



A2.2 – Educative resources for teachers

Module: End of Life Care

Sub-Module: Principles of Palliative Care



Lesson Outcomes

- Understanding palliative care as a holistic approach to suffering and the role of the caregiver in this process
- Developing skills on basic care actions aimed at meeting individual needs
- Promoting students understanding and practice of basic techniques and practices for symptom control in patients
- Comprehending the ethical, legal and spiritual aspects in end-of-life care
- Identifying the different types of losses and its impacts in families and the role of grief counselling

Topics

1. The impact of terminal illness on the patient and family
2. Attitudes towards death and the end of life
 - 2.1. Values related to the life path,
 - 2.2. The end of life and death
3. Principles and philosophy of palliative care
4. Organization of palliative care in health systems
5. Palliative Care interface with certain specific diseases and conditions
6. Skills of communication and systemic approach: management of bad news, family conference

Introduction

- The diagnosis of terminal/ advanced disease has a profound effect on even the closest and most loving of families.
- The psychosocial/ spiritual crisis it creates is severe both to patients, families and healthcare workers

“Since life begins, there is care, because it is necessary to “take care” of life so that it can remain.”

19th century

Care of the dying were:

- neglected by society
- provided by religious and charity

20th century

- Scientific-technological advances
- Changes in the course of diseases
- Increase in Longevity

People live longer but not necessarily better...

There is still a dominant, traditionally biomedical model:

Science at the service of a curative ideal → **Eliminate Diseases**

- Rigorous diagnosis, based on increasingly rigorous exams
- Mechanized treatment
- Cure

- A culture of **death denial**
- Full **illusion** about the control of life and disease
- Death came to be faced by healthcare professionals as a **DEFEAT**

Death

- Individual, unique and subjective experience
- A taboo in western society
- Several ways to "die"

