

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Care of a Child with Leukemia

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10 FAQs on CARE OF A CHILD WITH LEUKEMIA

1. What is leukemia? How does it happen? Are there different types of leukemia?
2. What is the stage of the cancer in our child? Is it curable?
3. How long will the treatment last? How difficult the treatment is? Will the child be able to handle the side effects?
4. Will the entire treatment be done as an inpatient?
5. Why do we need further treatment, if disease comes under control after induction chemotherapy?
6. What precautions we need to take while the child is undergoing treatment?
7. What should we do in case child develops fever? Can we wait for it to resolve or we need to report immediately?
8. What is a central line? Why is it required? Cannot we do without it?
9. To fight against infections pediatricians are recommending the vaccination. As my child is under treatment, for leukemia, we have missed many vaccinations, so can we give him the vaccines now? Can we give vaccines to his sibling?
10. My mother said that there are some Ayurveda medicines which will cure cancer. So, is it safe to take those medicines?

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Care of a Child with Leukemia

Q1

What is leukemia? How does it happen? Are there different types of leukemia?

- Leukemia is cancer of the white blood cells. Leukemia is the most common type of cancer in children. It develops in the bone marrow and spreads into the blood. As blood circulates everywhere in the body, leukemia cells also circulate in whole of the body.
- The exact causal relationship between any risk factor and leukemia is not known. However, some of the genetic conditions predispose to leukemia, e.g., Down syndrome, Fanconi's anemia, etc. Leukemia does not happen due to fault in parenting or adhering to any specific diet. It is also not a communicable disease. It happens across the socioeconomic, geographical and cultural barriers.
- The most common leukemia is *acute lymphoblastic leukemia* (ALL) which happens in around 70–80% of children whereas another 20–30% suffer from acute myeloid leukemia (AML). Although both are blood cancers but they behave differently and thus need different treatment approaches.

(As ALL is far more common in children and the overall care of a child with leukemia remains the same, thus we shall focus our discussion around ALL)

Q2

What is the stage of the cancer in our child? Is it curable?

As leukemia is a cancer of blood and the blood circulates everywhere in the body, the staging of leukemia is done based on type of leukemia and its molecular characteristics. An important parameter to decide the risk of disease is response to treatment which is judged by “minimal residual disease” monitoring. It is an upcoming tool to decide the line of management of leukemias. This is called as “risk stratification” and the broad categories are as mentioned here. This helps the clinician to decide the intensity of treatment and also to some extent the duration of treatment.

Over the years, pediatric oncologist and researchers have strived really hard to improve the success rates of pediatric leukemia. Treatment of pediatric ALL is a remarkable success story with outcomes improving from <10% few decades back to >90% in recent times, if we strictly adhere to the treatment and follow all the advice given by treating pediatric oncologist (**Fig. 1**).

