A PARENT'S GUIDE TO CHILDHOOD CANCER

THE PEDIATRIC ONCOLOGY DEPARTMENT TATA MEMORIAL CENTRE AND ST. JUDE INDIA CHILDCARE CENTRES
THE GOOD NEWS IS THAT CHILDHOOD CANCERS ARE CURABLE – IF DETECTED EARLY AND TREATED APPROPRIATELY.
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.
REMAINING 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. 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.

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.

6. **Show Affection**
   Be affectionate—it shows the child that you care. Children need reassurance when faced with a new and difficult situation.

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.

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The best thing you can do for a child who has been diagnosed with cancer is to remain positive and hopeful.
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 clump together they form a tumour. Tumours can grow in any part of the body. They tend to destroy the surrounding healthy organs and this is dangerous. Cells in these tumors are abnormal and divide without control or order.

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.

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**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.

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.

Diabetes
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 roadside vendors).

Diarrhea
These may start immediately after chemotherapy or occur several days later. Low WBC counts may or may not be associated with infection. The first sign of infection is usually fever (≥100°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.

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.

Low white blood cell counts (leukopenia) with or without infection
This complication usually starts about 6 to 7 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.

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 20,000/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.
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, doctors, hospital staff, family, friends, and even the child. 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.

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. Children who know the truth may share the information about the illness based on the child’s age to co-operate with treatment. You may refuse to believe that your child is suffering from cancer.
- **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.
- **Anxiety 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.

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 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.
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.

**Looking After a Child With Cancer**

**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.

**Low Blood Counts Cannot Be Altered by Any Specific Foods.**

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

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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.

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.
- 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.

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

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.

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.

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.

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 infections 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.
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, lime juice, amla.

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

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.

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.

Instructions for washing fruits and vegetables

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, chikis, 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).

To increase hemoglobin:

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.

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.

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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

NO
- Any fruit that is rough skinned or cannot be peeled (eg sitaphal, strawberries, litchi, raspberries, grapes, cherries, jamun)
- Smooth thin skinned fruits like chikoo should be unbruised. They should be washed well and peeled

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

FRUITS

YES

NO

VEGETABLES

YES

NO

CEREALS

YES

NO

BEVERAGES

YES

NO

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**Milk and Milk Products**

- **YES**
  - 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

- **NO**
  - Raw milk
  - Unpasteurized milk and unpasteurized curds.
  - Ice creams made outside the home
  - Fresh unpackaged paneer
  - Milk sweets available in the market

**Dals**

- **YES**
  - 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 x 10^9/L or 1000 cells/mm^3)
  - Other options are roasted chana, dal chikki, soyabean

- **NO**
  - Raw sprouts

**Nuts**

- **YES**
  - Roasted and cooked nuts
  - Boiled groundnuts
  - Boiled almonds, walnuts, cashew nuts, dates, dried figs and raisins

- **NO**
  - Uncooked nuts and dried fruit like raisins, dates and figs
  - Raw groundnuts

**Spices**

- **YES**
  - 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.

AVOID
1. Foods that are very hot or spicy
3. Eating for at least a few hours after a meal.
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 Electrolyte/Pedialyte in the correct amount of water as per instructions on the packet. It is important to follow instructions carefully.

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.
3. Make sure the drink is at room temperature or cool and drink it slowly.
4. Instead of drinking fluids with meals, drink 30 minutes before or after meals.

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, keri 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.

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. 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.

Other Tips

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

Dry mouth

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

Other Tips

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

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 must be cooked well eg. hardboiled egg, omlette, bhurji
- Any raw, undercooked or soft cooked eggs

- 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.

Dietary recommendations for non vegetarian families

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.
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. Judes 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

Mumbai

Parel

Centre 1:
St. Jude India ChildCare Centres
Dr. Mhaskar Hospital
31 B. D. D. Chawl
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SECTOR 22
Kharaghaz,
Navi Mumbai 410210
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Kolkata

St. Jude India ChildCare Centres
13/295 Action Area 1
DD-196 New Town
Kolkata 700056
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

e-mail: stjudechild@gmail.com

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St. Jude India ChildCare Centres

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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.gov/Treatment/ChildrenandCancer/index
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For any information on this guide please email stjudecancerguide@gmail.com
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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/fuls
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.