COMMON QUERIES

As a parent how can I best help the recovery of my child during cancer therapy?
Ensure best hygiene practices, keep a positive attitude, take care of your own health.

How do I prevent infections in my child during treatment?
Practice frequent handwashing with soap & water, give your child a bath daily, keep child's clothes & bed linen clean. If anyone at home has cough/cold/fever; keep your child away from them.

Should I tell my child about the diagnosis?
It is important that parents inform their child in an age appropriate manner. If required the parents may take help of a counsellor.

When should I rush to hospital during treatment?
If your child has a fever, decreased oral intake, decreased urine output, bleeding from anywhere, rashes over the body, lethargy, abnormal behaviour or headaches, please consult your treating doctor.

CPAA has published two interactive booklets "Amit Beats Leukemia" and "Victory Over Cancer - Surabhi's Campaign" which uses stickers and colouring materials to help parents interpret the child's experience of leukemia and solid tumours respectively. For copies please write to webmaster@cancer.org.in

SUGGESTED DIET

To avoid infections at this time when the child's immunity is compromised, it is important to give them safe boiled water, fresh, home cooked food, fruits but only those with thick skins.

TO SUMMARISE

Survivors should be regarded as heroes. They should be viewed positively and seen as living proof of a struggle successfully won. CPAA constantly works to challenge the stigma associated with cancer, to ensure that there is no discrimination against patients in society, in marriage and employment by promoting their stories and showing the reality of their new lives. Education, information and real life stories are powerful tools to break stigma and eliminate discrimination.

- Childhood cancer- exact cause is unknown in most cases, can be due to cancer predisposition syndromes.
- In case of underlying syndrome, surveillance for early detection is the key.
- Parents should not blame themselves.
- Children are not Miniature Adults- the biology of disease, dose and treatment protocol differs.

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CHILDHOOD CANCERS

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Childhood cancers differ significantly from adult cancers in all important aspects including common sites, type, treatment and cure rate. Statistics show that about 50,000 children, adolescents and young adults ages 0 to 19 years are diagnosed with cancer each year in India. Globally about 2,60,000 new cases are detected every year. However, a large number go undiagnosed due to the lack of awareness of symptoms.

COMMON WARNING SYMPTOMS:

Continued unexplained weight loss
Headache, often with early morning vomiting
Increased swelling or persistent pains in bones, joints, back or legs
Lump/mass especially in the abdomen, neck, chest, pelvis or armpits
Development of excessive bruising, bleeding or rash

Constant infections
A whitish colour behind the pupils
Nausea / vomiting persistently or repeatedly
Constant tiredness or noticeable paleness
Eye or vision changes which are suddenly and persist
Recurrent or persisting fevers of unknown origin

Many of these symptoms could be mistaken for other ailments. Attention should be paid if such symptoms persist. An early diagnosis always equates to a good prognosis!

COMMON CANCERS IN CHILDREN

- **Acute Lymphoblastic Leukemia:** Blood Cancer
- **Lymphoma:** Cancer of lymph nodes which is home to different white blood cells
- **Wilms' tumour:** Most common malignant kidney tumour
- **Retinoblastoma:** Cancer of the immature cells of the retina in the eye
- **Hepatoblastoma:** Most common liver cancer
- **Brain tumours:** Cancer of the brain
- **Osteosarcoma and Ewing's sarcoma:** Cancers of the bone
- **Neuroblastoma:** Cancer that develops from immature nerve cells found in several areas of the body

The most common cancer is Acute Lymphoblastic Leukemia (ALL) which comprises almost one third of all childhood cancers. Leukemia is commonly known as blood cancer, but actually it is a cancer of the Bone Marrow, the spongy tissue at the core of some of our bones. It contains stem cells which develop into the red blood cells (RBC) that carry oxygen through our body, the white blood cells (WBC) that fight infections and the platelets that help with blood clotting. When this process is disturbed, children develop the typical symptoms associated with ALL like fatigue, Bone pains, fever, weight loss and are subject to repeated infections.

**For details on treatment of leukemia please refer CPAA's brochure on the subject.*

Childhood cancer is not linked to any lifestyle factors. It does not discriminate by race or socioeconomic status. It cannot be prevented.

COMMON TERMS

Blast cells: Refers to immature cells. When a child has ALL, immature blood forming cells or blasts increase in the bone marrow instead of healthy red or white cells. An increase or decrease in the percentage of blast cells is used to track the efficacy of treatment.

Treatment: Chemotherapy is usually the treatment of choice and may continue for 2-3 years going through a number of phases.

PHASES OF TREATMENT

Intensive Chemotherapy usually continues for 6-8 months.

Maintenance is oral chemotherapy which may go on for 2 years.

Remission Once the blast cells are deemed to be within range for a prescribed period of time, the child can resume a normal life.

Follow up The child must continue to consult the treating doctor as advised. **Cure** A child is considered cured if blood reports remain normal for 5 years. **Relapse** If, unfortunately blast cells reappear, this is called a relapse. Treatment may be repeated or alternate treatment such as a Bone Marrow Transplant may be considered.

