections.

Body hygiene and skin care

- It is important to keep the child's skin and hair clean. The child must bathe twice a day and wear clean cotton clothes. Change soiled clothes frequently.
- Before the normal bath, the child must take a 'Sitz bath'. This prevents anal infection.
- After using the toilet, you and the child must wash your hands with soap and water.
- Clean the child's nose by blowing it gently into a soft tissue paper.
- Clean any cuts right away with warm water, soap and an antiseptic.
- Use lotion or oil to soften and heal the child's skin if it becomes dry and cracked.

Procedure for a Sitz bath:

1. Take half a tub of warm water
2. Add 2 caps of 10% Betadine solution.
3. Make the child sit in the water bath for 15-20 minutes

4. After this give the child a normal bath with soap and water.
5. If the child is very young and cannot sit up in a tub, then just clean the perianal area with diluted Betadine solution and plain water.

If the child is suffering from loose motions:

1. They should take a sitz bath 2-3 times a day.
2. The child's clothes must be changed if they are soiled.
3. Do not rub the perianal area otherwise the skin will ulcerate and be painful.
4. Allow the area to dry and then apply Zinc ointment. Make the child wear cotton diapers.
5. Wash your own hands with soap and water after you have helped the child in the toilet.



Nails and hair

Keep the child's and your own nails short and clean—no nail polish should be used.

If the child's hair is falling, trim or shave the hair off completely. This must only be done if blood counts are normal. Ensure that the blade used is new.

After shaving the head, the child should wear a cap or a scarf.

Playing

Encourage the child to wear a facemask continuously to prevent infection. The mask must be changed twice a day with a new, clean, washed mask.

Make sure the child plays with safe toys and does not put any sharp or small objects into their nose or ears.

Do not allow the child to play with any furry or dirty toys, or flowers and plants, as these may carry germs that cause infection.

Avoid sports and other activities that might result in injury.



Lung health

To prevent lung infections, avoid taking the child to crowded, dusty areas and construction sites.

Steam inhalation should be done twice a day.

Make the child do the following exercises:

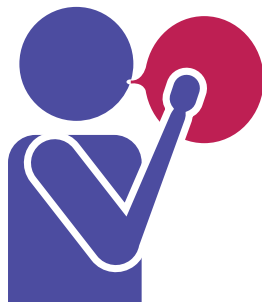
1. Deep breathing exercises (pranayam): Tell the child to take a deep breath, hold it for some time, and then relax.
2. Spirometry/ Bladder balloon exercise—the child should blow the spirometer/bladder balloon to its maximum capacity and hold for some time.

Parents' hygiene

It is extremely important for the parents and other people around the child to be hygienic. They should take a proper bath and wear clean clothes. Hair must be tied up properly. Nails must be cut and kept short and clean, and without any nail polish. Tobacco chewing or smoking should not be allowed anywhere near the child. Hands should be washed properly with antiseptic soap after going to the toilet and before coming near the child or serving food.

The child should not be brought into contact with anyone who is ill or has a cold / cough or any infections, loose motions, or skin rashes. In case the parents are not well, they should wear facemasks and try to stay away from the child.

Ensure that all visitors wash their hands before coming into contact with the child.



Clean living space

Bedroom / Bathroom

The bedpan and urinal used for the child should be cleaned and washed daily with a hypochlorite solution or Dettol solution.

Discard the waste products such as urine and vomitus immediately. They should not be kept lying under the patient's bed.

Keep the living area dry and clean, because moisture and humidity attract bacterial growth.

Store luggage properly in the cupboard.

Keep the child's bed clean and tidy. Change the bed sheets frequently.

Toilets and bathrooms should be cleaned daily with an antiseptic solution and the WC should be flushed properly after every use.

Floors should be swept and mopped twice a day with a phenyl solution.

Use nets on the doors and windows to prevent flies and mosquitoes.

Kitchen

Dispose garbage and waste materials properly.

