

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Care of a Terminally Ill Child

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10 FAQs on CARE OF A TERMINALLY ILL CHILD

1. As a parent of a terminally ill child, what are the concerns and care that are required to be addressed?
2. How do I take care of the physical needs of the terminally ill child?
3. What are the respiratory concerns and how to take care of it?
4. How do doctors address the nutrition of my terminally ill child?
5. What pain is my child going through right now and how can it be relieved?
6. How do I take care of my child's sociopsychological needs?
7. What measures will need to be continued or added in the management of my terminally sick child with an irreversible cause?
8. What can I do in the preparation and support of a child whose death approaches?
9. In case your child does not survive, where would you want the death to occur?
10. What kind of post death care is available?

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Care of a Terminally Ill Child

Q1

As a parent of a terminally ill child, what are the concerns and care that are required to be addressed?

Following are the concerns and care that are required for the care of a terminally ill child (**Fig. 1**):

- Physical needs of the terminally ill child
- Equipment for respiratory care and suction
- Nutrition and medicine support
- Need for special beds, toilets, chairs, wheelchairs, and bath requirements
- Skilled nursing care, physiotherapist, and other healthcare providers
- Spiritual, religious, and cultural needs, and requests
- Bereavement care

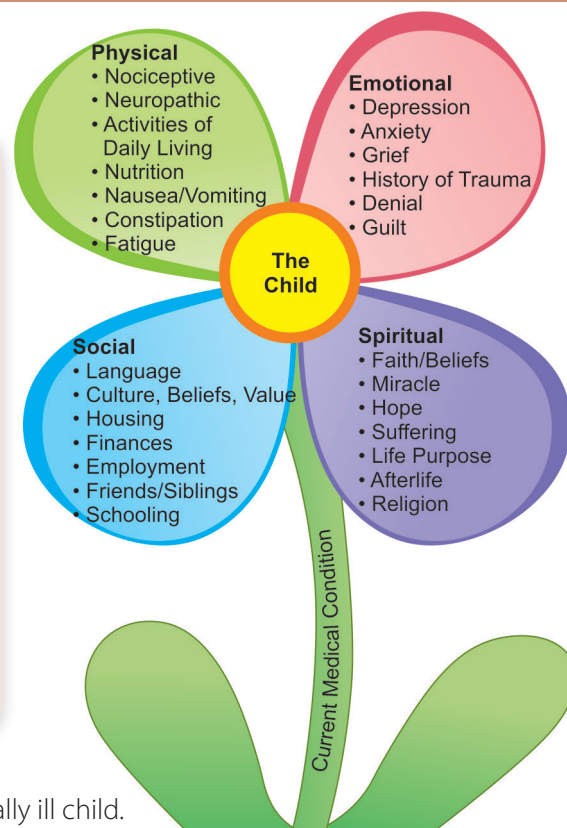


Fig. 1: Needs of terminally ill child.

Q2

How do I take care of the physical needs of the terminally ill child?

The daily physical needs of the terminally ill child include sleep, rest adequate nutrition, mouth, skin, stool and urine care.

- As far as possible a terminally ill child should be cared in a separate room restricting the number of visitors.
- Defined sleep time should be encouraged with minimum disturbances. There should be a bedside call bell to alert someone, if needed.
- Daily diligent mouth care as possible must be performed.
- Appropriate care of scalp hair and nail trimming should be done at timely intervals.
- Due skin care should be done with daily sponging keeping the child clean and dry with frequent change of posture to avoid pressure sores. Pressure ulcers are a localized injury to the skin and underlying tissue, usually over a bony prominence, caused by constant pressure.
- Pressure sores can be prevented by optimizing hydration, maximizing nutrition, repositioning, and use of pressure-redistributing equipment.
- Constipation, diarrhea, and incontinence are common problems. Local, culture specific, affordable care should be provided to keep the child clean without any embarrassment to who may be unable to control his or her bowel or bladder.

Q3

What are the respiratory concerns and how to take care of it?

Tracheal, nasal, and oral secretions may be difficult to manage in a terminally ill child. Repositioning the child may help drain the extra secretions. Respiratory changes may occur from pneumonia or the progression of the disease. The child may feel air hunger. Oxygen supplied through the nose or by a mask may help. Sometimes medicines can also ease the child's anxiety related to breathing troubles.