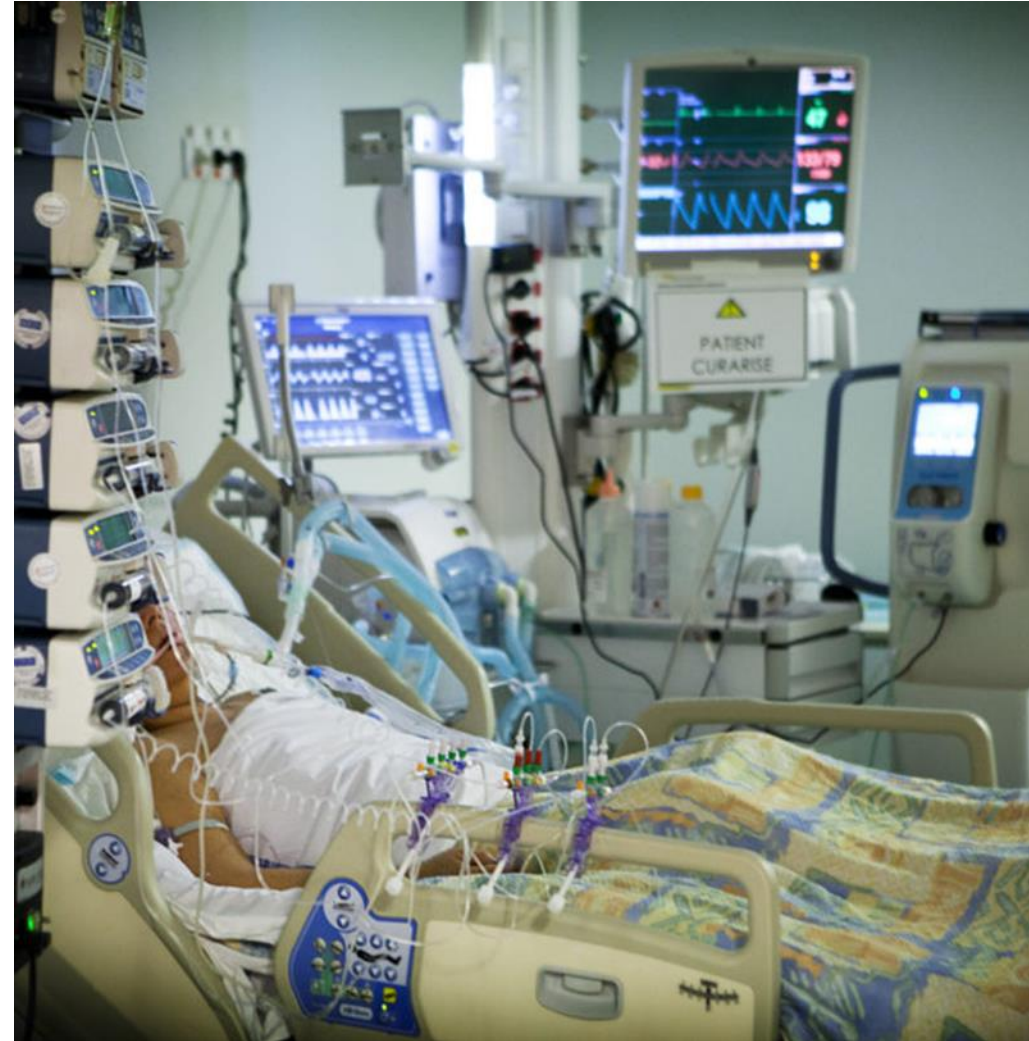


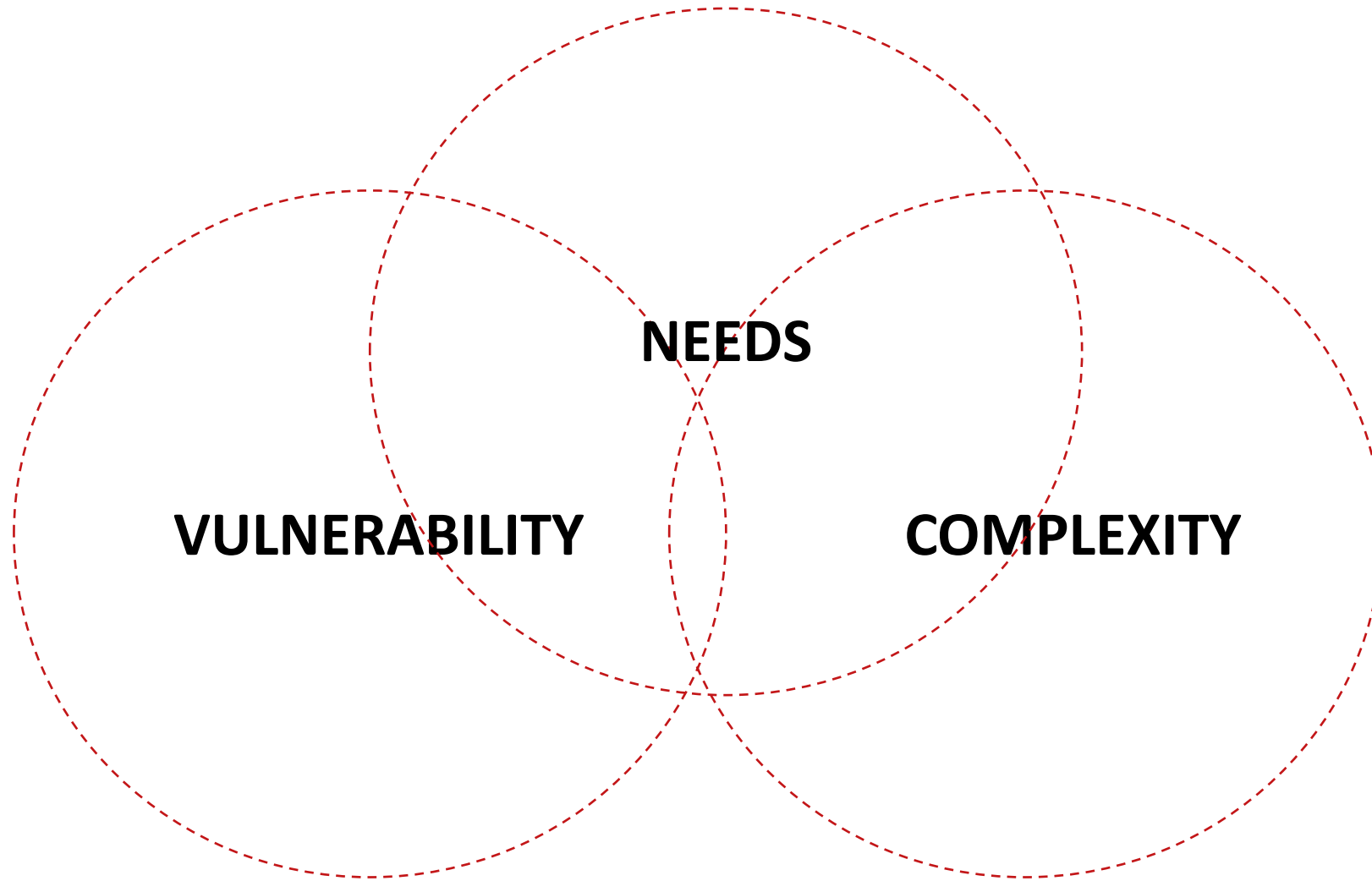
Death

- Difficult topic to address
- complex, obscure concept
- Unique and unrepeatable experience
- Tendency to look to myths or religion for some way to explain it or give it meaning
- Inexorably linked to Life

Transformation of the dying process

- Became longer
- Fear of suffering associated with terminal illnesses
- Transfer from place of death
- Technical-scientific development brought new possibilities
(healing but also death on request)







Dame Cicely Saunders (Nurse, Social Worker, Physician)