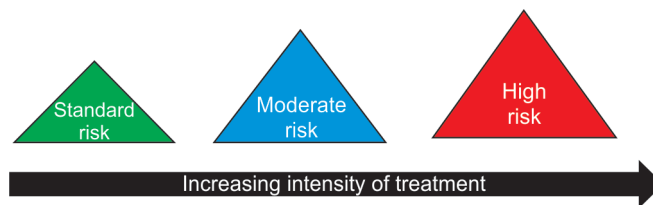


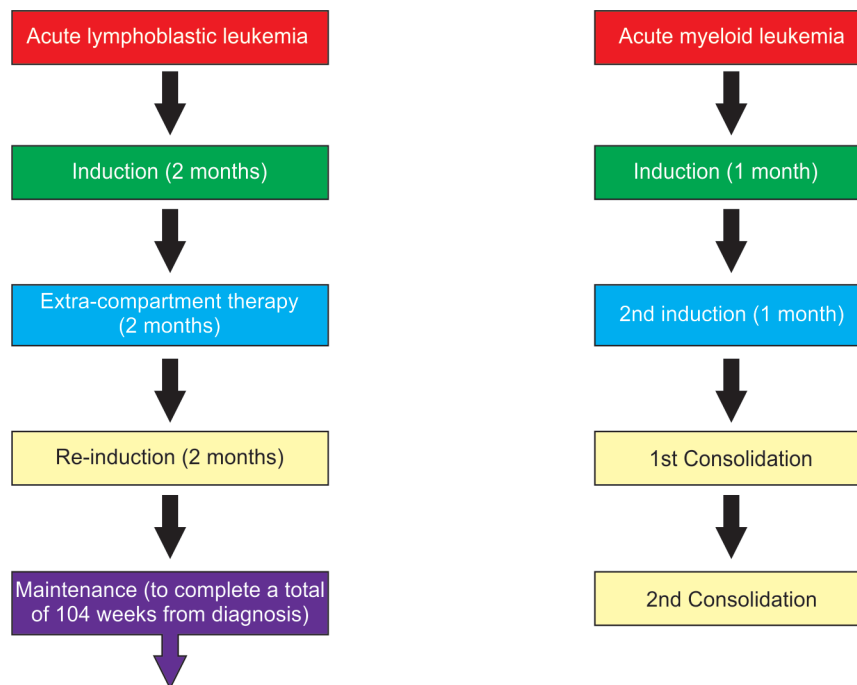
Fig. 1: Increasing intensity of treatment.

Q3

How long will the treatment last? How difficult the treatment is? Will the child be able to handle the side effects?

The duration of treatment depends upon various factors such as type of leukemia or stage of disease. Below-mentioned **Flowchart 1** demonstrates the for treatment of ALL and AML (**Flowchart 1**). These are standard phases of treatment, however, a number of times, the treatment is modified to suit the individual needs of the patient.

Flowchart 1: Treatment of acute lymphoblastic leukemia and acute myeloid leukemia.



- Leukemia treatment consists of chemotherapy in various forms such as oral tablets, syrups, injection that can be given intravenous/intramuscular and intrathecal, i.e., inside the spinal fluid.
- Chemotherapy has its side effects but most of side effects are temporary and manageable and children are able to tolerate chemotherapy very well as all chemotherapy are given according to child's weight. The adverse effects can be minimized by proper monitoring, following doctors' instructions given by the treating pediatric oncology team.

Q4

Will the entire treatment be done as an inpatient?

Depending on the clinical condition of the child at presentation, the treating pediatric oncologist decides the line of management which includes supportive care and actual treatment. After the initial admission, the duration of which shall depend on the clinical condition of the child, most of the treatment is on day-care basis which means that the child comes for the treatment, receives it after a short duration of admission for few hours and then goes back.

Although most of the treatment happens on day-care basis, but at times, when the child is not well having fever or any other complication, he might need admission for management of those complications for a longer duration as inpatient.

For the entire period of **Induction**, **Extra-compartment therapy**, **Reinduction**, or **Consolidation** the child should stay in close proximity to the hospital as the chemotherapy medicines leave the patient immune compromised thus significantly affecting the capacity to fight infection. In such a scenario even, common appearing infections can be life-threatening, if not attended as an emergency.

After the initial 5–6 months of the treatment, the maintenance of chemotherapy is home-based where the child takes oral chemotherapy medicines, and visits the treating pediatric oncologist every 2–3 weeks with blood tests to do necessary dosage modifications (**Fig. 2**).



Fig. 2: Maintenance of chemotherapy.

Q5

Why do we need further treatment, if disease comes under control after induction chemotherapy?

Figure 3 beautifully illustrates why the child needs treatment beyond induction. At the time of diagnosis, the cancer burden is very high inside the body. By end of induction, it comes down to a level at which the cancer cells are not visible on routine testing but still a significant number of cancer cells remain in the body. If we do not bring the cancer load further down, there remains a high risk of relapse, thus emphasizing the need of further treatment in the form of consolidation and reinduction and maintenance. Each of these phases has an extremely important role to play and none can be eliminated from the standard treatment approach.