Keep all foodstuffs covered.

Wash and dry utensils properly.

Hospital visitors

Only 1 or 2 visitors are allowed to be with the patient.

Instruct visitors to remove their footwear outside the ward.

Visitors must not touch the child without using hand-rub, sit on the child's bed or go very near the child.

If a relative is suffering from an upper respiratory infection, tuberculosis or other infection such as cold, cough, fever, loose motions, measles, chickenpox or any other kind of skin infections, do not allow them to visit the child.

Visitors who have recently taken Oral Polio Vaccine, Measles, Mumps, Rubella (MMR) or any other vaccine should not be allowed to come in contact with the child, because vaccines contain a weakened version of the same pathogen and in a child who is not well, it may cause a serious infection.

No small children are allowed to come to the hospital or sleep on the ill child's bed.

Vaccines

No vaccination to be given to the child during period of treatment except Hepatitis B vaccine. Please check with the doctor before giving any vaccinations.



DIET

Children recovering from cancer should follow a **Neutropenic** diet. This is a low bacteria diet, which decreases the amount of bacteria in foods and beverages and reduces the chances of infection developing in children with weakened immune systems.

Things to remember



YES

Get the child to drink more liquids.

Store food hygienically: cover everything and store food in a clean, dry place.

Boil water.

Give the child cooked food rather than raw food.

If raw fruits or vegetables are to be given, wash them in a solution of potassium permanganate and then peel all fruits and vegetables.

Keep hot foods hot and cold foods cold.

Buy individually small packaged foods, which are better than larger portions that result in leftovers.



NO

Do not buy or use a product if it is out of date.

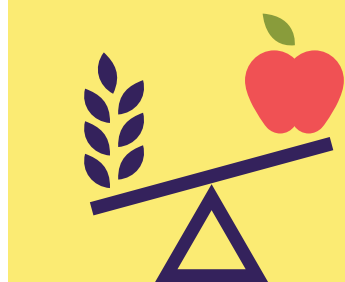
Do not expose food to large groups of people or people who have infections.

Do not use old, mouldy or damaged fruits and vegetables.

Do not consume food prepared in unhygienic conditions eg from roadside vendors .

Do not consume foods available in open containers.

Do not buy or use food in cans that are swollen, dented or damaged.



Instructions for washing fruits and vegetables

Potassium Permanganate

Solution: Mix enough Potassium Permanganate granules in water to make a light pink solution. Soak fruits/ vegetables in this for 5 minutes, and rinse well. This will effectively remove pesticides, bacteria and other pests. Too much potassium permanganate can be harmful, so be careful that the water is just light pink in colour, and not dark purple.

OR

Using Vinegar: Take a cup of vinegar and three cups of cooled boiled water, add a teaspoon of baking soda and store this solution in a bottle or a spray . This is useful in removing wax and bacteria, especially from 'over-glossy' produce such as apples, eggplant etc. For best results, use the vinegar solution to wipe / wash the fruits and vegetables. Rinse well with plain water before use.



Dietary instructions during treatment

During chemotherapy, make sure the child is drinking plenty of water and other liquids. This will help to reduce the toxic effects of the drugs and minimize the side-effects of chemotherapy (nausea, vomiting, loose motions, loss of appetite, taste alterations and food aversions).

Encourage the child to eat small frequent meals.

The food intake may be less during chemotherapy. Offer the child a balanced diet with foods which are high in nutrition E.g. fruit milkshakes with protein supplements, chikkis, laddoos, vegetable / dal /parathas etc.

Ideas to make food more nutritious:

Use combination of flours for making rotis. For example, to 1 kg wheat flour, add 100 grams oats flour, 100 grams soya flour and 100 grams of chana flour.

Add til seeds, groundnuts, flax seeds (alsi) to the plain bhakri/ rotla (jowar, bajra, nachni)

Use skim milk powder or any protein powder supplement to regular milk, buttermilk, milkshakes custards and puddings.

