

## Appendix 1. Formal definitions and explanations of Palliative Care, End of life care, specialist palliative care and Primary palliative care

### Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

### *WHO Definition of Palliative Care for Children*

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- 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 or not 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.

World Health Organization: Definition of palliative care

Found at: <https://www.who.int/cancer/palliative/definition/en/>

Accessed 10/4/2020

#### End of life care.

Care given to people who are near the end of life and have stopped treatment to cure or control their disease. End-of-life care includes physical, emotional, social, and spiritual support for patients and their families. The goal of end-of-life care is to control pain and other symptoms so the patient can be as comfortable as possible. End-of-life care may include palliative care, supportive care, and hospice care.

National Cancer institute. NCI Dictionary of Cancer Terms. Found at <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/end-of-life-care>

Accessed 10/4/2020

#### Specialist palliative care

There is no standard definition for specialist palliative care, but it is generally considered to be care delivered by organisations or individuals for whom the delivery of palliative care is their principal role. Specialist palliative medicine is delivered by specialists with intensive training in palliative medicine.

#### Primary Palliative care.

There is no formal definition of primary palliative care. the following is from the Primary Palliative Care Reference Group of the European Association for Palliative Care:

Palliative care still only reaches a minority of potential beneficiaries and is often introduced too late to prevent much distress. People with multi-morbidities and non-malignant conditions, frailty and dementia are still less likely to receive any form of palliative care than those with cancer. To gain universal coverage, a coordinated primary care and public health approach is necessary. Our vision is that palliative care is fully integrated in primary care systems internationally so that all patients have early access to a palliative care approach in the community (in their own home and in residential care facilities).

European Association for Palliative care (EAPC) Primary Care reference group.

Found at:

<https://www.eapcnet.eu/eapc-groups/reference/primary-care>

Accessed on 10/4/2020