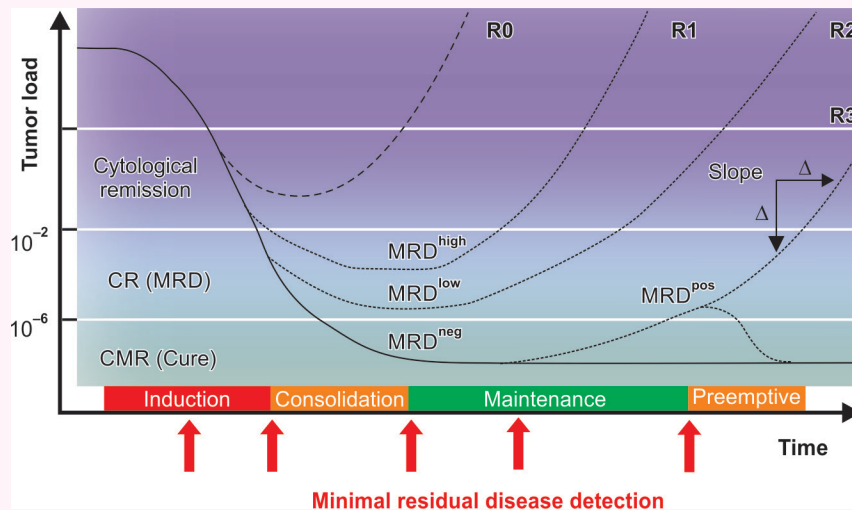


Fig. 3: Demonstrates why the child needs treatment beyond induction.

Q6

What precautions we need to take while the child is undergoing treatment?

Parents have an extremely important role to play while the child is receiving treatment for leukemia. They are the primary caregivers and know the child in best possible way. Parental advice can be broadly divided into two broad categories:

1. **Dietary precautions:** As we are aware that the ongoing treatment for leukemia leaves the child immunocompromised. There are phases when due to chemotherapy the child develops ulcers inside the stomach called as “mucositis”. Due to all these factors, the child is at increased risk of infections. Diet plays an important role in mitigating the risk of infection. There are various neutropenic diet schedules available online which might or might not be of practical use. In general, our advice is *anything which is properly cooked can be consumed, fruits which can be peeled of nicely can be consumed, processed milk and milk products can be consumed, and pickles should not be consumed.*

During first 2–3 weeks of treatment due to chance of tumor lysis syndrome, avoid fruit juice and high potassium diet.

2. **Hygiene:**

General hygiene: Utmost care should be taken to maintain general standards of hygiene especially the oral and perianal hygiene.

Oral hygiene: As we are aware that our oral cavity has significant bacterial load, most of which are opportunistic bacteria which try and gain access into the systemic circulation, whenever there is a mucosal breach and immunocompromised state. Thus, the whole objective of meticulous oral hygiene is *first* to decrease the bacterial load and *second* to prevent mucosal breach as much as possible.

How to decrease oral bacterial load: This objective can be achieved by regular brushing using soft brushes/baby brushes (small headed, soft brushes with round-ended filaments) or by using cleaning sponges (which can be used either in isolation or in combination with toothbrush to clean the debris). Chlorhexidine mouth washes can be used either as add on to brushes/cleaning sponges or in situations where brushes/cleaning sponges cannot be used due to severe mucositis.

How to prevent mucosal breach: This can be done by keeping the mucosa soft and moist. This can be achieved by frequent oral gargles and use of candies/lozenges.

Apart from these two primary objectives, optimal pain control is also an essential component of oral hygiene as at times, it is difficult to optimize oral hygiene, if the analgesia is suboptimal.

All the above-mentioned interventions not only help to prevent infection, they also give a feeling of general wellbeing and helps in maintaining enteral nutrition.

All Children should Clean their Teeth Twice Daily

Chlorhexidine is not recommended except; if unable to brush teeth, clean mouth with oral sponges moistened with water or diluted chlorhexidine.