(1918 – 2005)

She warned of the need to offer scientific, rigorous and quality care to people with incurable, progressive and advanced diseases, for whom it was often said 'there is no longer anything to be done'



St. Christophers Hospice, Londres, UK



Cicely Saunders Institute, Londres, UK



ELSEVIER

Patient Education and Counseling 41 (2000) 7–13

Patient Education
and Counseling

www.elsevier.com/locate/pateducou

The evolution of palliative care

Cicely Saunders*

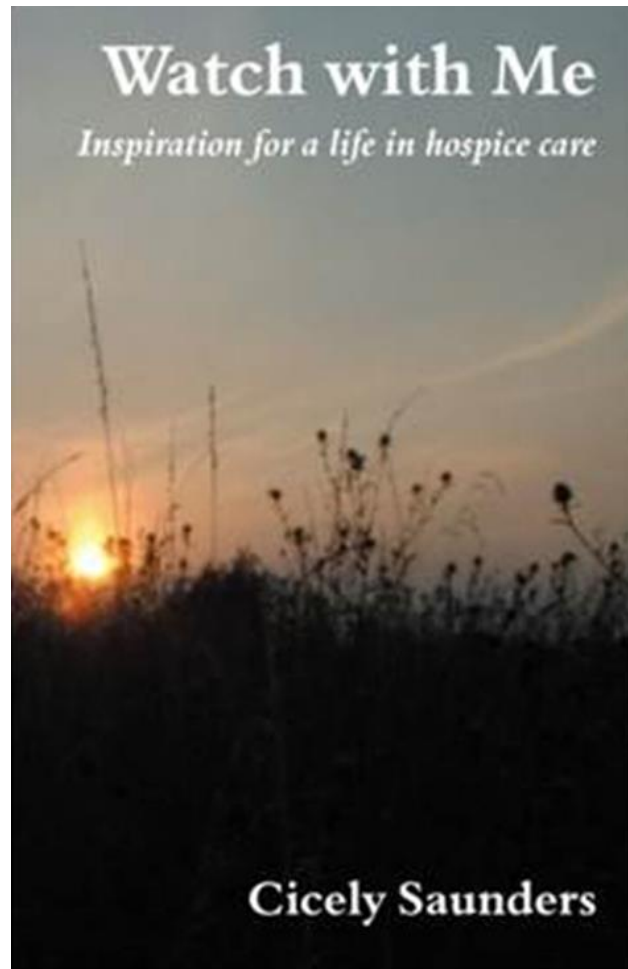
St. Christopher's Hospice, Sydenham, 51–59 Lawrie Park Road, London SE26 6DC, UK