Care of a Tracheostomy

A few terminally ill children may have a tracheostomy tube inserted in the windpipe bypassing the upper airway (**Fig. 2**). The tracheostomy care includes keeping the skin around the tracheostomy dry and cleaning the area at least twice a day or as may be required. Suctioning is a way to keep the airway clear. Suction the tracheostomy, if there is an increase in secretions with increasing respiratory difficulty, limiting the suction time to <5 seconds with an appropriately sized suction catheter size and insertion depth. If the tracheostomy tube is accidentally removed, kindly report to the emergency department immediately.



Fig. 2: Tracheostomy tube in situ.

Q4

How do doctors address the nutrition of my terminally ill child?

There are multiple challenges for the nutritional care of terminally ill children. These include the type of food, delivery route, palatability, affordability, availability, acceptability, and tolerance.

The enteral route is preferred over other routes, with food intake at regular intervals. If oral intake is inadequate, then a nasogastric or gastric tube is another choice for supplemental nutrition. A nasogastric tube is placed in through the nose that extends to the stomach for delivery of medicines and nutrition.

Percutaneous Endoscopic Gastrostomy

A gastric tube is placed through the skin into the stomach called as “percutaneous endoscopic gastrostomy (PEG) tube” used for feeding the child (**Fig. 3**). Care of PEG tube includes cleaning the skin insertion site and under the plastic flange at least two times per day. Rotate (turn) the tube completely each day (starting 3–5 days after insertion). To avoid weakening the tube, the clamp on the tube should be placed in a new position everyday. If you are using your PEG tube for feeding, then you need to take care of the child’s mouth, by cleaning his or her teeth, and using a mouth rinse. Flush the tube twice a day with 20 mL of tap water, when you are not using it for feeding (cooled boiled water, if under 6 months old or immunosuppressed). If the PEG is accidentally removed kindly report to the emergency department immediately.



Fig. 3: Percutaneous endoscopic gastrostomy (PEG) tube.

Q5**What pain is my child going through right now and how can it be relieved?**

Pain management is an important component in the critically ill child. Pain may happen because of the illness, or for other reasons. Every effort should be taken to alleviate pain.

- One needs to discuss pain control choices and management plans for a child with pain.
- The agents used for the pain management are based on the severity of the pain include opioid and nonopioid analgesics.
- The non-pharmacologic ways to manage pain include prayer or meditation, distraction, relaxation, acupuncture, and massage therapy as applicable.

Q6**How do I take care of my child's sociopsychological needs?**

Give your child time to play and engage in other age-appropriate activities, such as watching television, reading and drawing as may be applicable. Encourage your child to maintain friendships and other meaningful relationships. Child may be provided as much privacy and independence as possible.

Q7

What measures will need to be continued or added in the management of my terminally sick child with an irreversible cause?

There will be a time that your child may show a cessation of breathing or deterioration in the function of the heart which usually is taken care of with supportive measures, e.g., start of artificial breathing, blood pressure increasing agents, cardiopulmonary resuscitation (CPR), etc. After due discussion with all family members involved in the decision making process and in the care of this child, it may be desirable to support a peaceful transition of life. We will try our best to leave no stone unturned to ease the pain for both the family and the child. We encourage you to ask questions and involve people you trust (family physician amongst others). Please remember that we are working in the best interests of the child at the same time are not allowed to withhold or withdraw life support.

Q8

What can I do in the preparation and support of a child whose death approaches?

You can expect some changes in his/her appearance that occur as death approaches. Some of them may be physical such as weakness and fatigue, decreasing appetite and intake, skin changes (e.g., cooling and mottling), sedation or confusion, changes in the pattern of breathing, increase in noise with breathing from respiratory secretions, and loss of ability to close the eyes.

As a parent you need to prepare emotionally for the terminal event and peaceful transition of life. Parents and caregivers are encouraged to maintain their daily and familiar routine as much as possible.

Q9

Where would you want the death to occur?

The locations can include your home or in hospital units. There are challenges with each setting and benefits of them too. Cancer patients who had been going through these problems for long prefer home, while a few others the ICU. Please remember to involve the child in this process when appropriate. If your preferred site is at home, medical social workers will help to arrange for a hospice service or for other resources within the community.

Q10

What kind of post death care is available?

Medical social workers will help to connect you with the appropriate religious person, and similarly will help to create a small support group for you from your area who will keep in touch with you. At any time, if you need any help from the hospital or with regard to any psychological help that you require we would be more than happy to extend help. Anyway, as a routine we would be in touch with you on the day following the demise and from then on as per your need that either you or our social worker feels. We are always with you.