

# Palliative Care - NCD Prevention and Management

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# Terminology

- What is your understanding of the following?
  - Palliative Care
  - Hospice Care
  - End of Life Care
  - Supportive Care
  - Survivorship



# Palliative and Supportive Care

- Usually used interchangeably
- Both *Palliative Care* & *Supportive care* – ensuring that patients live:
  - as well as possible- (Focus is on **Good Quality of Life-QoL**)
  - for as long as possible- (Quality & Quantity).
- Studies have shown that patients and providers have a more favorable impression of the term “supportive care” than “palliative care.”
- Many patients and providers hesitate to seek “palliative care” because they mistakenly fear it is akin to giving up on treatment. **THIS IS NOT TRUE!!!**

**Table 1** World Health Organization (WHO) definition of 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 counseling, 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.

World Health Organization. WHO Definition of Palliative Care. 2002. Available online: <http://www.who.int/cancer/palliative/definition/en/>. Accessed March 9, 2014 (15).



## WORLD HEALTH ORGANIZATION'S DEFINITION OF PALLIATIVE CARE FOR CHILDREN



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 [own] homes.

WHO 2002

# Palliative Care

- specialized medical care for both adults and children living with serious illnesses (across all ages) .
- It is focused on providing patients with **relief from the symptoms and stress** of a serious **illness—whatever the diagnosis.**
- The goal is to **improve quality of life for both the patient and the family.**
- Provided by a **team** (doctors, nurses, counselors and other specialists who work with a patient's other doctors to provide an extra layer of support).
- Palliative care is **appropriate at any age** and at **any stage** in a serious illness, and can be provided **together with curative treatment.**

*(Center to Advance Palliative Care)*

# Supportive Care

**The prevention & management of the adverse effects of cancer, Other NCDS as well as other life threatening illnesses and its treatment.**

**Minimizes treatment toxicity /addresses negative effects of cancer treatment (febrile, neutropenia, anti-emetics, mucositis, and dermatologic toxicities)**

This includes management of:

- ✓ physical & psychological symptoms
- ✓ side effects across the continuum of the cancer experience from diagnosis through treatment to post-treatment care.
- ✓ Enhancing rehabilitation
- ✓ Secondary cancer prevention
- ✓ Survivorship
- ✓ End-of-life care
- ✓

*(Multinational Association of Supportive Care in Cancer (MASCC)).*

International Cancer Institute 2020.

[www.intercancer.com](http://www.intercancer.com)

# Survivorship

- A person who has had cancer is commonly called a cancer survivor.
- Living with a history of cancer is different for each person.
- Most people have the common belief that life is different after cancer.
- Other common reactions that people have after cancer include:
  - Appreciating life more.
  - Being more accepting of themselves.
  - Feeling more anxious about their health.

# Hospice care

Focuses on the quality of life for people and their caregivers who are experiencing an **advanced**, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.