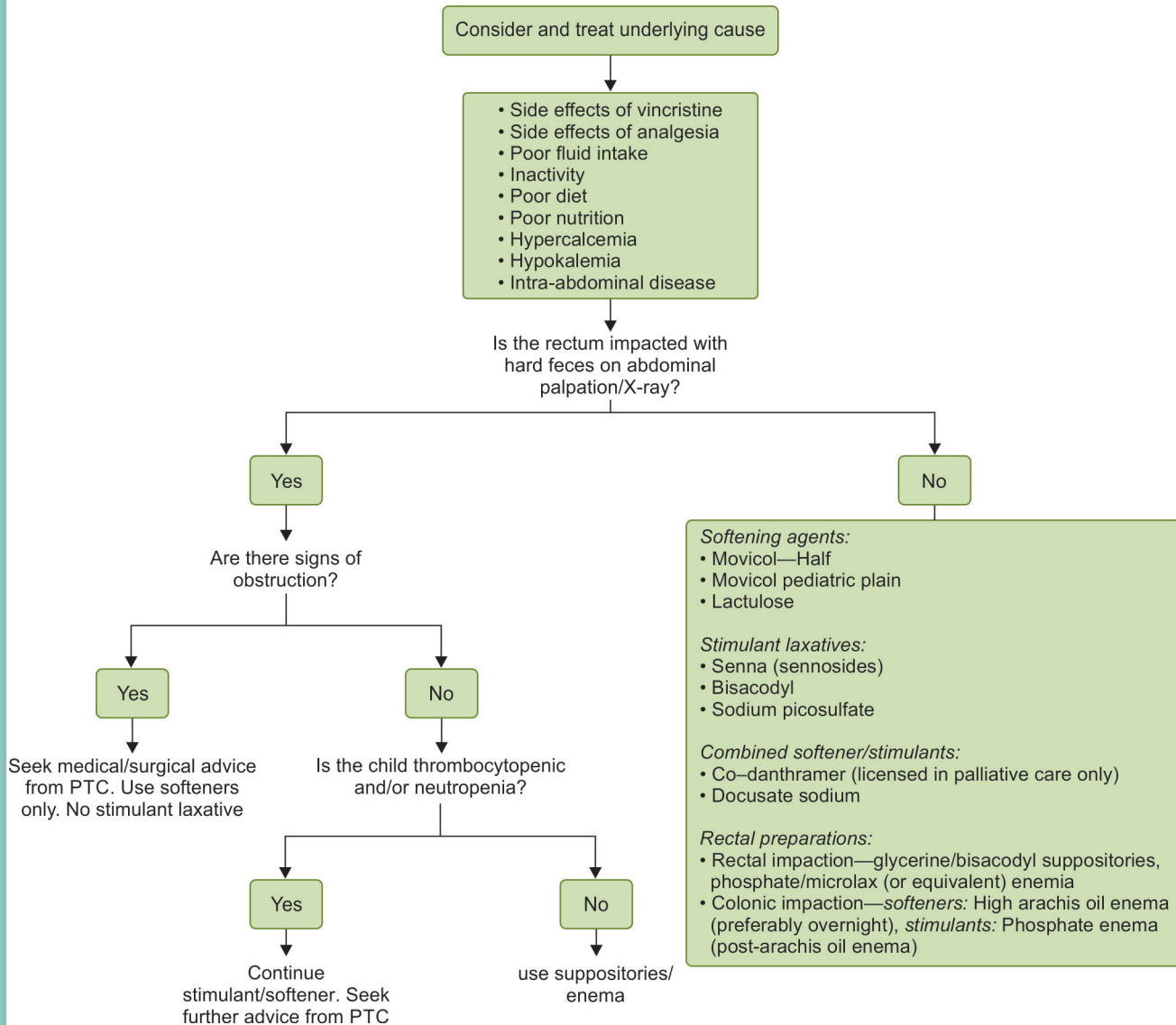
Perianal Care

Minimize Perianal Bacterial Load and Avoid Constipation

Perianal area also has a big bacterial load. Any factor which causes a breach in the skin increases the risk of bacterial translocation from surface to the bloodstream. The children frequently get constipated either due to nonorganic habitual factors or due to organic reasons such as ongoing treatment. Whatever might be the reason all measures should be taken to avoid constipation. Apart from avoiding constipation, regular sitz bath with betadine should also be performed thrice a day to minimize bacterial load in perianal area.

Pathway for Treatment of Constipation (Flowchart 2)

Flowchart 2: Pathway for treatment of constipation.



