Palliative care for people with neurodegenerative disorders

Family and societal perspectives

Dinithi Vidanage, Maliga Wijesiri, Katarina Galof

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in
Higher Education

Aim of the lecture

- At the end of the session, the student should be able to;

1. define the key terms ‘palliative care’, ‘end-of-life care’ and ‘hospice’

2. describe the ethical and legal aspects of end-of-life care/palliative care

3. identify the role of care giver in end-of-life care/palliative care

Co-funded by the Erasmus+ Programme of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

Content

1. Definition of terms palliative care, end-of-life care and hospice
2. What can you do in last stages of disease
3. Palliative care in ND (why is it so special for degenerative diseases - non communicative diseases)
4. Assisting with daily living
5. Palliative care in home environment, help for relatives

Ethical - living will, Euthenasia (discussions)

6. Religion/prayers/chanting
7. Easing lives of patients as well as of care givers
8. Recognizing the pain

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Definitions

- Palliative Care - is the active care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. It may be delivered by any health care professional.

- Terminal Care - is the care of a person in the last days or weeks before they die (i.e., the final part of palliative care).

- Specialist Palliative Care - palliative care delivered by those with specialist training in palliative care (nurses / consultants in palliative medicine). Usually for more difficult/complex cases.

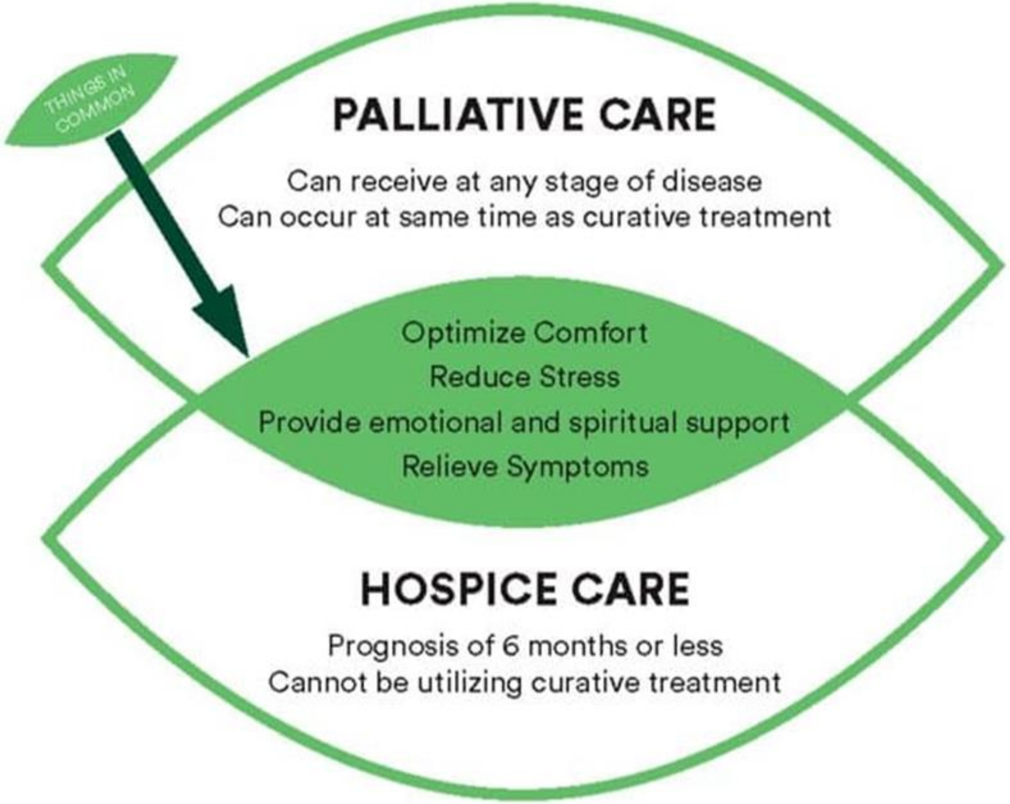
(Burns, 2018)

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

Palliative vs hospice care



PALLIATIVE CARE

Can receive at any stage of disease
Can occur at same time as curative treatment

Optimize Comfort
Reduce Stress
Provide emotional and spiritual support
Relieve Symptoms

