

KEHPCA



partnering
educating
advocating
palliative care
for all

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Importance of inclusion of Persons Living With Palliative Care Needs (PLWPCNs) in advocacy

The meaningful involvement of people living with palliative care needs

- The meaningful involvement of PLWPNs is possible when professionals, organisations, or institutions recognise the value of their lived experiences.
- It requires the use of appropriate mechanisms to leverage this value by accessing their knowledge, skills, and insights

Meaningful involvement is;

- Listening to persons living with PC needs to understand their views and priorities
- Inviting PLWPNs to play an active role in projects
- Recruiting them to take responsibility over projects

Case study

Maria has been battling breast cancer for many years. Her numerous visits to different hospitals and many procedures have made her feel so awful.

She was invited to participate in 3 days spokes persons training by KEHPCA. During the training, she kept reflecting how there were many missed advocacy opportunities concerning the care and support she received.

After the training, Maria has been part of the PLWPCNs advocates for palliative care in many fora. She has given presentations in international conferences, has addressed MCAs assembly in her county, has established and continue to teach patient support groups, Whatapp groups, churches and schools on importance of palliative care based on her experience.

Marias Advocacy gains

- County government dedicated a budget to pay NHIF for patients with cancer
- County set aside some funding and involvement of the first lady to undertake awareness sessions
- Hospital facilities plans include PLWPNs decisions
- Individual patients well informed about NCDs - prevention, care and support, reduced stigma, support for each other
- Lived experiences become a basis for decision making other than theories (Locally, nationally and internationally)

Areas of advocacy for PLWPNs

- Increased availability, access, and funding for early diagnosis of NCDs.
- Affordability of treatment and financial protection for those affected by NCDs.
- Access to trained quality healthcare providers at all levels
- Ensuring universal and equitable access to treatment for NCDs.
- Comprehensive care (combined medical, psychological, and social support) for those with NCDs.
- Disease management education and counselling for self-care skills for those with NCDs.
- The creation of standards and guidelines to link clinical and community support programs for NCDs.
- Improved access to psychological care for those with NCDs.
- Addressing end of life and palliative care for PLWPNs

Lessons on advocacy...



“Only the wearer knows where the shoe pinches.”
George Herbert



Cont...Lessons

- Good health profoundly affects both the patient and family's daily functioning.
- The UHC discussion cannot be complete without inclusion of palliative care
- Palliative care discussions by all, including media personalities, PLWPNs should be included in all levels of health care

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