Use milk instead of water in cooking whenever possible. Add cream to vegetables, soups and other dishes.

Serve butter, oils, ghee with soups, sandwiches, salads and vegetables.

Grate cheese in soups, sauces, sandwiches, vegetables, mashed potato, rice and noodles. Add chopped hard boiled eggs to salads, vegetables and other dishes.

Sprinkle chopped nuts on fruits (banana, apple, pear), ice-cream, salads and vegetables.

Include red, yellow and orange coloured fruits and vegetables in the diet

Emphasize protein rich foods in the diet:

Milk and milk products, dals and pulses, nuts, ragi (nachni), bajra, lobia, soaked garden cress seeds (halim dana/ aliva), sesame seeds (til) and cooked soyabean and protein supplements.

To increase hemoglobin:

Consume iron rich foods like ragi, wheat germ, soyabean, lentils, turnips green, spinach, jaggery, green vegetables, beetroot, dried dates which are cooked (khajoor), mint (phudina).

Remember to have foods rich in vitamin C along with iron-rich foods to increase iron absorption. E.g. orange juice, limejuice, amla.



DIETARY RECOMMENDATIONS

BEVERAGES



YES

Boiled and cooled water

Freshly made ice from boiled cooled water

Canned or packaged juices

Fresh fruit juice made at home



NO

Water from taps, wells

Unboiled milk

Ice made from tap water

Open drinks left at room temperature for more than 1 hour

Fruit juice from roadside vendors

CEREALS



YES

All kind of cereals like ragi, jowar, bajra, wheat, rice, oats, rajgira etc

Freshly prepared rice, chappati/roti (hot and direct from stove), pasta, noodles

Bread and wheat bread (preferably toasted)

Homemade cakes & biscuits



NO

Reheated, refried or leftover food

Any bread with uncooked dried fruits

Cakes with creams

Bakery products like toast or khari from roadside vendors

FRUITS



YES

Thick smooth skinned fresh fruits (eg. Banana, oranges, mosambi, water melons, musk melons, pomegranate, peach, guava, apples, pears, papaya, apricot etc). Wash and peel all fruits

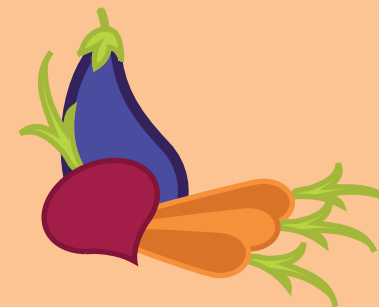
Smooth thin skinned fruits like chikoo should be unbruised. They should be washed well and peeled



NO

Any fruit that is rough skinned or cannot be peeled (eg sitaphal, strawberries, litchi, raspberries, grapes, cherries, jamun)

VEGETABLES



YES

All vegetables should be washed well, peeled and then pressure-cooked

Carrots and cucumbers can be eaten after washing with potassium permanganate and peeling.

Vegetables like tomatoes, which cannot be peeled, should be washed with potassium permanganate and cooked in boiling water for one minute.

Rough surfaced vegetables that have been cooked for at least one minute in boiling water (eg cauliflower, broccoli)

All canned and cooked vegetables

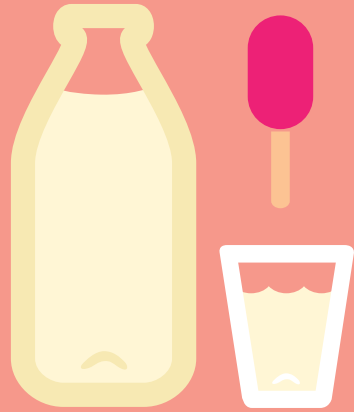


NO

Raw vegetables

Vegetables which are not peeled or cooked

MILK AND MILK PRODUCTS



Boiled milk

Pasteurized milk and pasteurized curds

Cheese made from pasteurized milk

Prepackaged or freshly homemade pasteurized ice cream

Commercially made nutritional products, supplements and baby formula

Use pre-packed curds as a culture to be used for setting curds.