HOSPICE CARE

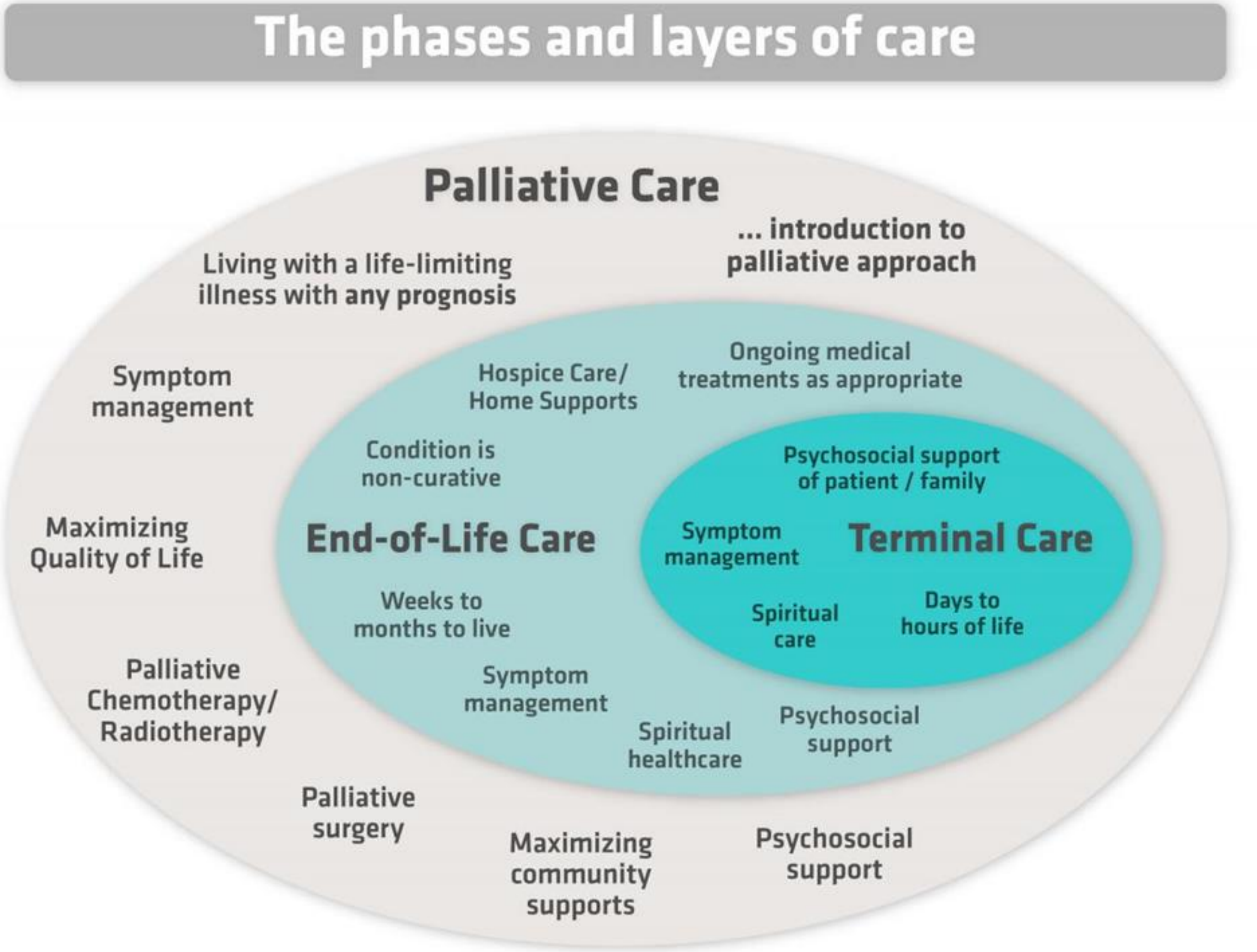
Prognosis of 6 months or less
Cannot be utilizing curative treatment