Sitz Bath

Betadine sitz bath plays an extremely important role in decreasing bacterial load in perianal area. It is recommended that the patient sits in lukewarm water with betadine lotion for a minimum of 15–20 minutes at least three times a day. The cartoon in **Figure 4** shows the right way of taking sitz bath.



Fig. 4: Cartoon taking a sitz bath in a right way.

Q7

What should we do in case child develops fever? Can we wait for it to resolve or we need to report immediately?

While on treatment for leukemia, the child often has low neutrophil counts due to ongoing treatment. If the child develops fever while the neutrophil counts are low, it is called as *febrile neutropenia* which is considered to be a medical emergency. Let us know more about febrile neutropenia, its relevance, and its treatment.

Definition of Febrile Neutropenia

Neutrophils $<0.75 \times 10^9/L$ and
fever* $>38.0^\circ C$ (assessed by any means) for >4 hours or on two occasions at least 4 hours apart

OR

fever* $>38.5^\circ C$ (assessed by any means) on one occasion

OR

clinical suspicion of sepsis in the absence of fever, e.g., unexplained abdominal pain or generally unwell.

- Fever in a neutropenic child is a medical emergency. It requires urgent investigation, and usually requires institution of empirical antibiotic therapy.
- Any child who maybe neutropenic should be seen and assessed by a doctor as soon as possible, if temperature $>38^\circ C$.
- If the above criteria for febrile neutropenia are fulfilled at the time of first assessment, or once they are fulfilled after a period of observation, empirical antibiotic therapy should be initiated as soon as possible (door to needle time <1 hour) after appropriate cultures are taken.
- If the above criteria are not fulfilled initially but the child looks unwell, the child should still be admitted for observation.
- If the child is febrile and the neutrophil count is expected to fall below $0.75 \times 10^9/L$ in the next 24–48 hours depending on the intensity of previous chemotherapy received, commence empirical antibiotics or monitor carefully until criteria for commencing antibiotics are fulfilled or fever resolves.
- Do not give paracetamol to a febrile, neutropenic child until it is clear that the criteria for starting antibiotics are fulfilled.
- Classic signs of infection may be masked by ongoing treatment especially steroids during ALL induction and re-induction. If in doubt and a neutropenic child on steroids seems unwell, antibiotics should be initiated after being assessed by the clinician.

*Fever should be unrelated to the transfusion of blood products.

Q8

**What is a central line? Why is it required?
Cannot we do without it?**

Central lines are an extremely important component of treatment for leukemia. It works as a life-line for these patients as once inserted everything happens through the central lines whether its blood samples or chemotherapy administration or administration of supportive care in the form of antimicrobials or blood products. While they serve as a life-line for patients, they also increase the risk of infections as they form a direct connect between outside environment and the blood. Any breach should thus be avoided so as to keep the lines free from infection.

There are three different types of central venous catheters, and it largely depends on the unit policy about their preference of one over other.

Q9

**To fight against infections pediatricians are recommending the vaccination. As my child is under treatment, for leukemia, we have missed many vaccinations, so can we give him the vaccines now?
Can we give vaccines to his sibling?**

While receiving treatment for leukemia all routine vaccinations should be withheld and only specific vaccination such as flu vaccine should be given after consulting the pediatric oncologist. In this process, many kids miss their routine vaccine shots. After completing treatment, catch-up vaccination can be started after 3–6 months of treatment completion, and as per the age, we can give vaccination under guidance of “Pediatric Oncologist”.

Vaccination of Siblings

During active treatment of leukemia, patient’s sibling vaccinations can be continued as per schedule except live vaccines such as oral polio to be avoided. Any planned vaccination for the sibling should only be done after consultation and in agreement with treating pediatric oncologist.

Q10

My mother said that there are some Ayurveda medicines, which will cure cancer. So, is it safe to take those medicines?

- No single medicine can cure leukemia, hence while child on chemotherapy other drugs such as Ayurveda medicine should be avoided as these drugs can increase toxicity of chemotherapy, and also some can decrease effectiveness of chemotherapy drugs.
- Hence, without consultation of treating pediatric oncologist, any other drugs should not be given.