Quality of Life for Children with Cancer

A series of modules on pediatric palliative care

End-of-life care

PAHO
WHAT IS END-OF-LIFE CARE?

End-of-life care offers a system to help the family handle this stage as well as possible.

It mitigates the suffering of patients when death is inevitable and supports parents who are experiencing one of life’s greatest losses: the death of a child.

WHAT ARE THE FUNDAMENTAL PRINCIPLES OF END-OF-LIFE CARE?

1. **Parents and caregivers make the decisions in close interaction with the attending physician, who knows the child.**

2. **Children have intrinsic dignity, values, and rights like all human beings.**

3. **Medical care should be guided by the well-being of the child, satisfying their wishes whenever possible. The decision to withdraw or forego intensive treatment is only justified if it will not help the patient’s well-being and only adds to the suffering or prolongs the child’s deteriorating health.**
At this stage, children have specific organic, psychological, family, social, and spiritual needs. Meeting these needs requires the work of an interdisciplinary and committed team of health professionals.

*Members of this team include doctors, nurses, psychologists, and social workers. There should also be a spiritual adviser (pastor, priest, etc.) if the child or family requests one.*

End-of-life is the period before death, which is often difficult to predict and can last from days to hours. It is important to have continuous, open communication with the palliative care team, so that all questions about the patient’s progress are answered and the best possible care is provided.

*The palliative care team should be informed* of whether the caregiver and family are prepared for the child’s death to occur at home. Otherwise, this will happen in the hospital, with the respective accompaniment. Please note that this decision may change at any time.
HOW CAN I RECOGNIZE THIS STAGE?

These signs may indicate the beginning of the end-of-life:

- Sleeping progressively more.
- Disconnection from surroundings.
  Decreased interaction with others, confusion, hallucinations
  (perceiving stimuli that do not exist), loss of consciousness,
  staying in bed constantly.
- Further loss of appetite.
- More weight loss.
- Difficulty swallowing.

Symptoms or changes that occur at this stage of the disease:

- Decreased urination.
- Incontinence.
- Changes in breathing.
- Noisy breathing, due to the accumulation of secretions in
  the respiratory tract, caused by the disappearance of the
  usual defense mechanisms.
- Mouth movements when breathing.
- Noises when exhaling, such as moans.
- Breathing faster or slower than normal and with pauses
  (apneas).
- Eyes half-open and inability to blink, due to decreased
  response to stimuli.

*It is common to notice changes in the patient’s temperature or cold sweating. Changes in skin color are usually most apparent on the lips, fingers, and toes.*
WHAT IS MOST IMPORTANT AT THIS STAGE?

It is important to focus on a single objective: Providing comfort to the child.

To achieve this, only treatments that enhance the child’s well-being should be given; anything that diminishes the child’s quality of life and brings suffering should be suspended.

It is essential to ensure a familiar, quiet, and private environment for the child. Manage the symptoms together with the team of health professionals, avoiding bothersome interventions that cause discomfort or prolong the child’s agony.
This series of modules on palliative care aims to provide essential information to mothers, fathers, and others caring for children with cancer, so that they can provide the best care and take appropriate actions to meet the developmentally appropriate physical, socio-emotional, and spiritual needs of their loved ones, as well as needs arising from the disease itself.

ACKNOWLEDGEMENTS

Silvana Luciani, Chief of Noncommunicable Diseases, PAHO, Washington, D.C.
Mauricio Maza, Liliana Vásquez, Soad Fuentes-Alabí, Karina Ribeiro and Sara Benítez, Noncommunicable Diseases, PAHO, Washington, D.C.
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The patients and families who assisted in the development and validation of this material.

This guide has been developed within the framework of PAHO's Global Initiative for Childhood Cancer.

PAHO/NMH/NV/cvn8/21–0040
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