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Phases of care



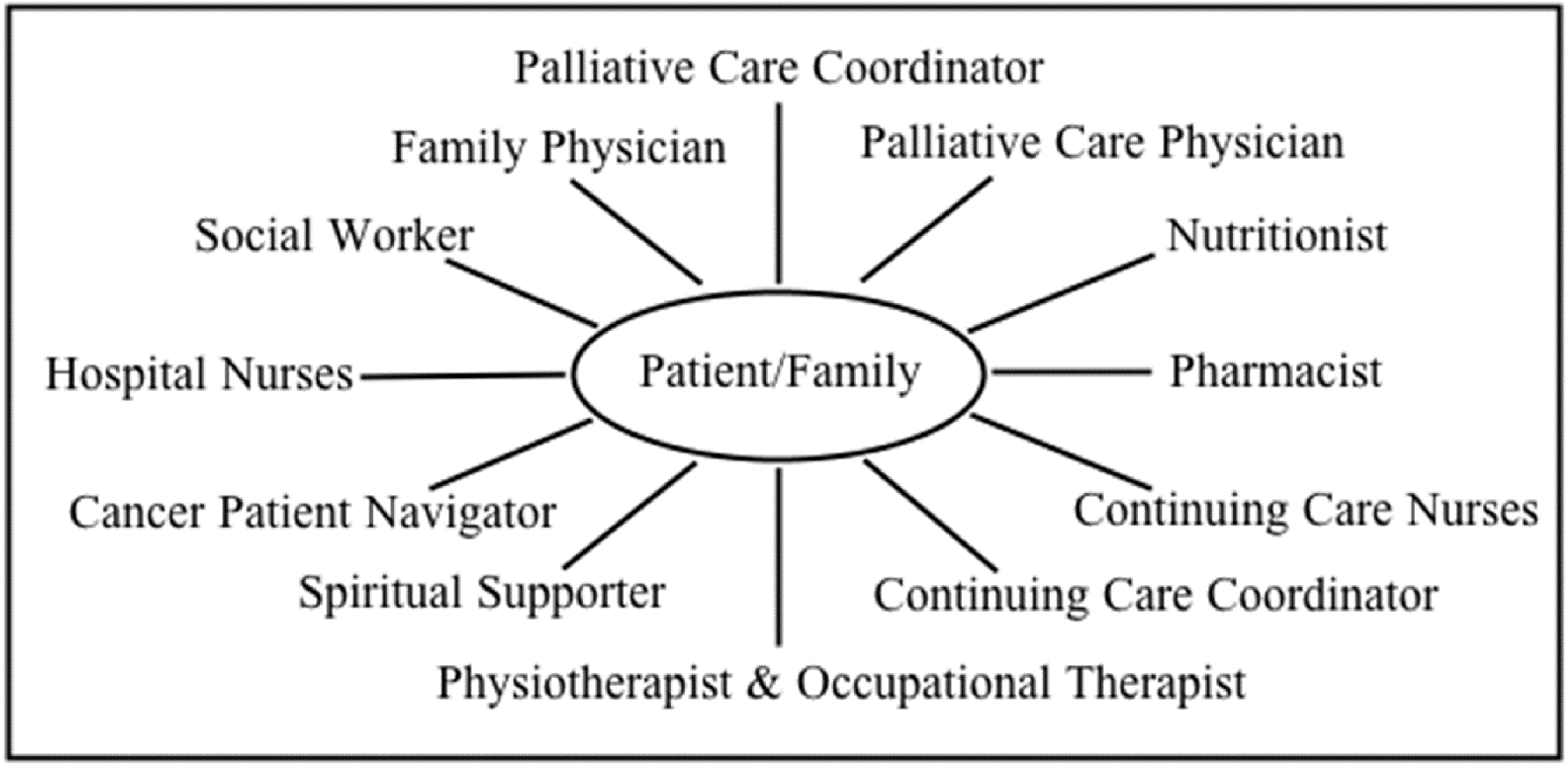
Co-funded by the Erasmus+ Programme of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in Higher Education

Palliative care team



Patient/Family

- Palliative Care Coordinator
- Palliative Care Physician
- Nutritionist
- Pharmacist
- Continuing Care Nurses
- Continuing Care Coordinator
- Physiotherapist & Occupational Therapist
- Spiritual Supporter
- Cancer Patient Navigator
- Hospital Nurses
- Social Worker
- Family Physician

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Palliative care in older people

- Palliative care is 'an approach that improves the quality of life of patients and their families facing the problems 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 is not just for when the person is dying or at the end of their life; it is for any time during a terminal illness.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Assisting with daily life

- https://www.sralab.org/sites/default/files/2017-07/barthel.pdf

- **THE BARTHEL INDEX**
- **Feeding, bathing, grooming, dressing, bowel…etc.**

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Lawton IADL Scale

- https://www.alz.org/careplanning/downloads/lawton-iadl.pdf

- Ability to use telephone
- Laundry
- Shopping

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in
Higher Education

Principles of a good death as identified by Age Concern

- To know when death is coming and to understand what can be expected.
- To be able to retain control of what happens.
- To be afforded dignity and privacy.
- To have control over pain relief and other symptoms.
- To have choice and control over where death occurs (i.e. a home or elsewhere).
- To have access to any spiritual and emotional support required.
- To have access to hospice care in any location, not only in hospital.
- To have control over who is present and who shares the end.
- To be able to issue advance directives which ensure wishes are respected.
- To have time to say goodbye and control over other aspects of timing.
- To be able to leave when it is time to go and not have life prolonged pointlessly.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Palliative care – Quality of life

- Palliative care is specifically used to improve the quality of life of older people.
- WHOQOLBREF quality of life scale can be used to assess the QOL of elderly during palliative care management
- The assessment of QOL includes following four aspects
  - Physical health
  - Psychological
  - Social relationships
  - Environment
- The questionnaire consisted of 2 global items (overall QOL and general health) and 24 items in the domains of physical, psychological, social relationship, and environmental.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

WHOQOLBREF

Domain	Facts incorporated with domain
1. Physical Health	Activities of daily living Dependence on medical substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality/ religion/ personal beliefs Thinking, learning, memory, and concentration

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

Domain	Facts incorporated with domain
3. Social relationships	Personal relationships Social support Sexual activity
4. Environmental	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for reaction/ leisure activities Physical environment (pollution/ noise/ traffic/ climate) Transport

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in
Higher Education

The importance of 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 patient’s 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

World Health Organization, WHO Definition of Palliative Care, 2015, World Health Organizsation

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Palliative care and ageing

- People and their families with the following conditions may benefit from palliative care.
  - Progressive dementia
  - People dying as a result of the ageing process
  - Advanced heart disease
  - Advanced respiratory disease
  - End-stage renal failure
  - End-stage liver disease
  - Secondary cancers
  - Degenerative neurological conditions

Co-funded by the Erasmus+ Programme of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

Palliative care and Ageing Con’t

- Specialist palliative care services support people with life limiting illness in a number of ways, including:
  - direct care for people requiring specialist palliative care interventions for management of complex symptoms/care needs
  - consultation and advice to other services and health care teams providing end of life care
  - education and training on palliative care and end of life issues
  - undertaking and disseminating research about caring for the dying and their families/carers.