Homemade or packaged paneer

Homemade milk sweets



Raw milk

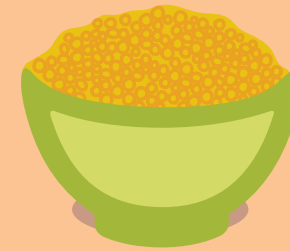
Unpasteurized milk and unpasteurized curds.

Ice creams made outside the home

Fresh unpackaged paneer

Milk sweets available in the market

DALS



All dals are a good source of proteins

Make thick dals

Add dal to soups

Mix flour of dals while making rotis.

Pulses should be soaked overnight and sprouted. This increases their nutritional value. Boil the sprouts when the neutrophils in the CBC report are in the low range (less than $1.0 \times 10^9/L$ or 1000 cells/mm^3)

Other options are roasted chana, daal chikki, soyabean



Raw sprouts

NUTS



Roasted and cooked nuts

Boiled groundnuts

Boiled almonds, walnuts, cashew nuts, dates, dried figs and raisins



Uncooked nuts and dried fruit like raisins, dates and figs

Raw groundnuts

SPICES



All kind of spices

PROBLEM SOLVING— COMMON COMPLAINTS

Loss of appetite, nausea or vomiting:



The child should avoid trying to drink or eat until vomiting stops.

After vomiting is controlled, the child should drink small amounts of cool, clear liquids (that do not contain milk) such as fruit juices, kanji, soups, tea or chaas. Then advance to full liquids (liquids that contain milk) and eventually a soft diet and/or full diet



1. Drink liquids at least an hour before or after mealtime instead of with meals.
2. Sip cold liquids throughout the day.
3. Suck on ice cubes.

1. If nausea is a problem in the morning, dry foods such as toast or plain biscuits, can be eaten. (However, if mouth/ throat is sore or there is the problem of a dry mouth, do not do this).
2. Eat small meals or snacks, whenever hungry— eating 3 regular meals a day is not necessary.
3. Eat foods that are cool, or at room temperature if warm food causes discomfort
4. Suck on a candy - this will help to change the taste in the mouth.

The child should:

1. Eat and drink slowly.
2. Chew food well for easy digestion.
3. Wear loose fitting clothes.
4. Avoid strong smells that bother the child eg cooking smells, smoke or perfume.
5. Not lie flat right after finishing a meal. Rest in a chair instead.
6. Breathe deeply and slowly when feeling nauseated.
7. Keep the mouth clean; brush at least twice a day.
8. Take a walk before meals, when possible. This may provoke hunger.



AVOID

1. Foods that are very hot or spicy
2. Greasy/oily foods. Go for a light and soft diet.
3. Eating for at least a few hours
4. Eating before treatment if nausea usually occurs during chemotherapy.

Other tips:

1. Distract the child by talking, listening to music, or watching a movie or TV show.
2. Use relaxation techniques to calm the child down.
3. Vary the child's diet by trying new foods and recipes.
4. Change the child's mealtime routine. For example, make the child eat in a different location.
5. Maintain a food diary to understand when nausea and vomiting occurs and its potential cause.

Loose motions

You must be very careful that the child does not get dehydrated.



Prepare an ORAL REHYDRATION SOLUTION (ORS) by mixing a packet of Electral / Pedialyte in the correct amount of water as per instructions on the packet. It is important to follow instructions carefully.

You can also prepare an ORS solution at home.

Recipe for making a 1-litre ORS solution:

1. 1 litre of clean, boiled and cooled water
2. One level teaspoon of salt
3. Eight level teaspoons of sugar
4. Stir the mixture till the sugar dissolves.

Store the solution in clean, covered container.

Let the child sip the ORS drink slowly. The ORS solution should not be gulped down.