Bone Marrow or Stem Cell Transplant (BMT/ SCT) The patient is subjected to high levels of chemotherapy to destroy the diseased bone marrow and then infused with healthy bone marrow or peripoetic stem cells from a carefully matched donor. The patient must be supported in a completely sterile environment until their own bone marrow is able to generate healthy cells. **Autologous BMT/ SCT:** Cases where the patient's own marrow or stem cells may be harvested and frozen for transplant.

Allogenic BMT/ SCT In a majority of cases, a donor such as a sibling or a matched unrelated donor must be found.

MYTHS OR FACTS

Childhood Cancer can be caused by: Cell phones, Power lines, Microwaves or Artificial sweeteners

Fact: We still don't know enough of what causes cancer in children.

Childhood cancer is contagious. Children with cancer are disease carriers and can be a threat to others.

Fact: Childhood cancer isn't contagious and is not infectious, nor can it be transmit-ted. It's absolutely safe to play, socialize and interact with childhood cancer patients as well as survivors.

All cancer treatments are toxic

Fact: The goal is to use minimal toxic therapies but treatment has to be balanced with cure. Toxic medicines are necessary to ensure children can lead normal lives once treatment is completed, and side effects are to be expected.

Alternative therapies can cure cancer

Fact: Some alternative therapies may prove harmful especially during chemotherapy or radiation. They may interfere with how these treatments work. It is recommended to avoid all alternative therapy until after main line therapy is completed and even then after informing the treating doctor.

Eating Sugar can make cancer worse, so stop during cancer chemotherapy

Fact: There has been no rigorous study to show that eating sugar will make your cancer worse or that if you stop eating sugar, your cancer will shrink or disappears.

Early diagnosis = Better Outcome

Fact: Delayed diagnosis results in a worse prognosis, greater morbidity of treatment and higher costs of care.

Vaccination is responsible for the global increase in cancer cases. Vaccination cannot be given during chemotherapy

Fact: Vaccines do not cause cancer. It is very important that no live vaccines or oral polio vaccination should be given during the course of chemotherapy. Vaccines can be safely given:

- After completion of therapy
- 6-12 months after Chemotherapy
- 2 years after Allogenic BMT/ SCT
- 1 year after Autologous BMT/ SCT

Survivors no longer need continuing, follow up care.

Fact: Continuing follow up care remains important for survivors. Vigilance and regular monitoring are recommended to avoid secondary cancers or chronic health conditions related to their initial cancer treatment.

Cancer treatment of children and adult is similar

Fact: No, it is not. The protocols differ significantly. Cancers that affect adults are very different from those that we see in children, with a few exceptions. The treatment depends on the type of cancer. Generally speaking, children can tolerate chemotherapy better than adults.

Children with solid organ tumors do not need chemotherapy if com-pletely resected by surgery

Fact: Discuss with your oncologist about need for chemotherapy or radiotherapy. Most tumors will require some chemotherapy (pre & post-surgery) to prevent the tumor from returning.

Can children attend school while undergoing chemotherapy?

Fact: Usually no, but it is important for them to stay connected by Home Schooling

- Children may be allowed to attend school depending on the type of cancer and the phase of treatment
- The Cancer Care team may be called upon to explain the child's diagnosis and care to teachers and peers
- It is important for a child to connect with peers and it would make it easier to integrate after treatment is completed, but infection must be avoided at all cost.

Childhood Cancer Survivors can never have a normal life; they will have a miserable, sad and dismal future

Facts: Most survivors are able to return to school and regular activities after treatment. Adjustment after treatment becomes easier with supportive family, teachers, peers, friends and community. Awareness helps immensely.

Survivors do poorly in school and employment.

Fact: Most survivors go on to lead perfectly normal lives

- Most survivors are high performing achievers who do very well in their education, career and personal lives.
- There are survivors who may have cognitive and learning disabilities (even children who did not have cancer could suffer from such syndromes), but this is not true for everyone

All survivors are genetically inferior and will have fertility problems. They can never have children

Fact: Some survivors may have fertility and reproductive issues, for example those who have had to undergo radiation to their reproductive organs, but it is NOT true for most survivors. It depends on the type of cancer and the treatment given. Doctors will advise patients on steps that can be taken to preserve fertility where possible.

Childhood cancer survivors have lower survival rate than adults

Fact: Childhood cancer patients do well with modern chemotherapy and treatment protocols. If they do not relapse, there is every chance of complete recovery without significant long term effects. Even those who undergo BMT/ SCT successfully have every possibility of leading a normal productive life. However, some childhood cancer survivors are at increased risks for late effects and secondary cancers; this isn't linked to life expectancy.

Infants do not feel pain and children tolerate pain better than adults

Facts: Young children experience higher levels of pain during procedures than older children. Infants are unable to tell you that they are hurt, but their behaviour reflects the intensity of pain.

Children become accustomed to pain or painful procedures.

Facts: Children are unique in their ways of coping; their behaviour may not show a specific indication of their pain level. They may exhibit fear of returning to the hospital. Distraction techniques help with coping.