Co-funded by the Erasmus+ Programme of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

Palliative care - challenges for older people

- loss of independence
- having to rely more on others for assistance
- losing control of their life
- not being able to think as clearly as they used to
- changes in physical appearance and functional abilities
- depression/anxiety
- increased social isolation and/or feelings of loneliness
- not feeling valued
- feeling a sense of being a burden to others
- not being treated with respect or understanding

(Cherny N. et al (eds) 2015, Oxford Textbook of Palliative Medicine, Fifth Edition, Oxford University Press, Oxford, p. 10)

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Responding to the needs of palliative care Cont’d

- Develop a care plan
- Do not assume
- Check advance care planning

(Balaban, R.B., A Physician's guide to talking about end-of-life care. Journal of General Internal Medicine, 2000. 15: p. 195-200)

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Managing physical symptoms during palliative care

- People who need palliative care may experience some of the following symptoms, depending on their illness. These symptoms can impact on their quality of life and be distressing for their family and carers.

- We need to be familiar with these symptoms and work with our team to determine what can be addressed:
  - Pain
  - Delirium
  - Nutrition and hydration
  - Breathlessness
  - Oral health problems.
  - Palliative care patients may experience more than one symptom at a time

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Palliative care - Grief and Loss

- Grief is a common and especially significant concern for carers and family members.
- Reassure family and caregivers - grieving is the normal response to the death of a loved one.
- Early actions can be taken to minimise distress associated with grief. It can manifest as
  - Sadness
  - Anger
  - Fear
  - Distress
  - Despair
  - Anxiety
  - guilt
  - worrying thoughts
  - sleep disturbance
  - social withdrawal and/or decreased ability to maintain an organised lifestyle

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in
Higher Education

The Gold Standards Framework

- The Gold Standards Framework, a programme developed primarily for use in primary care based on the 7 C's: communication, coordination, control of symptoms, continuity, continued learning, carer support, and care of the dying.
- The emphasis on anticipatory care (to reduce crises and inappropriate admissions) and the transfer and communication of information to out-of-hours services are particularly important.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

Palliative care and dementia: current problems

1. Place of death & Resuscitation
2. Pain
3. Artificial nutrition and hydration
4. Access to specialist palliative care
5. Care planning
6. Neuropsychiatric symptoms

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in Higher Education

Place of death & Resuscitation

Despite the wish of the majority of dementia patients (and their families) to die in their own home, most will die in hospital in acute wards where staff may be poorly trained or have insufficient time to manage their individual needs, or in care homes where there may be inadequate staff training in palliative care, poor symptom control and lack of psychological and emotional support

In severe dementia cardiopulmonary resuscitation (CPR) is unlikely to be successful. Outside hospital the chances of survival are low and CPR itself may be harmful

If families (or people with dementia) wish to discuss the prognosis and how things might go in the end of life, clinicians would have to discuss whether CPR would be performed or not