A child under the age of two needs at least a quarter to a half-cup of the ORS drink after each watery stool.

A child aged two or older needs at least a half to a whole cup of the ORS drink after each watery stool.

Other tips:

1. Drink plenty of fluids to replace the fluids lost through diarrhea.
2. Drink caffeine-free drinks such as lassi, chaas, kanjis, soups, clear broth, strained fruit juices (without added sugar) or lemon-lime soda. Make sure the drink is at room temperature or cool and drink it slowly.
3. Instead of drinking fluids with meals, drink 30 minutes before or after meals.



1. Eat 6-8 small meals each day
2. Eat food at or near room temperature
3. Follow the BRAD-CK diet:-
B—buttermilk, banana (ripe), bread, biscuits
R—rice, rice kanji
A—apple (stewed), arrowroot kanji, annar (pomegranate)

T—toast

C—curds , carrot soup, paneer

K—khichadi, kanji, khus khus

4. Other good options are noodles, poha and any preparation made out of wheat or rice flour, soy milk, hard boiled eggs, boiled or mashed and baked potatoes without skin, boiled cooked carrots , cooked

fruits without the skins and mashed vegetables.
5. Eat more potassium rich foods such as banana, oranges, potatoes, peaches, apricots unless the doctor has told you otherwise.



AVOID

1. Fried, greasy or spicy foods
2. Extra sweet foods like sweets and chocolates
3. Caffeine, which is present in tea and coffee and some beverages like Coca Cola.
4. Milk and milk-based products (mithai)
5. Raw and unpeeled fruits and vegetables
6. Nuts
7. High fiber foods like broccoli, corn, dried beans, cabbage, peas, cauliflower; which can cause diarrhea and cramping.

Constipation



1. Drink plenty of fluids.
2. Warm and hot fluids work especially well.
3. Include thick soups, fruit juices, kanji in the diet.



Eat a lot of high fiber foods like green vegetables, fresh fruits, nuts, dried fruits like cooked raisins, dates, dried figs, roti made of unsieved flour, whole wheat breads, bran and popcorn

Feeling of fullness in the stomach



1. Eat small amounts of meals often and slowly. Do not leave long gaps between meals.



1. Eating 1-2 hours before and after any chemotherapy.
2. Oily and greasy foods.
3. Gas-forming foods like cabbage, cauliflower, cucumber, watermelons, pulses, onions, lentils.
4. Very late night meals.
5. Drinking liquids half an hour before and after the meals.

Other Tips

1. For heartburn, let the child sit up for about 1 hour after eating instead of lying down.
2. The child should eat in a relaxed manner without hurrying.
3. The child should wear loosefitting clothes.



Sore mouth/ throat

Good oral care is important during cancer treatment. Chemotherapy drugs can cause sores in the mouth and throat and can make them dry and irritated or cause them to bleed. Mouth sores are not only painful; they can become infected by the many germs that live in your mouth. It is important to take every possible step to prevent mouth sores.



1. If required use a straw to drink fluids.
2. Consume milkshakes which are smooth.
3. Suck on ice cubes



1. Eat foods cold or at room temperature.
2. Eat soft and pureed foods like soft cooked rice/ khichadi, biscuits soaked in milk, plain upma, macaroni, boiled and mashed apple

or pear, boiled and mashed potato, homemade paneer, pudding, ice cream, cheese, jelly and custard, scrambled eggs, banana, mashed vegetables.

3. Use butter, ghee, cream to make the foods tasty and easy to swallow.
4. Mix 2-3 spoons of protein powder and few drops of water to make a thick paste that can be licked by the child.



1. Hot and warm foods that can irritate a tender mouth and throat.
2. Irritating, acidic foods such as tomatoes, citrus foods (oranges, mosambi, and lemon) and spicy or salty foods.
3. Hard foods like raw vegetables, toasts, dry foods like khakhra, chikki, nuts, roasted pulses and also fruits which have more seeds like pomegranate, guava.