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE Volume 94 September 2001

The evolution of palliative care

Cicely Saunders OM DBE FRCP

J R Soc Med 2001;94:430–432



- How do we die?
- Mortality
- The experience of suffering
- The ethics of care
- Searching for meaning(...)



*“ Watch with me’. I think the one word ‘watch’ says many things on many different levels, all of importance to us.
(...) It means really looking at him, learning what this kind of pain is like, what these symptoms are like, and from this knowledge finding out how best to relieve them. “*

‘Not only skill but compassion also’

These patients are not looking for pity and indulgence but that we should look at them with respect and an expectation of courage.”



<https://www.youtube.com/watch?v=KA3Uc3hBFoY>

International Associations of Palliative Care



APCP | Associação Portuguesa de Cuidados Paliativos | 25 ANOS
<http://www.apcp.com.pt/>



EAPC | European Association of Palliative Care
<https://www.eapcnet.eu/>



SECPAL | Sociedad Española de Cuidados Paliativos
<https://www.secpal.com/>



IAHPC | International Association for Hospice and Palliative Care
<https://hospicecare.com/home/>

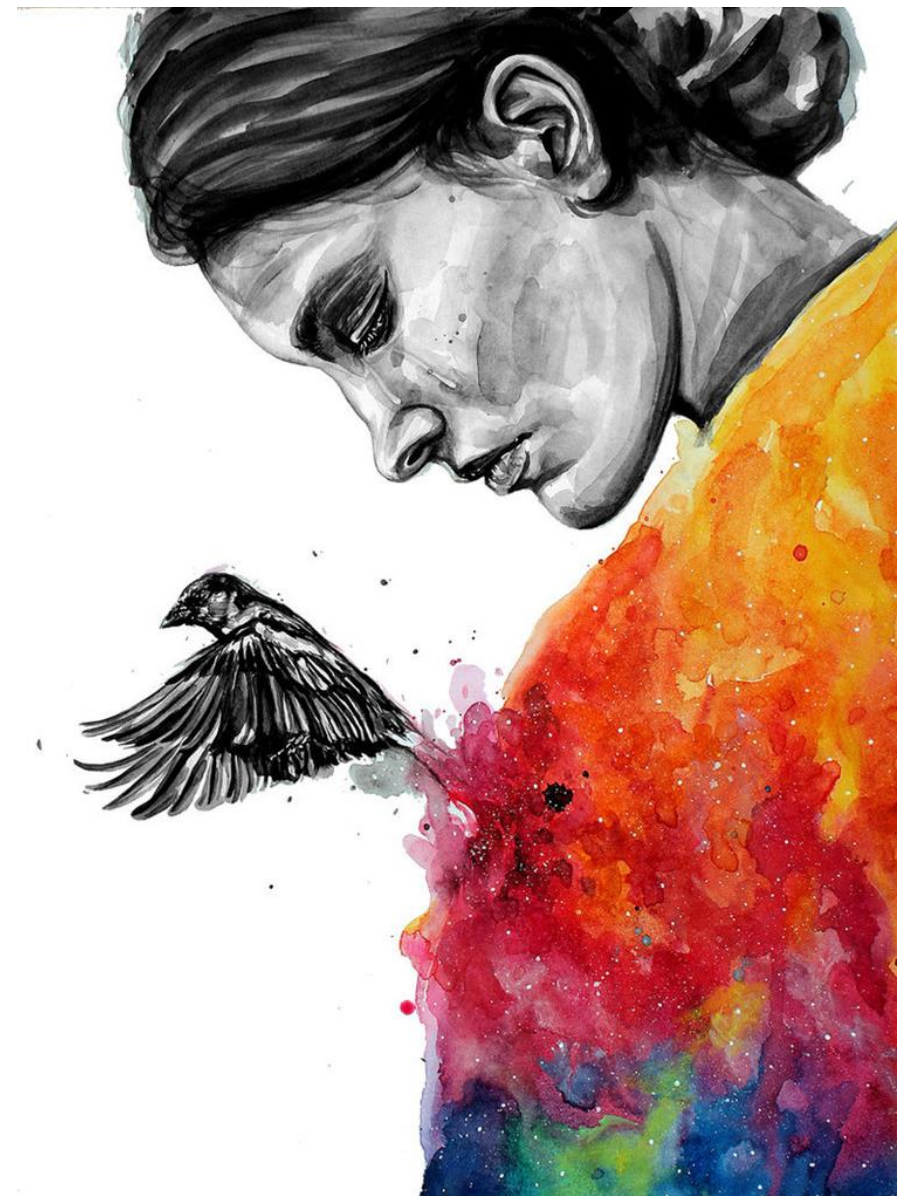
What is Palliative Care?