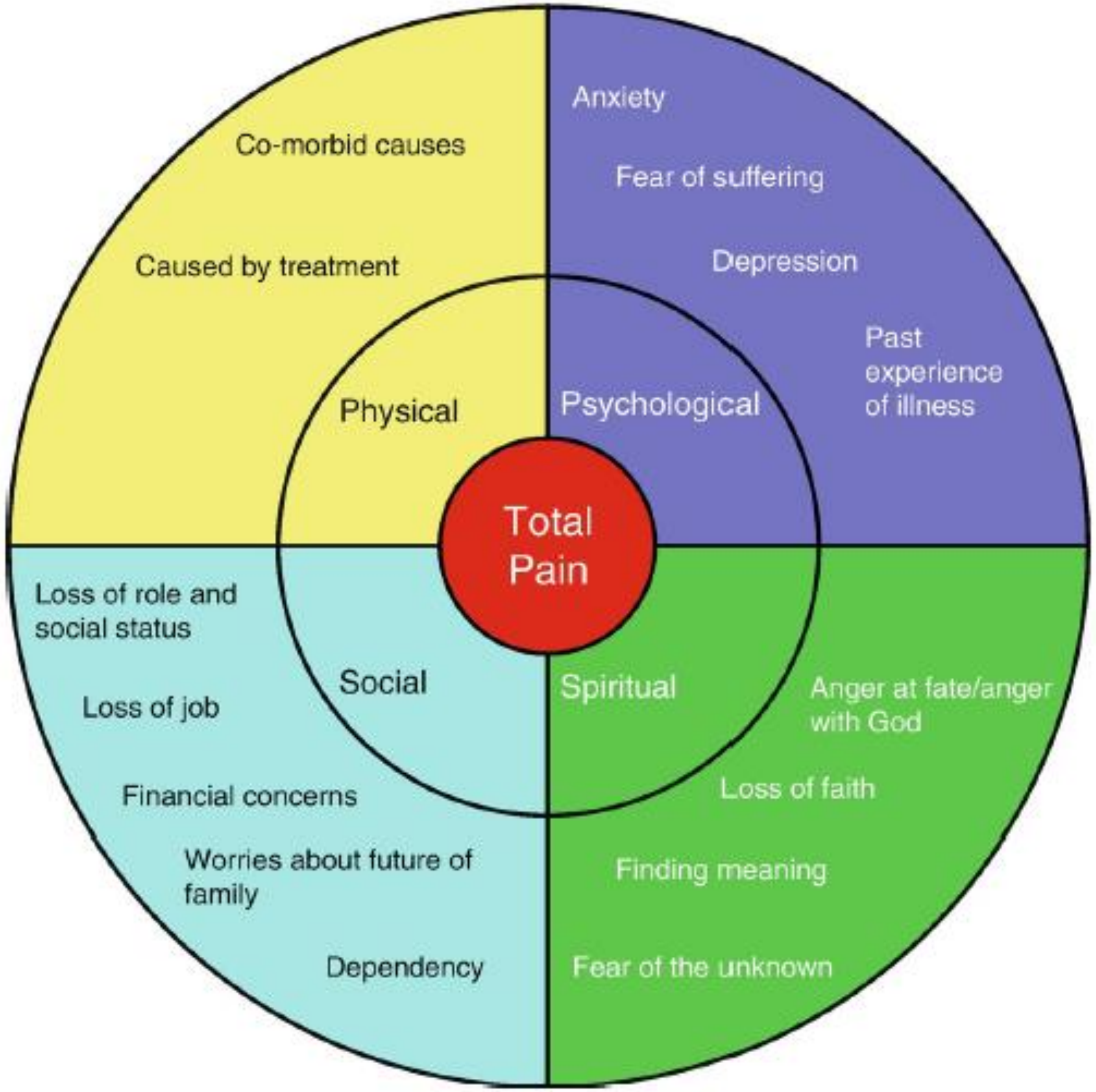
Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Pain

- Assessment all types of pain
- Treat each type of pain individually
- Continual reassessment of treatment goals (pain, function, mood, sleep, social interaction)



Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Capacity building in
Higher Education

Artificial nutrition and hydration

- In dementia there is a loss of appetite, a loss of the experience of hunger and of the need for a routine of regular meals

- Dyspraxia and sequencing problems may cause difficulties with the process of feeding; swallowing problems become increasingly noticeable

- In more severe stage, aspiration pneumonia becomes a concern.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in Higher Education

Access to specialist palliative care

- Patients with dementia are less likely to be referred to palliative care teams, prescribed fewer palliative care medications and are infrequently referred or denied access to hospice care

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Care planning

- Patients with dementia are less likely to have advance care planning than those with terminal cancer: advance directives (including withholding tube feeding), “Do not resuscitate” orders, and “Do not hospitalise” instructions

- More likely to experience uncomfortable or aggressive intervention at the end of life: blood tests, intravenous therapy, arterial blood gases and feeding tubes

Advance Care planning (ACP) is essentially a process of discussion between an individual and their care providers, which may include family/friends, about the kind of care they would like to receive now and in the future.

DH Guidance on Advance Care Planning. End of Life Care Programme 2008

Co-funded by the Erasmus+ Programme of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Comr
cannot be held responsible for any use, which may be made of the information contai

Neuropsychiatric symptoms

- Agitation (51-71%) and apathy, depressive and behavioral symptoms are common symptoms in the course of the disease
- Neuropsychiatric symptoms were associated with lower quality of life and unmet needs as pain and social needs were associated with verbally agitated behavioral symptoms

- Non-pharmacological interventions tailored to the individual may be more appropriate to treat behavioral symptoms, e.g., aromatherapy, massages of hand, or foot can be effective. Presence of a carer and being in interaction with others and individualized interventions may help to reduce symptoms like agitation, aggression, apathy, anxiety