Dry mouth



1. Drink plenty of liquids.
2. Suck on ice cubes.
3. Keep sipping boiled and cooled water or fruit juices frequently.



1. Consume vegetables cooked in gravy that are soft and easy to swallow.
2. Consume roti which has been dipped in dal for few minutes, which makes it easy to swallow. Soften rotis with ghee, gravy or soups.
3. Suck hard candy to improve saliva production.

Other Tips

1. Use vaseline or moisturizer if lips are dry.
2. Encourage good mouth care as per doctor's advice.

AFTER DISCHARGE CARE

Continue to follow instructions for hygiene and diet regularly. During discharge, if you are having any doubts regarding medicines, then clarify them with the doctor immediately.

Give the proper medicine at the right time and in the correct dose.

Store medicines separately in an airtight container away from sunlight/ heat.

Purchase the brand of medicine prescribed by doctors – do not make changes without asking.

Do not give the child any herbal/ ayurvedic/unani or other medicines prescribed by any other doctor without asking your treating doctor since other medicines may harm the child and decrease the effect of chemotherapy.

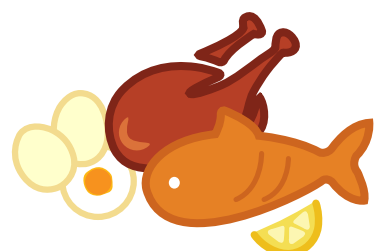
Conduct regular follow-up with blood investigations.

Keep the Bone Marrow site / LP skin prick site clean. Remove the bandage next day with soap and water.

If the child vomits the medicine within 1 hour of taking it, repeat the dose and inform the doctor.

Syrup should be given to the child with a clean syringe or spoon. The syringe / spoon should be washed and dried after every use. The syrup should be stored properly in a dry, clean and cool area or in a refrigerator.

Dietary recommendations for non vegetarian families



You may decide to give the child eggs and meat after you reach home where these items can be cooked hygienically. Please source the eggs and meat from reputed vendors and follow the instructions below.

EGGS



•Eggs must be cooked well eg. hardboiled egg, omlette, bhurji



•Any raw, undercooked or soft cooked eggs

NON VEGETARIAN



•To be eaten only if the neutrophils are in the normal range
•Pressure-cooked non-vegetarian food
•De-skinned chicken



•Meats that are not well cooked
•Salted and dried fish eg bombil
•Shell fish eg crabs
•Organ meats like liver
•Pork

For blood and/or platelet donation:

Please arrange for donors and donate blood or platelets as advised by the doctors and preserve the donation cards. In case of difficulty in getting blood donors, please meet the blood bank social worker for guidance.

For patients with blood cancer/ leukemia, 8-10 blood donors of any blood group should come to the hospital and donate as soon as possible. Also, 1-2 platelet donors of same blood group (not immediate

family members) should come and get tested. After this testing should be done monthly.

A PLATELET DONOR CAN GIVE PLATELETS EVERY WEEK. A BLOOD DONOR CAN GIVE BLOOD ONCE IN THREE MONTHS.



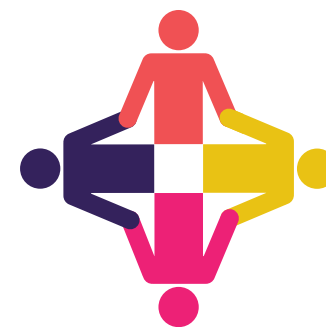
SOCIAL SUPPORT

Please arrange for a cost certificate from your doctor.

Arrange for your Ration card and Income certificate from your Local District Tehsildar or an affidavit from a Notary before meeting the Hospital social service department for help.

Please preserve bills of the money spent to get any help from social organizations.

Please do not bribe any hospital staff. If anyone demands money please inform your doctor.