- Palliative care is the active, total care of patients whose disease is not responsive to curative treatment.
- Palliative care takes a holistic approach, addressing physical, psychosocial and spiritual care, including the treatment of pain and other symptoms.
- Palliative care is interdisciplinary in its approach and encompasses the care of the patient and their family and should be available in any location including hospital, hospice and community.
- Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death and sets out to preserve the best possible quality of life until death.

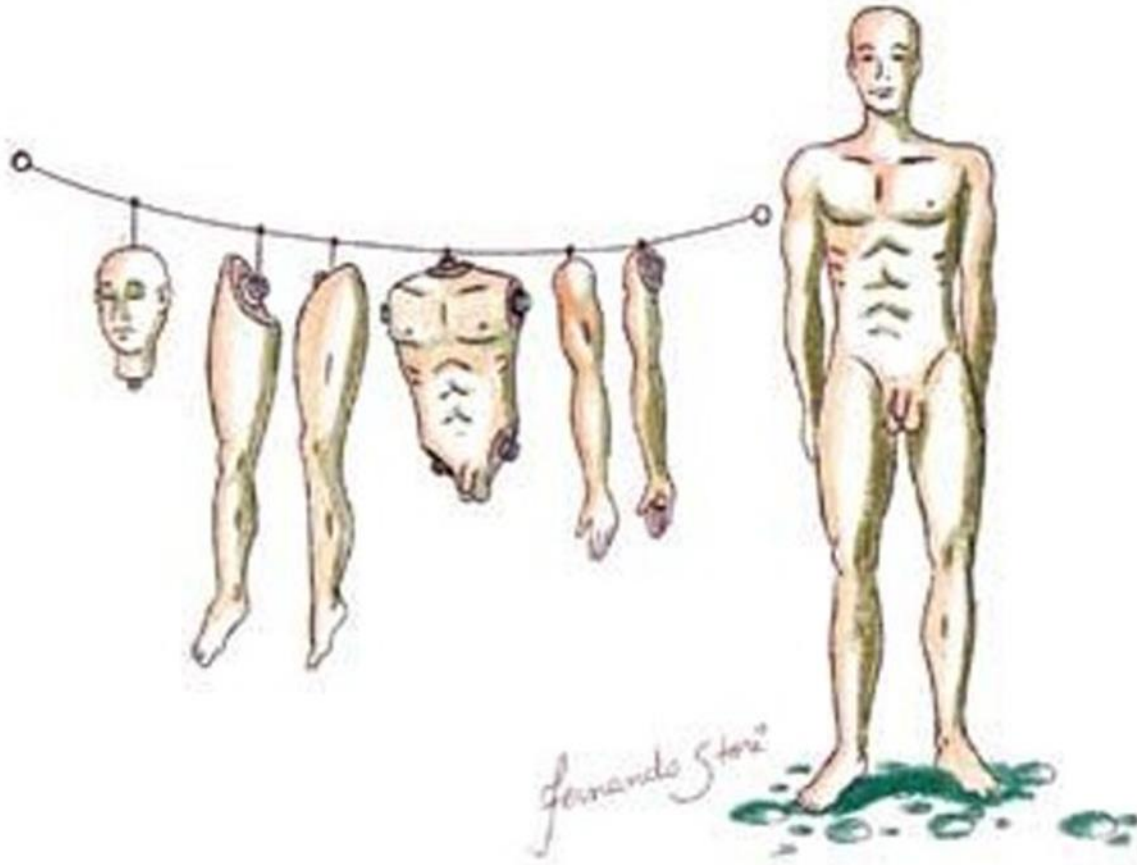
EAPC definition

NEEDS

(more than diagnosis or prognosis)







PERSON

Holistic approach



Follow-up
SUPPORT

CURE

RELIEF

| sometimes | chronic diseases |

COMFORT

| allways | palliative care |

Principles and Philosophy



Box 1. WHO definition of palliative care

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends to neither hasten nor 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;
- 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 investigations needed to better understand and manage distressing clinical complications.

Source: WHO (2009)

FUNDAMENTAL AREAS / PILLARS

- Symptom management
- Team work
- Communication
- Family support (including grief and bereavement)



Palliative Care

Hospice Care

Terminal Care

End of Life Care

Supportive Care

Comfort Care

Total Care

Holistic Care

Care of the dying

Review Article

Concepts and Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care”: A Systematic Review

David Hui, MD, MSc, Zohra Nooruddin, MD, Neha Didwaniya, MD, Rony Dev, MD, Maxine De La Cruz, MD, Sun Hyun Kim, MD, Jung Hye Kwon, MD, Ronald Hutchins, MSLS, Christiana Liem, MLS, and Eduardo Bruera, MD
