

Bereaved Children

Bereaved children and children facing loss and grief will benefit from palliative care

Other Children

Children who require supportive rather than palliative care, for example HIV affected children will benefit from palliative care

Why is Pediatric Palliative Care (PPC) different from Adult Palliative Care (APC)?

PPC differs from palliative care delivered to adults in several important ways.

Children with palliative care needs range in age from prenatal to adult (those with conditions followed by paediatric sub specialists or those whose developmental and/or physical challenges are better served by paediatricians); PPC teams must thus be able to care for patients with wide-ranging diagnoses whose understanding of illness and decision making changes significantly throughout the developmental spectrum. Paediatric trajectories of illness, clinical models of care delivery, funding mechanisms, research paradigms, educational initiatives, communication strategies, ethical concerns, staffing ratios and management, and effective pain/symptom management interventions are all significantly different from those that are effective for adult patients

What are the Goals of Paediatric Palliative Care?

- To prevent or relieve the, physical and emotional distress, produced by a life-threatening, medical condition or its, treatment, optimizing pain and symptom management.
- Help patients with, life-threatening/life-limiting conditions and their families live as normally as possible,
- Provide patients and their families with timely and accurate information.
- Support patients and families in decision-making and goal setting.
- Promoting hope and dignity for patients and families.
- Caring for the whole family by listening, respecting their beliefs and recognizing each family and child is different,
- Provide continuity of care – supporting families during hospitalization and coordinating discharge with Medical team, follow up with special needs clinic as appropriate

What is the difference between Palliative Care and Hospice Care?

- Palliative care is appropriate for any stage of life-threatening/life-limiting condition – ideally begins at the time of diagnosis. Availability does not depend upon whether or not patient's condition can be cured.
- Hospice care is designed to assist patients and their families in the last stages of life when aggressive treatments are no longer beneficial.
- Both services provide pain and symptom management.

Criteria for Palliative Care Referral

Genetic/ Perinatal Criteria

- Trisomy 13, 15, 18
- Congenital Heart Defect
- Potter Syndrome
- Anencephaly
- Holoprosencephaly
- Myelomeningocele
- Lethal forms of dwarfism/ osteogenesis imperfecta
- Giant omphalocele/ Gastroschisis
- Congenital Diaphragmatic Hernia

Neonatal Criteria

- Extreme prematurity
- Hypoxic ischemic encephalopathy
- Certain GI conditions: i.e. NEC/Short Gut, biliary atresia
- Renal agenesis
- Severe chronic lung disease
- Severe IVH, PVL
- Brain reduction syndromes, i.e. hydranencephaly, lissencephaly
- Seizure disorders
- Hydrocephalus

Paediatric Criteria

- Trauma/Head injuries
- Near drowning
- Metabolic Disease
- Mitochondrial Disease
- HIV/AIDS
- Severe Combined Immune Deficiency
- Progressive neurodegenerative conditions, i.e. muscular dystrophy, spinal muscular atrophy, leukodystrophy
- Cancer



OPEN SOCIETY INSTITUTE
& Soros Foundations Network

Kenya Hospices and Palliative Care Association
Chaka Court, Off Argwings Kodhek Rd,
Next to Chaka Place, Hurlingham
P.O. Box 20854-00202, Nairobi Kenya
Tel: +254 (20) 2729302
Cell: +254 (0) 722 507219
Email: info@kehpc.org
Website: www.kehpc.org



Paediatric Palliative Care

What is Paediatric Palliative Care?

The World Health Organization's definition for palliative care appropriate for children and their families is as follows;

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, and even in children's homes. (WHO 2002)

(The principles apply to other Paediatric chronic disorders (WHO; 1998a):

Paediatric Palliative Care (PPC) and/or Hospice Care is both a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex and/or life-threatening conditions and their families. This care focuses on enhancing quality of life, minimizing suffering, optimizing function, and providing opportunities for personal and spiritual growth.

Planned and delivered through the collaborative efforts of an interdisciplinary team with the child, family and caregivers as its center, PPC/HC can and should be provided along with concurrent disease-modifying therapy or as the main focus of care.

PP/HC is achieved through a combination of active and compassionate therapies intended to comfort and support the child, as well as family members and other significant people in the child's life.

Effective management of pain and other distressing symptoms, together with psychosocial and spiritual care, are of critical importance beginning at diagnosis and continuing throughout the entire course of a child's life and beyond.

Therapies take a holistic approach, assisting children and families in fulfilling their physical, psychological, educational, social and spiritual goals while remaining sensitive to developmental, personal, cultural and religious values, beliefs and practices.

Children with life threatening illnesses and their families require comprehensive, compassionate, and developmentally appropriate palliative care.



Categories of children requiring palliative care:

Category 1

Life threatening conditions for which curative treatment is appropriate but can fail. Access to palliative care service may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life.

Examples:

Advanced or progressive cancer or cancer with a poor prognosis; Irreversible organ failures of heart, liver, kidneys; Complex and acquired heart disease; severe malnutrition; pulmonary Tb; XDR and MDR TB; Head Injury post MVA

Category 2

Conditions where premature death is inevitable, where there maybe long periods of intensive treatment aimed at prolonging and improving quality of life, allowing participation in normal activities.

Examples:

Cystic fibrosis; HIV/AIDS infected on HAART; Neuro-degenerative conditions; Renal Failure where dialysis is available.

Category 3

Progressive conditions where no cure is possible. Treatment is exclusively palliative and may extend over many years.

Example:

Downs Syndrome with sever Congenital Heart Disease; Mucopolysaccharidoses; Renal Failure with no dialysis available;

Category 4

Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the possibility of premature death.

Examples:

Multiple disabilities such as following brain or spinal cord injury; complex health care needs and a high risk of an unpredictable life-threatening event or episode; Cerebral Palsy; Fetal Alcohol Syndrome; Birth Asphyxia; Downs Syndrome, Sickle Cell Anemia.

Extremely preterm babies will benefit from palliative care as well.

In our modern society, with the advancement of medical technology and specialized care, we expect children to outlive their parents. Unfortunately that isn't always the case. Many children die each year from accidents or trauma, congenital conditions, prematurity, inherited disorders, or acquired illness.

Palliative Care begins when the illness is diagnosed and can be provided in any care setting, including the patient's home

“The aim of palliative care for children and their families or guardians is to promote the quality of life, maintain dignity and ameliorate suffering ”