ACCOMMODATION

St. Jude India ChildCare Centres

St. Jude India ChildCare Centres with its centres in Mumbai and Kolkata, provides free of cost housing for children suffering from cancer along with their parents. They also provide nutritional support, transportation services to the hospital, educational and counseling services to keep families engaged and motivated during their time away from the hospital. St. Jude's aims at providing a "home away from home" for these children, by offering them the physical and emotional necessities that will give them a better chance of beating cancer.

Our centres are located in Mumbai and Kolkata.

Our website is : www.stjudechild.org



St. Jude India ChildCare Centres

Mumbai

Parel

Centre 1:

St. Jude India ChildCare Centres
Dr. Mhaskar Hospital
31 B. D. D. Chawl
Sakhubai Mohite Marg
Off N. M. Joshi Marg (Delisle Road)
Police Station
Mumbai 400 013
Telephone number: +91 22 23092800

Parel

Centre 2 & 3:

St. Jude India ChildCare Centres
74, Jer Bai Wadia Rd
2nd Floor, Indian Cancer Society
Boiwada, Parel (E)
Mumbai 400 012
Telephone number: +91 22 24171614

Navi Mumbai

Centres 4, 5, 6 & 7:

St. Jude India ChildCare Centres
TATA Memorial Hospital
Advanced Centre for Training &
Research in Childhood Cancers

SECTOR 22

Kharghar,
Navi Mumbai 410210
Telephone number: +91 22 64526602

Kolkata

St. Jude India ChildCare Centres
13/295 Action Area 1
DD-196 New Town
Kolkata 700156
Contact no: +91 33 65400896

St. Jude India will also soon have centres in Jaipur and Delhi. Please contact the Parel centre, Mumbai for more details or log onto www.stjudechild.org email: stjudechild@gmail.com



BIBLIOGRAPHY

Children's cancer and Leukaemia Group:
<http://www.cclg.org.uk/index.php>

Cancer Research UK
<http://www.cancerresearchuk.org/home/>

Macmillan Cancer Support
www.macmillan.org.uk/Cancerinformation/Cancertypes/Childrenscancers/

The Children's Hospital of Philadelphia
<http://www.chop.edu/service/oncology/home.html>

American Cancer Society
<http://www.cancer.org/Treatment/ChildrenandCancer/index>

National Cancer Institute
<http://www.cancer.org/Treatment/ChildrenandCancer/index>

ACKNOWLEDGEMENTS

A Parent's Guide to Childhood Cancer has been compiled and edited by Ayesha Mangaldas on behalf of St. Jude India ChildCare Centres with the expert advice and support of Consultant Pediatrician; Dr Raju Khubchandani and the Pediatric Oncology Team at Tata Memorial Centre, Mumbai; Dr Shripad Banavali, Dr Brijesh Arora, Dr Tushar Vora, Dr Girish Chinnaswamy and the panel of nutritionists; Poonam, Purvi and Swati. This guide would not have been possible without the unstinting support of this team and their valuable inputs and advice.

We would like to thank the design team at Beyondesign - www.beyondesign.in - for their amazing effort and help.

We would like to thank Dr Purna Kurkure for pointing us in the right direction.

A big thank you to all the team members and staff at St. Jude's that provided crucial and timely feedback.

We would like to acknowledge our gratefulness to the websites and cancer guides we referred to. These are listed in the Bibliography Section. We used these sites for basic information and image ideas. These are great places to visit for more details on Childhood Cancer.

WHEN TO CONTACT THE DOCTOR IMMEDIATELY:

IF THE CHILD HAS:

1. Fever more than 99°F
2. Severe headache
3. Severe abdominal pain/ chest pain
4. Repeated vomiting and/or loose motion
5. Severe weakness
6. Drowsiness
7. Breathing difficulty—fast or slow respiration
8. Convulsion/fits
9. Bleeding from any site
10. Not eating at all.
11. Not passed urine for more than 12 hours.

Bring the child immediately to the Hospital OPD or Casualty Ward.





St. Jude India ChildCare Centres