

# **Palliative Care - Normative Elements**

- 1. Definitions**
- 2. PC in existing instruments**
- 3. Affirmation of the right**
- 4. Scope of the right**
  - 1. State obligations**

# Palliative Care - Normative Elements

## Definitions

WHO 1 (2018):

*The prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with life-threatening illness .*

*These problems include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members.*

# Palliative Care - Normative Elements

## Definitions

WHO 2 (2017) (Fact sheets):

*Palliative care is an approach that **improves the quality of life of patients** (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*

*Palliative care is a crucial part of integrated, people-centred health services, at all levels of care: it aims to relieve suffering, whether its cause is cancer, major organ failure, drug-resistant tuberculosis, end-stage chronic illness, extreme birth prematurity or extreme frailty of old age.*

# Palliative Care - Normative Elements

## Definitions

WHO 3 (2015) Global Report on Ageing and Health (Box 5.8)

*Palliative care aims to improve the quality of life of people experiencing a **significant decline in their intrinsic capacity** and who have a limited life prognosis; it also aims to help patients and their families by preventing or relieving physical, psychosocial or spiritual suffering.*

*This concept has been evolving: previously, palliative care focused mainly on people with terminal cancer and on institutional and specialist care. During the past decade, however, its scope has expanded considerably to include a wider range of health conditions, care settings and caregivers' groups. Now, it also addresses the well-being of families.*

# **Palliative Care - Normative Elements**

## **Definitions**

### **National Palliative Care Research Center and CAPC**

(based on public opinion survey 2011)

*Palliative care is specialized medical care for people with **serious illness**. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.*

*Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. **It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.***

# Palliative Care - Normative Elements

## Definitions

### **IAHPC – consensus definition**

(127 organisations endorsed)

*Palliative care is the **active holistic care** of individuals **across all ages** with serious health-related suffering due to severe illness, and **especially of those near the end of life**. It aims to improve the quality of life of patients, their families and their caregivers.*

Palliative care: ....

- Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.

# **Palliative Care - Normative Elements**

## **Definitions (some problematic ones)**

### **European Charter of the rights and responsibilities of older people in need of long-term care and assistance (2010)**

*Palliative care is the active, total care of the patients whose disease is **not responsive to curative treatment**.... (source: European Association for Palliative Care)*

### **Interamerican convention definition:**

*“Palliative care”: Active, comprehensive, and interdisciplinary care and treatment of patients **whose illness is not responding to curative treatment** or who are suffering avoidable pain.....*

# Palliative Care - Normative Elements

## Definitions

### In conclusion

Palliative Care alleviates suffering **whatever the prognosis** and not just at the end of life.

It can be used to alleviate pain or discomfort during curative treatment.

### Barriers to Palliative Care

It is not understood that palliative care **is not:**

- Only for the dying
- An alternative to disease prevention and treatment but **should be integrated** with them
- That palliative care not only relieves suffering, but also **anticipates and prevents it**



# **Palliative Care - Normative Elements**

## **Palliative Care in international frameworks/ instruments/reports**

CESCR , General Comment 14.(2000) (34)

CEDAW GC 27 (45)

Madrid International Plan of Action on Ageing, 2002  
(Issue 2: Universal and equal access to health-care services)

### **Reports of the Independent Expert**

A/HRC/30/43, Care and Autonomy, 2015 (p 86, 87, 115, 131)

A/HRC/33/44 Comprehensive Report 2016 (par. 122)

A/HRC/36/48 Assistive technologies, 2017 (par. 81)

A/HRC/39/50 Social exclusion ,2018 (par. 61)

# **Palliative Care - Normative Elements**

## **Palliative Care in international frameworks/ instruments/reports**

WHO Global report on ageing and health, 2015

WHA69.3 Global strategy and action plan on ageing and health 2016–2020: towards a world in which everyone can live a long and healthy life, 2016

WHA69.24 Strengthening integrated, people-centred health services

WHA67.19 – Strengthening of palliative care as a component of comprehensive care throughout the life course

# **Palliative Care - Normative Elements**

## **Regional Policy frameworks**

Inter-American Convention on Protecting the Human Rights of Older Persons, 2015 (art. 6,11,12,19)

AU Protocol to the African Charter on the Rights of Older Persons (2016 Art. 11 Residential Care)

CoE Recommendation CM/Rec(2014)2

CoE (Rec 2003)24 on organisation of PC

European Charter of the rights and responsibilities of older people in need of long-term care and assistance (2010)

# **Palliative Care - Normative Elements**

## **Affirmation of the right**

Older persons have the right to quality palliative care that is available, acceptable, accessible and affordable without discrimination of any kind.

# **Palliative Care - Normative Elements**

## **Scope**

The right applies to holistic palliative care in all settings and is not limited to pain relief or any particular treatment or setting

Or

The right applies:

1. To all settings: i.e. Private and public, at home, community based, residential, institutions, hospitals, hospice, prisons or any other setting.
2. At any time of a life-limiting condition and is not limited to pain relief, specific disease or end of life care.
3. To holistic care for the physical and mental integrity, social and spiritual needs of older persons at any age with full respect to their preference and dignity.

# **Palliative Care - Normative Elements**

## **State Obligations**

Member States (State Parties) shall take appropriate and effective measures:

- a. To ensure quality palliative care is available, acceptable and accessible for older persons.
- b. To integrate Palliative Care into the public health system and universal health coverage.
- c. To ensure the adequate training in palliative care of health, social and spiritual care providers and volunteers.
- d. To enable timely access to information about available options of palliative care support and services

# **Palliative Care - Normative Elements**

## **State Obligations**

- e. To enable access to essential technologies and medicines, including internationally controlled essential medicines, for palliative care of older persons including the treatment of moderate to severe pain.
- f. To review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical purposes.
- g. To prevent the cruel, inhuman and degrading treatment of older persons, including as a result of the failure to provide adequate care and adequately treat pain, discomfort and other symptoms.

# **Palliative Care - Normative Elements**

## **State Obligations**

- h. To ensure older persons are able to express their free, prior and on-going informed consent to their palliative care and overall health and social care.**
- i. To facilitate the preparation of advanced directives, living wills or any legally binding document through which older persons may wish to indicate their preferences on all their palliative care options from diagnosis to end of life care.**
- j. To provide timely information of any changes in the national legislation that may impact their advance directives and enable a periodic revision of the personal directives.**



# **Palliative Care - Normative Elements**

## **State Obligations**

- k. To ensure older persons have access to palliative care in a setting that is consistent with their needs, will and preferences, including at home and long-term care settings.
- l. To enable supported decision-making where necessary, whilst retaining the legal capacity of the older person.
- m. To ensure older persons have access to a range of supports to exercise legal capacity, including the appointment of one or more trusted persons to assist them to make decisions based on their instructions, will and preferences.

# **Palliative Care - Normative Elements**

## **State Obligations**

- n. To ensure those close to the older person, including family members, are able to access support a range of services including on administrative procedures and bereavement.
- o. To recognize in national legislation the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering.
- p. To remove regulatory, educational, and attitudinal obstacles that restrict availability to essential palliative care medications.

# **Palliative Care - Normative Elements**

## **State Obligations**

- q. To put in place measures to safeguard against the misuse of narcotic and psychotropic drugs and other medications.
- r. To regulate and monitor the compliance of all palliative care providers with professional obligations and standards.

# **Palliative Care - Normative Elements**

**Thank you**

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