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Spiritual needs

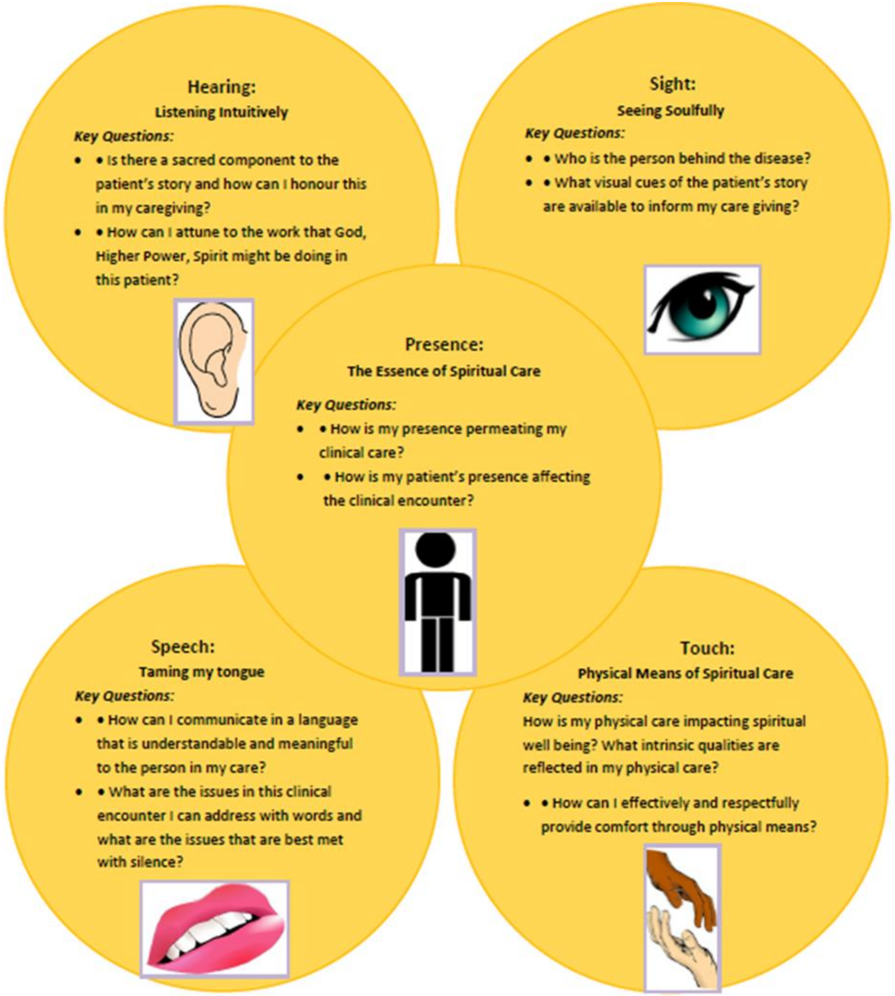
- Healthcare professionals should know about interventions like support group programmes that can enhance meaning making of participant’s subjective experiences and help to define purpose in live.
- Spiritual legacy work is an opportunity for people with progressive neurologic diseases to talk about their spirituality with healthcare chaplains.
- Dignity therapy is a way to help patients to deal with unfinished business and to enhance self-acceptance and role preservation. Developing belief and value based care models for people with life-limiting neurodegenerative conditions and their caregivers to prevent health related suffering has to be ongoing.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

5 senses of spiritual care



Hearing:

Listening Intuitively

Key Questions:

- • Is there a sacred component to the patient's story and how can I honour this in my caregiving?
- • How can I attune to the work that God, Higher Power, Spirit might be doing in this patient?

Sight:

Seeing Soulfully

Key Questions:

- • Who is the person behind the disease?
- • What visual cues of the patient's story are available to inform my care giving?

Presence:

The Essence of Spiritual Care

Key Questions:

- • How is my presence permeating my clinical care?
- • How is my patient's presence affecting the clinical encounter?

Speech:

Taming my tongue

Key Questions:

- • How can I communicate in a language that is understandable and meaningful to the person in my care?
- • What are the issues in this clinical encounter I can address with words and what are the issues that are best met with silence?

Touch:

Physical Means of Spiritual Care

Key Questions:

How is my physical care impacting spiritual well being? What intrinsic qualities are reflected in my physical care?

- • How can I effectively and respectfully provide comfort through physical means?

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in Higher Education

Issues in end-of-life care of older people

- Dying patients frequently do not receive basic nursing care or assistance with eating and drinking.
- Alternatively, staff may focus on meeting physical needs at the expense of psychological and spiritual care.
- Older people are less likely to receive appropriate pain control than their younger counterparts. This is especially for patients with dementia. They are less likely to take opioids for pain due to cultural beliefs.
- Older people are less likely to receive hospice care.
- In care homes end of life care may be impeded by inadequate staff training, poor symptom control and lack of psychological and emotional support.
- Comorbidity and drug reactions make symptom control more difficult

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Improving end of life care

- Improved education: palliative care teams are keen to provide education to supplement the skills of those caring for patients at the end of their lives.
- This may include training in;
  - holistic assessment
  - symptom management- both physical and psychological
  - communication skills.
- Improved communication with the palliative care team
- Integrated Care Pathways: an integrated care pathway for the dying patient has been developed ("the Liverpool care pathway"). This is being increasingly used to improve care for patients dying both in hospital and at home.
- The pathway is designed for patients with a known diagnosis who have deteriorated to such an extent that death appears inevitable.
- Symptoms are monitored and treated expectantly with an emphasis on comfort, communication and preparation for death with spiritual support.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

Ethical and legal aspects of end-of-life care

- Advance directives are becoming more common and provide helpful information for the clinician in making difficult decisions in the interests of the patient who is otherwise unable to give consent.
- Such directives may be of limited value as they often do not describe the precise clinical situation in advance.
- A living will cannot force a doctor to carry out treatment which they feel is inappropriate.
- The mental capacity act which came into force in 2007 allows patients to nominate a “health advocate” to assist in decision making about treatment.
- Legal distinctions between allowing death and assisting death are difficult to define, and while patients have the right to determine treatment while capacity is retained, there is no legal right to die.
- Issues concerning feeding and hydration are covered in the BGS guidance on “Nutritional advice in common clinical situations” (part of the BGS Good Practice Guide of Guidelines, Policy Statements and Statements of Good Practice).

