Quality of Life for Children with Cancer

A series of modules on pediatric palliative care

General information about pediatric palliative care
Pediatric palliative care is all care provided to prevent and alleviate the suffering of children and adolescents and their families when faced with problems associated with life-threatening illnesses. These problems include the physical, psychological, social, and spiritual suffering of patients, as well as the psychological, social, and spiritual suffering of their family members.

**OBJECTIVE**

The goal of palliative care is to improve the well-being of the patient and family throughout the illness, as well as to reduce physical, emotional, and spiritual suffering.

**WHO PROVIDES PALLIATIVE CARE?**

The entire health care team

This includes pediatricians and doctors in different specialties involved in the care of the child, nursing staff, psychologists, social workers, therapists, nutritionists, and volunteers, among others. In cases of advanced illness, a medical team that specializes in palliative care also participates.
IS PALLIATIVE CARE ONLY APPROPRIATE AT THE END OF A PATIENT’S LIFE?

Palliative care provides greater benefits to the patient and their family if it begins at the time of diagnosis. Palliative care is provided in conjunction with specific treatments for each disease, in order to support the patient and the family throughout the disease process.

When the disease course is unfavorable, the palliative care team will continue to care for the patient during the end-of-life and will accompany the relatives during the period of mourning.

At the end-of-life, palliative care may be provided in the hospital, in a special care facility (hospice), or at the patient’s home, according to the preferences of the child or family.

WHO SHOULD RECEIVE PALLIATIVE CARE?

Any child who has a life-threatening and/or life-limiting condition or disease.

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Cancer, severe cerebral palsy, neurodegenerative diseases, complex congenital heart diseases, HIV-AIDS, metabolic diseases, cystic fibrosis, severe congenital anomalies, and certain chromosomal alterations are some of the life-threatening and/or limiting diseases or conditions that may benefit from palliative care.
CAN PALLIATIVE CARE HELP MY CHILD?

Palliative care helps prevent and relieve pain and other physical symptoms, as well as reduce the suffering, stress, anxiety, and fear associated with serious illness.

One premise of palliative care is that:

“**You can always do more when caring for a child.**

Evidence suggests that people who receive palliative care live more fully.

HOW CAN PALLIATIVE CARE HELP ME, MY CHILD, AND MY FAMILY?

- It relieves the patient’s pain and other physical symptoms.
- It offers emotional, social, and spiritual support to the child and his or her family.
- It encourages communication between the health care team and the family.
- It organizes activities to improve the patient’s quality of life.
- It allows information to be shared with the family and guides decision-making regarding the child’s care and treatment.
- It connects the family to local community resources and support services.
- If needed, it allows planning and provision of end-of-life care.
- It provides support and care to the family while in mourning.
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.

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