

Indian Academy of Pediatrics (IAP)



## GUIDELINES FOR PARENTS

# Care of Children with Cancer

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### 10 FAQs on CARE OF CHILDREN WITH CANCER

1. Why did my child develop cancer? Did I do anything wrong or miss any important care that led to the development of cancer?
2. What is chemotherapy? What are the common side effects to look out for during chemotherapy?
3. What should be done in case my child develops fever?
4. My child cannot eat because of nausea and poor appetite. What should I do? What kind of diet I should give to my child?
5. How should I care for my child's hygiene during chemotherapy?
6. My child has a central venous line for chemotherapy. How should I care for it at home?
7. Should I continue with his vaccinations? Should he get the "Pulse Polio" and other childhood vaccines?
8. My teenaged child is very withdrawn after learning about the diagnosis of cancer. How should I deal with this? How should I help my child cope with loss of friends and missing school?
9. What and how much information about the cancer should I share with my child?
10. Can cancer spread to other family members? Can my other kids sleep or play or eat with this child?

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## Care of Children with Cancer

### Q1

**Why did my child develop cancer?  
Did I do anything wrong or miss  
any important care that led to the  
development of cancer?**

Cancer is an uncontrolled division of cells. The normal human body has some systems in place that keeps the division of cells under check. When this system fails, the cells keep dividing and this leads to growth of misshapen, poorly functioning cells that are cancer cells. These cells have a tendency to spread from their place of origin to other sites in the body. This spread is called metastasis.

Parents often have a feeling of guilt when their child develops cancer. They feel that they did not take good care of their child, or exposed them to some foods or electronic devices, or some feel that their pregnancy related issues led their child to have cancer. These are myths. Do not feel guilty. You could not have done anything to prevent the occurrence of cancer in your child. Sometimes children have some underlying disease such as Down syndrome or Fanconi anemia which predisposes development of cancer. But this is rare and in most cases, no reason can be found that leads to development of cancer or its spread.

## Q2

### What is chemotherapy? What are the common side effects to look out for during chemotherapy?

Chemotherapy is treatment with drugs to destroy cancer cells. These drugs kill the rapidly dividing cancer cells. These drugs also cause some damage to normal tissues which have rapidly dividing cells, such as the bone marrow and the lining of the gut. This accounts for much of the toxicity that is associated with chemotherapy. Fortunately, the normal tissues recover within days to weeks and resume their normal functions.

- Chemotherapy is given in cycles with periods of rest in between. This gives your child's body a chance to recover and build new healthy cells.
- Chemotherapy is given by intravenous injection (occasionally intramuscular), oral tablets or liquid suspensions. Some chemotherapy drugs are directly injected in the fluid that surrounds the brain and spinal cord through a procedure called "lumbar puncture".
- Common side effects are fatigue, nausea, diarrhea, vomiting, mouth sores, anemia and increased risk of infection. These side effects can be reduced and mitigated with proper drugs prescribed by your doctor.
- Long-term side effects depend on the type of treatment. Children especially with brain tumors and those getting radiotherapy have long-term issues such as hormonal imbalance, poor growth, and some effects on intelligence. Other late effects of some kinds of chemotherapy are potential damage to the heart muscle or effects on bone health.

## Q3

### What should be done in case my child develops fever?

Life-threatening infections may occur in children on cancer treatment. Often, the only manifestation is fever. Please bring your child urgently to the hospital emergency room (ER) in case of fever more than 100.4°F (38°C). You may give paracetamol to bring the fever down but this should not delay the urgent admission in ER. Your child may have special tests to determine the cause for fever and given antibiotics to control the infection.

## Q4

### **My child cannot eat because of nausea and poor appetite. What should I do? What kind of diet I should give to my child?**

Nausea is a side effect of most drugs used for chemotherapy. Your doctor will give your child medicines before, during, and after chemotherapy to keep nausea to a minimum. However, nausea is not entirely preventable. Dry foods such as puffed rice or biscuits are easier to keep down.

Cancer itself causes poor appetite, and chemotherapy, surgery, and radiotherapy all make it worse. Please ask for a referral to the nutritionist at your hospital.

- Children on treatment for cancer should be given fresh home-cooked food. Please ask your child what he/she would like.
- Both vegetarian and non-vegetarian foods are fine.
- The food must contain protein, carbohydrate, and fat in proper amounts. Include rice and roti, all kinds of dal, vegetables, and milk products.
- Eggs, fish, and chicken are good options, if your family is non-vegetarian.
- All kinds of fruits are good. Please ensure that the fruits are thoroughly washed before eating.
- Avoid oily, spicy, and deep fried foods as these may cause discomfort and may be difficult to digest.
- Small frequent portions of food are often helpful.
- Use local produce to make food interesting and appetizing for your child.

Ensure water intake of about 1.5–2 L depending on the age of your child. Avoid nutritional supplements and use only if recommended by your doctor or nutritionist. Expensive is not necessarily better.

Q5

### How should I care for my child's hygiene during chemotherapy?

Hygiene is a very important part of a child's care during cancer therapy.