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

Responding to the needs of palliative care

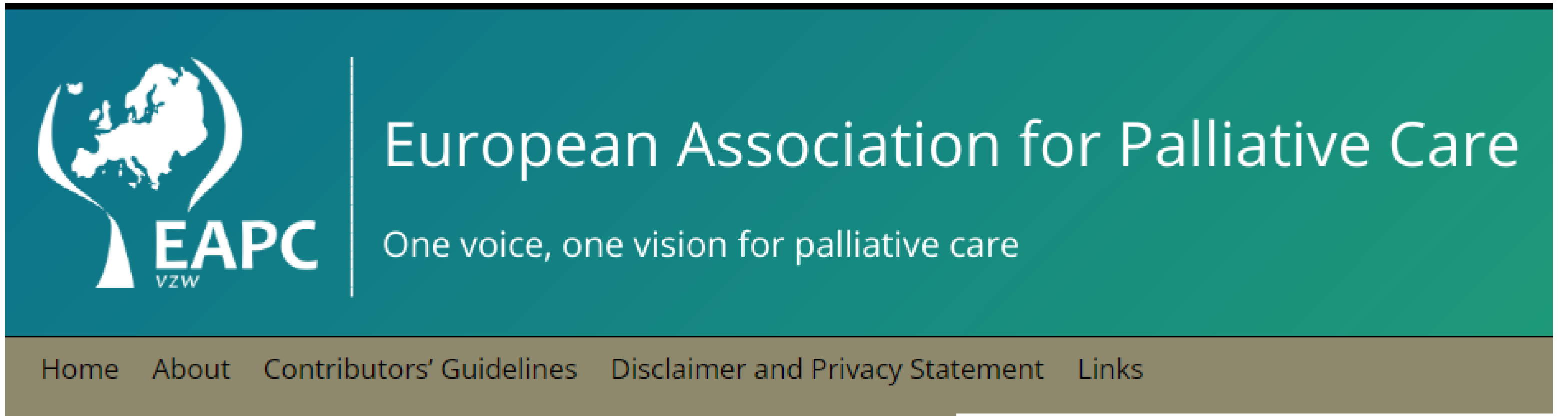
- Communication
  - The key principles of communication are:
  - Individualized communication
  - Listen
  - Check and clarify
  - position yourself at their eye level
  - Maintain dignity by:
    - Greeting the person and calling them by name
    - Treating the person as an adult
    - Giving them privacy
    - Finding out about their earlier life
    - Maintaining their comfort.
  - Consider non-verbal language - movements, posture, gestures, facial expression and eye contact.
  - Ask open questions.
  - Avoid providing lengthy explanations early in your interaction and take time to hear issues from the person's perspective.

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

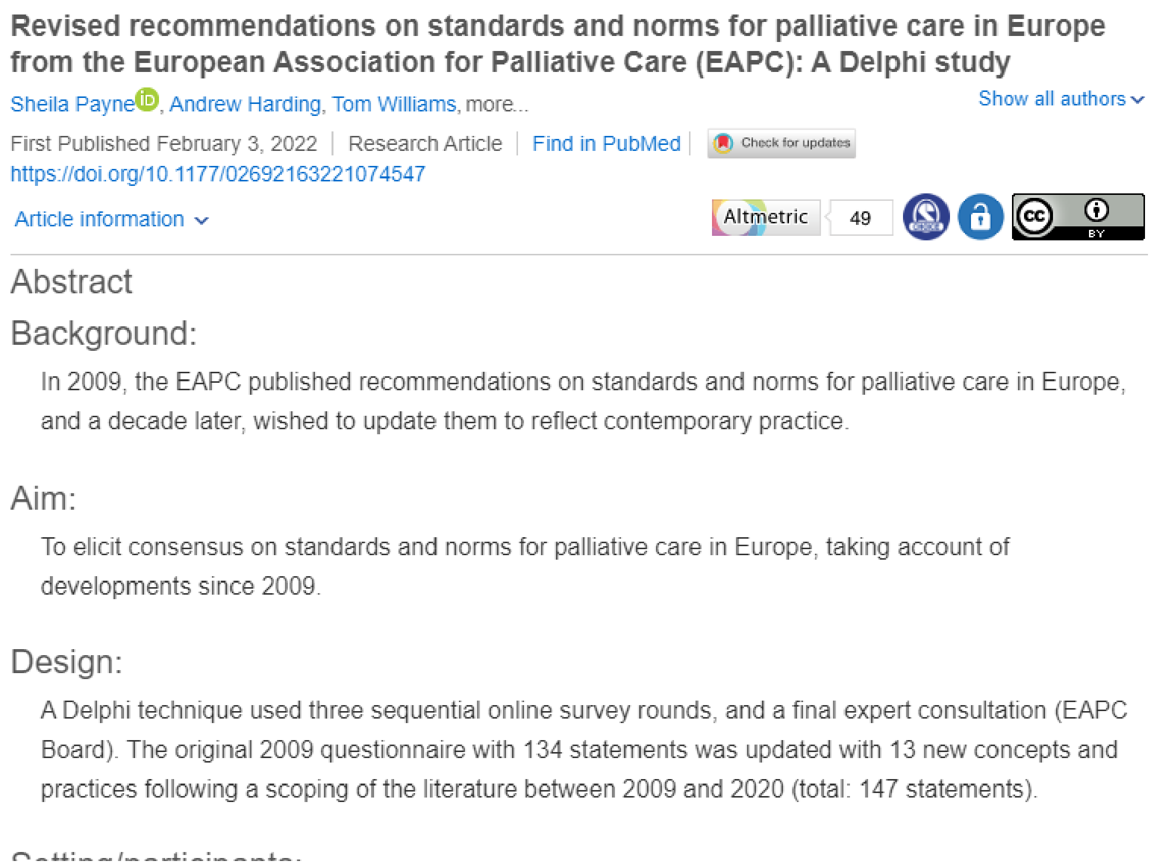
This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in
Higher Education