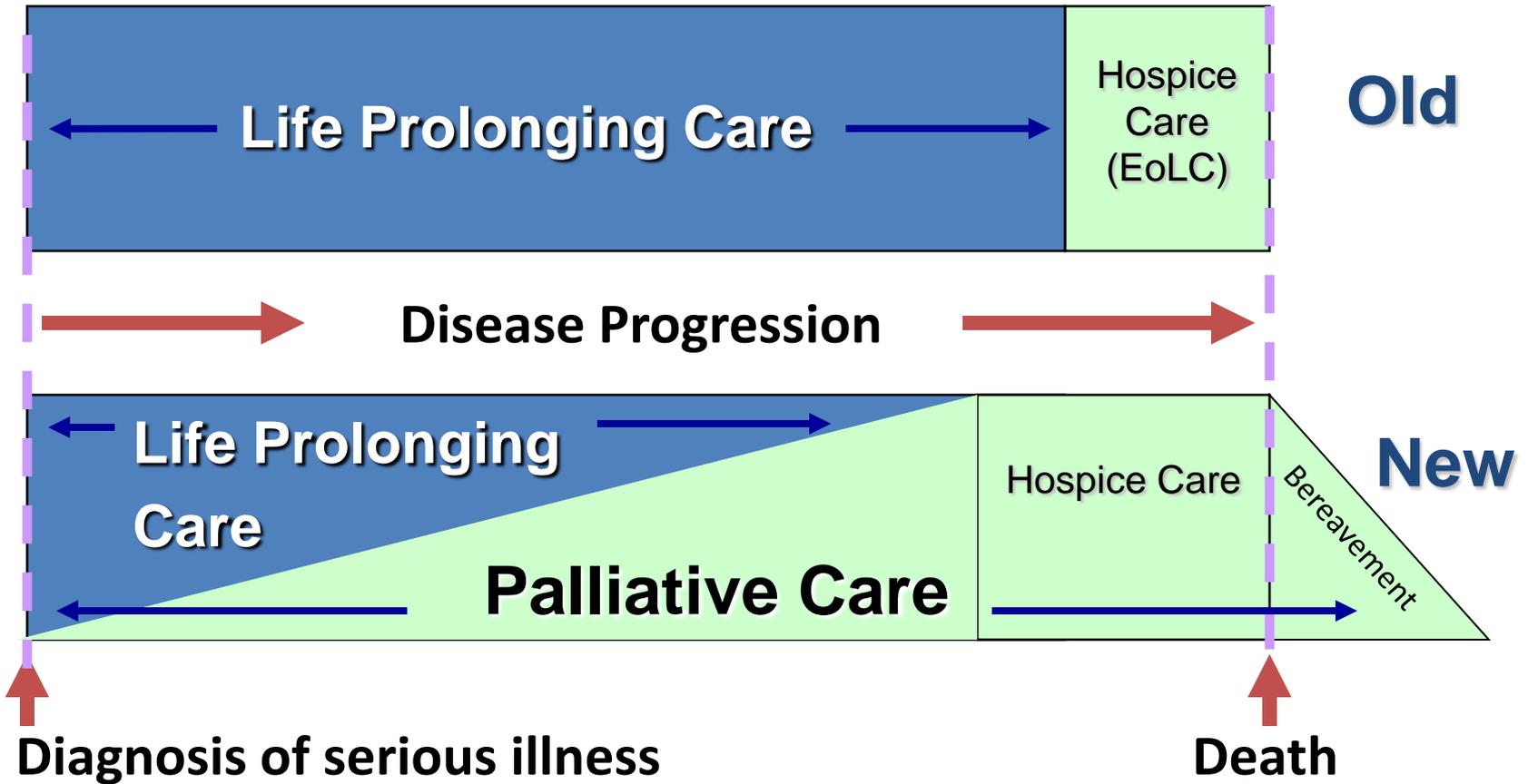


# End of Life Care

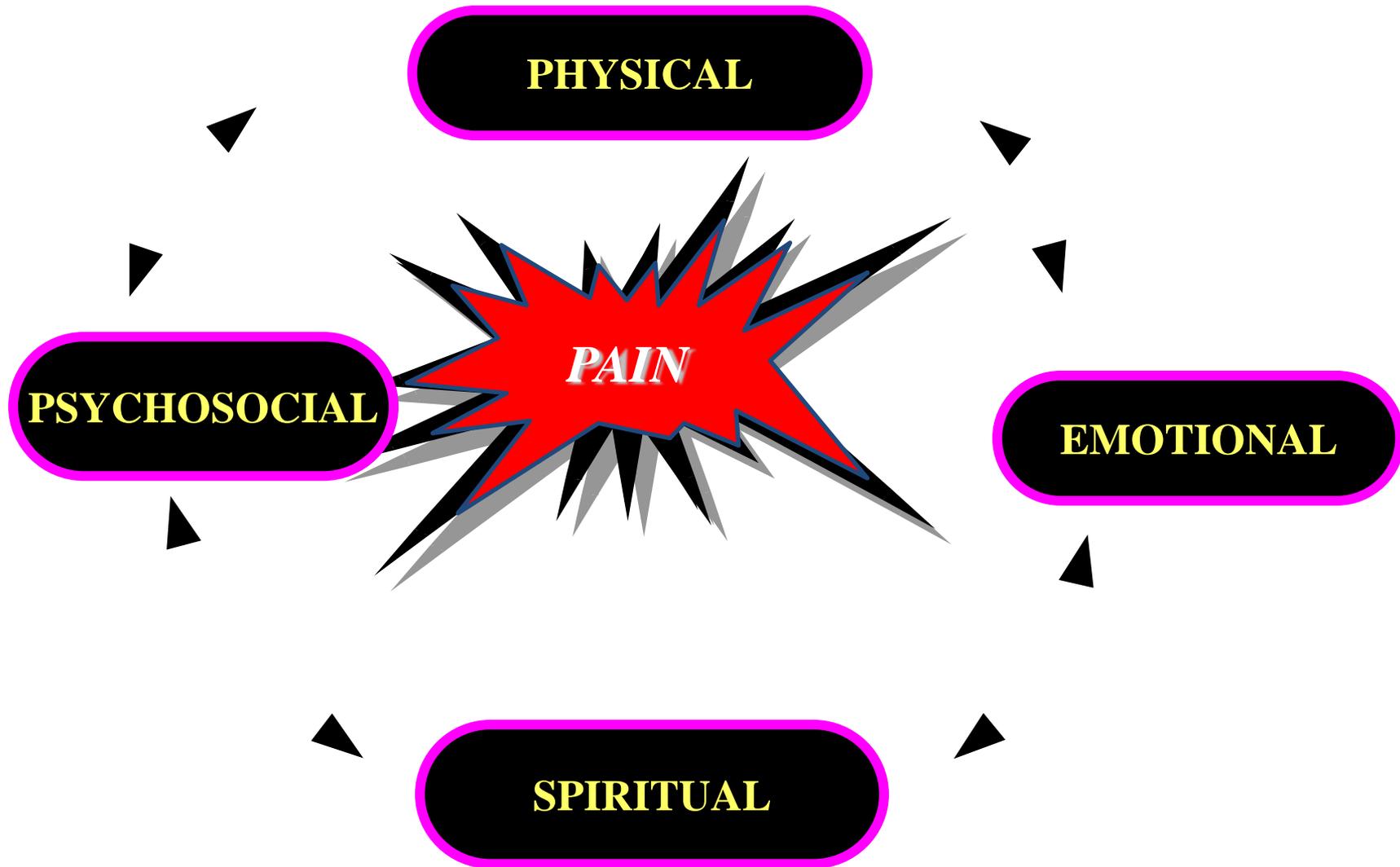
- Care given to people who are near the end of life and have stopped treatment to cure or control their disease.
- End-of-life care includes **physical, emotional, social,** and *spiritual* support for patients and their families.
- The goal of end-of-life care is to control pain and other symptoms so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



