CONCEPT NOTE; August 2019

Theme: “Action Against A Suffering Child”

"I couldn’t stand seeing my little son writhing in pain. No one ever told me my boy would die. I never understood what was happening medically until the palliative care team came. They were mindful and compassionate despite our hopelessness", said a grateful mother in Kilifi

Project background

Kenya Hospices and Palliative Care Association (KEHPCA) is the umbrella body for hospices and palliative care units. It was established in 2007 with the mandate to scale up palliative care services in Kenya so that quality palliative care services are accessible to all who need it. Since its inception, KEHPCA has led the increase of palliative care facilities in Kenya from 14 to 70 to date. Over 30,000 patients receive this care annually compared to about 5,000 annual patient turn over in 2007. KEHPCA has worked closely with the Ministry of Health, the county governments, member institutions (Hospices, Palliative Care units and Hospitals) and many partners to scale up palliative care services.

Palliative care is a holistic approach that has been recognized by World Health Organization (WHO). It aims to improve quality of life of both the patient and care givers. Palliative care is accorded to both adults and children with serious health suffering (SHS) due to illnesses like cancer, HIV/AIDS, liver failure, renal failure, diabetes, hypertension, congenital malformations among others. This focuses on; physical care (including pain), social, spiritual and psychological support. It helps them live as actively as possible and prepare them for end of life when condition
deteriorates. Palliative care should be provided from the time of diagnosis onwards and should be accessed in all levels of care.

**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 (WHO).

**The need**

There is limited data on pediatric palliative care (PPC) services in Kenya in terms of sites providing services, children in need of the care and those actually being served. An assessment conducted by UNICEF in 2013 on the need for pediatric palliative care established that in 2012, 545 children received specialized pediatric palliative care (<1% of the need in Kenya) out of a possible 264,102 patients in need. The research estimated the number of children needing palliative care in Kenya as 120.5 per 10,000 children. [http://www.icpcn.org/wp-content/uploads/2014/02/Palliative-Care_Three-Country-Report.pdf](http://www.icpcn.org/wp-content/uploads/2014/02/Palliative-Care_Three-Country-Report.pdf)

According to the Lancet Commission on Global Access to Palliative Care and Pain Relief report 2017, worldwide, the burden of SHS in children is primarily associated with HIV disease (40%), premature birth and birth trauma (20%), and congenital malformations (more than 10%). In low-income countries, more than 50% of the burden of paediatric SHS is associated with HIV disease.

Currently, there are three (3) functional children palliative care centres. A survey done by KEHPCA in 2017 with feedback from 23 palliative care sites highlighted the following gaps as major barriers influencing access to PPC services in Kenya;

- a. Lack of PPC Training
- b. Lack of palliative care unit
- c. Lack of an appropriate child friendly paediatric palliative care centre / resources
d. Reluctance in referring children for palliative care services; Doctors seek other curative measures

e. Negative attitude

f. Opiophobia

Funds raised from this event will help bridge the highlighted gaps. This will be a stepwise approach with year one focusing on integration/establishment of pediatric palliative care in three (3) counties. We shall continue with this noble cause until we have all the 47 counties with at least one comprehensive palliative care centre for children.

It is our appeal to you and other well wishers to support KEHPCA in the attainment of the goal of relieving the suffering of our children who are affected by serious health suffering. Your support will enable;

a. Providing pediatric palliative care training for healthcare workers in health facilities.

b. Setting up pediatric palliative care units within the already existing palliative care sites.

c. Renovate and equip existing pediatric palliative care sites

For more information, please contact Josephine through;

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DINNER PACKAGES

- TABLE OF 8 - KSH 100,000
- TABLE OF 6 - KSH 80,000
- TABLE OF 4 - KSH 60,000

5 WISHES

- MEDICAL
- LEGAL
- FINANCIAL
- SPIRITUAL
- SOCIAL