European Association for Palliative Care

One voice, one vision for palliative care



Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care (EAPC): A Delphi study

Sheila Payne, Andrew Harding, Tom Williams, more...

First Published February 3, 2022 | Research Article

https://doi.org/10.1177/02692163221074547

Abstract

Background:

In 2009, the EAPC published recommendations on standards and norms for palliative care in Europe, and a decade later, wished to update them to reflect contemporary practice.

Aim:

To elicit consensus on standards and norms for palliative care in Europe, taking account of developments since 2009.

Design:

A Delphi technique used three sequential online survey rounds, and a final expert consultation (EAPC Board). The original 2009 questionnaire with 134 statements was updated with 13 new concepts and practices following a scoping of the literature between 2009 and 2020 (total: 147 statements).

Co-funded by the Erasmus+ Programme of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP
This publication [communication] reflects the views only of the auth
cannot be held responsible for any use, which may be made of the information contained therein.

nEUROcare - Sri Lanka
Capacity building in Higher Education

CANADIAN Virtual Hospice

Palliative care is still widely misunderstood by many Canadians. Here are 10 common myths we often encounter.

10 MYTHS ABOUT PALLIATIVE CARE

MYTH 1: Palliative care hastens death.

FACT: Palliative care does not hasten death. It provides comfort and the best quality of life from diagnosis of an advanced illness until end of life.

MYTH 2: Palliative care is only for people dying of cancer.

FACT: Palliative care can benefit patients and their families from the time of diagnosis of any illness that may shorten life.

MYTH 3: People in palliative care who stop eating die of starvation.

FACT: People with advanced illnesses don't experience hunger or thirst as healthy people do. People who stop eating die of their illness, not starvation.

MYTH 4: Palliative care is only provided in a hospital.

FACT: Palliative care can be provided wherever the patient lives – home, long-term care facility, hospice or hospital.

MYTH 5: We need to protect children from being exposed to death and dying.

FACT: Allowing children to talk about death and dying can help them develop healthy attitudes that can benefit them as adults. Like adults, children also need time to say goodbye to people who are important to them.

MYTH 6: Pain is a part of dying.

FACT: Pain is not always a part of dying. If pain is experienced near end of life, there are many ways it can be alleviated.

MYTH 7: Taking pain medications in palliative care leads to addiction.

FACT: Keeping people comfortable often requires increased doses of pain medication. This is a result of tolerance to medication as the body adjusts, not addiction.

MYTH 8: Morphine is administered to hasten death.

FACT: Appropriate doses of morphine keep patients comfortable but do not hasten death.

MYTH 9: Palliative care means my doctor has given up and there is no hope for me.

FACT: Palliative care ensures the best quality of life for those who have been diagnosed with an advanced illness. Hope becomes less about cure and more about living life as fully as possible.

MYTH 10: I've let my family member down because he/she didn't die at home.

FACT: Sometimes the needs of the patient exceed what can be provided at home despite best efforts. Ensuring that the best care is delivered, regardless of setting, is not a failure.

Aussi disponible en français.

Copyright Canadian Virtual Hospice 2015

virtualhospice.ca

https://champlainpalliative.ca/myths-about-palliative-care/

ission
ed therein.

References

- https://www.who.int/news-room/facts-in-pictures/detail/palliative-care
- https://onlinelibrary.wiley.com/doi/full/10.1002/wps.20998
- https://bmjopen.bmj.com/content/bmjopen/11/6/e044502.full.pdf
- https://globaldementia.org/en/resources/area/health-information-systems
- https://apm.amegroups.com/article/view/39826/pdf
- https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

Co-funded by the
Erasmus+ Programme
of the European Union

Reference number: 618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP

This publication [communication] reflects the views only of the authors, and the Commission
cannot be held responsible for any use, which may be made of the information contained therein.