- He/she should be given daily bath.
- The groin area should be washed thoroughly.
- If there is a peripherally inserted central catheter (PICC) line *in situ*, then it should be protected from exposure to water.
- Mouth care has to be done by brushing with a soft toothbrush twice a day and rinsing the mouth with clean water after every meal. Oral thrush is common in children with compromised immunity, and the doctor may prescribe medications in case this happens.
- One should avoid using ear buds or tongue cleaner.
- Often during periods of low blood counts, the doctors will prescribe sitz bath to prevent infections around the bottom area. Make the child sit in a tub with warm water, and add potassium permanganate or liquid Betadine.

Q6

### My child has a central venous line for chemotherapy. How should I care for it at home?

The central venous line (CVL) may be a peripherally inserted central catheter (PICC) line or a Hickman line. The PICC line is usually placed in the upper arm and the Hickman line in the chest. The CVL is the lifeline of children with cancer. It helps to administer chemotherapy, blood products, and antibiotics as well as draw blood for tests. It takes away the pain of repeated needle pricks which can sometimes be extremely challenging in children on treatment for cancer.

The central line needs a weekly dressing. Many central lines need to be flushed using saline flush/PosiFlush/heplock. Most units will have provision of central line dressing and flushing by trained nurses. Parents can also be trained to do the same. This has to be done with all sterile precautions, after wearing gloves. The central line should be protected from water and it should be covered during bath so that water does not seep through. Any pain or redness at or around the central line site should be immediately reported.

**Q7**

**Should I continue with his vaccinations? Should he get the “Pulse Polio” and other childhood vaccines?**

- Chemotherapy can lead to suppression of immune response in your child. Ideally, all the routine immunization should be deferred till 6 months after completion of chemotherapy.
- Live vaccines such as measles, mumps, and rubella (MMR), Bacillus Calmette–Guérin (BCG), chickenpox, and “oral Polio” must not be given during chemotherapy as these may cause serious infections. Inactivated vaccines such as diphtheria-pertussis-tetanus (DPT) should also be deferred until 6 months after chemotherapy to get proper response.
- Vaccination may be resumed from the point at which it was stopped.
- OPV is a live oral vaccine and must be avoided during and after chemotherapy. Even siblings should be given injectable polio vaccine instead of oral polio vaccine.
- Annual influenza vaccine is the only vaccine given during chemotherapy.
- Tetanus toxoid can be given in case your child suffers from injury and has not completed primary immunization.
- Rabies prophylaxis should be given in case of dog bite during immunization along with rabies immunoglobulin.

All nonimmune household contacts and siblings should take chickenpox vaccine and preferably influenza vaccine.

**Q8**

**My teenaged child is very withdrawn after learning about the diagnosis of cancer. How should I deal with this? How should I help my child cope with loss of friends and missing school?**

A diagnosis of cancer is devastating for both the family and the child, especially if the child is old enough to understand the meaning of the word and all the perils it stands for. The anxiety about physical pain and suffering, change in physical appearance especially loss of hair, the complete disruption of normal life, and the looming presence of the possibility of dying all cause immense emotional upheaval in the child. The child may suffer from extreme anxiety and panic attacks, emotional withdrawal and depression. These problems are only too easily overlooked by parents in the whirlwind of hospital visits, chemotherapy, complications of cancer treatment, and financial worries. Children also are very sensitive to anxiety and grief in their parents. Sometimes, children and especially teenagers are very reluctant to talk about their fears and emotions. Gentle probing may help your child open up to you. Open family discussions where emotions can be aired are very helpful.

Do encourage your child to stay in touch with friends over phone or on social media. Ask the school to send work that the child can do at home. Discuss the matter in detail with the school “Principal”. Most schools are very supportive and online education has made things easy. Your doctor will provide you with a certificate of illness and will specify the duration of leave from school. Try to keep life as normal as possible during the course of treatment. Many hospitals have counselors and teachers who can help.

Q9

### What and how much information about the cancer should I share with my child?

Please be open with your child. Talk to him/her about the diagnosis, treatment plans, and expected complications. Please do not try to hide anything because this may make your child lose faith in you. Try to answer all questions as honestly as you can. Your doctor will help you with this. There is a lot of online information on cancer meant for older children and your hospital may also provide you with booklets and pamphlets. Please make sure that you and your child are receiving correct information about cancer and treatment. Your doctor will certainly make time for you and your child and address all queries.

Q10

### Can cancer spread to other family members? Can my other kids sleep or play or eat with this child?

Cancer is a noncommunicable disease and it does not spread from person to person. Siblings or friends can play, sleep, or eat with the child who is undergoing treatment for cancer. However, we should make sure that the other children are not suffering from any viral illness, diarrhea, or runny nose. If the child comes in contact with anyone suffering from chickenpox or measles, please inform your doctor urgently. Children with cancer have compromised immunity and such infections may be dangerous. The severity of infections can also be disproportionately high. Hence, outdoor activities should be restricted to non-crowded open places, and visits from relatives and friends should be kept to a minimum.