# OLD VS NEW APPROACH



**Total Pain** = *all of me is wrong* (Sounders)



# Palliative care

- Relationship building with patient and family caregivers
- Symptom, distress, and functional status management
- Exploration of understanding and education about illness and prognosis
- Clarification of treatment goals
- Assessment and support of coping needs
- Assistance with medical decision making
- Coordination of, and referrals to, other care providers

# Psychological issues Anxiety

- Fear of the future-fear of dying
- Fear of being dead
- Worsening symptoms
- Loss of independence
- Concern for the carer,
- Financial issues
- Failure to adjust to loss of function
- Feeling of should be doing more
- Reluctance to use oxygen out of home environment and to use wheelchair.
- Reluctance to 'give in to the illness

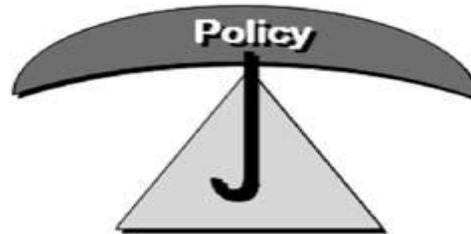
# WHO Public Health approach to PC

## Policy

- Palliative care part of national health plan, policies, related regulations
  - Funding / service delivery models support palliative care delivery
    - Essential medicines
- (Policy makers, regulators, WHO, NGOs)

## Drug Availability

- Opioids, essential medicines
  - Importation quota
  - Cost
  - Prescribing
  - Distribution
  - Dispensing
  - Administration
- (Pharmacists, drug regulators, law enforcement agents)



## Implementation

- Opinion leaders
  - Trained manpower
  - Strategic & business plans – resources, infrastructure
  - Standards, guidelines measures
- (Community & clinical leaders, administrators)

## Education

- Media & public advocacy
  - Curricula, courses – professionals, trainees
  - Expert training
  - Family caregiver training & support
- (Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

# WHO Resolution 2014

The resolution on palliative care calls all member states to:

- Develop, strengthen and implement palliative care **policies**
- Support palliative care initiatives including:
  - **Providing support to caregivers**
  - **Education and training:** Include palliative care as a part of integrated training for all healthcare workers who routinely work with people with serious illness
  - **Ensure access to essential medications:** availability of medicines essential for the provision of palliative care
  - **Foster partnerships between** government and civil society to increase access to palliative care
  - **quality improvement**

# Palliative Care Developments in Kenya



- Registered in November 2005, secretariat in February 2007. **9 employees**
  - **Mission**  
To promote and support acceptable, accessible and affordable quality Palliative Care for individuals and families by creating networks of informed and empowered institutions in Kenya
  - **Vision**  
***Quality Palliative care for all in Kenya***
  - **Goal:** To improve the quality of life of persons affected with life threatening illnesses and their families”
- ✓ Advocacy
  - ✓ Education & Training
  - ✓ Scaling up services
  - ✓ Technical Support to partners including the MoH/ counties
  - ✓ Key participants in policy /strategy formulations-Lead role for pc-national and regional level
  - ✓ Research (Kings College/APCA/ICPCN/RTI)

# Services in Kenya

## PALLIATIVE CARE SERVICES IN COUNTIES



## **Achievements**

- **Palliative care integrated in undergraduate medical & nursing curricula**
- **PC integrated in government, mission & private hospitals**
- **KMTC started a diploma in PC for nurses**
- **PC included in the:**
- **National Kenya patients' rights charter**
- **National Cancer Control Program**
- **Cancer Treatment Guidelines**
- **National framework for NCDs**
- **PC in HBC**
- **PC in UHC**

# Summary

- ❖ Palliative care is an **integral** part of health and should be available at every level of care.
- ❖ Relief from pain and suffering is a **human right**
- ❖ **PC is in our Patients' Rights Charter, in our Health Law, in our UHC plan.**
- ❖ Persons living with NCDs require PC from the beginning to the end.
- ❖ PC just not focus on end of life, it also works to mitigate symptoms that are distressful during an illness.
- ❖ It supports loved ones
- ❖ It prevents /mitigates pain and suffering.
- ❖ It is about **LIVING**, and living well-QoL (**quality of life**)

*You matter because you are you, you matter  
to the end of your life. We will do all we  
can, not only to help you die peacefully, but  
also to live until you die*

Dame Cicely Saunders (1918-2005).

Thank you