Department of Palliative Care and Rehabilitation Medicine (D.H., Z.N., N.D., R.D., M.D.L.C., E.B.) and Research Medical Library (R.H., C.L.), The University of Texas M. D. Anderson Cancer Center, Houston, Texas, USA; Department of Family Medicine (S.H.K.), Myong Ji Hospital, Kwandong University, College of Medicine, Gyeonggi, and Department of Internal Medicine (J.H.K.), Kangdong Sacred Heart Hospital, Hallym University, Seoul, Republic of Korea

Comparing Palliative Care and Hospice Care

VS

Palliative Care

Physical and psychosocial relief

Focus on quality of life

Multidisciplinary Team Approach

Any stage of disease

May be concurrent with curative treatment

Hospice Care

Physical and psychosocial relief

Focus on quality of life

Multidisciplinary Team Approach

Prognosis 6 months or less

Excludes curative treatment



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.

Organisation of Palliative Care

Settings and Services

- Palliative care is an **interdisciplinary and multiprofessional** undertaking which attends to the needs of the Patient
- PC services and policies must offer a **wide range of resources**, such as home care, in-patient care in specific or conventional units, day hospital and out-patient clinics, emergency call-out and respite care facilities.
- **Informal caregivers should be supported** in their caregiving
- All professionals involved in the care of patients with advanced, progressive disease should have **easy access to specific expertise** if and when they need it.
- **Specialist palliative care should be available for all patients** when they need it, at any time and in any situation.

Challenges

Shortage of PC specialists

Lack of knowledge of PC still exists with some providers

Regional, socioeconomic, racial and ethnic groups influence access to PC

Care team members may be reluctant to discuss PC

Many patients are unaware of PC services

Opportunities

Increase access to PC

Develop communication strategies to help patients through the decision making process

Leverage HIE technology to improve appropriate referrals

Educate all providers and staff about PC

Increase patient satisfaction, while reducing provider burnout

How and Where of Palliative Care

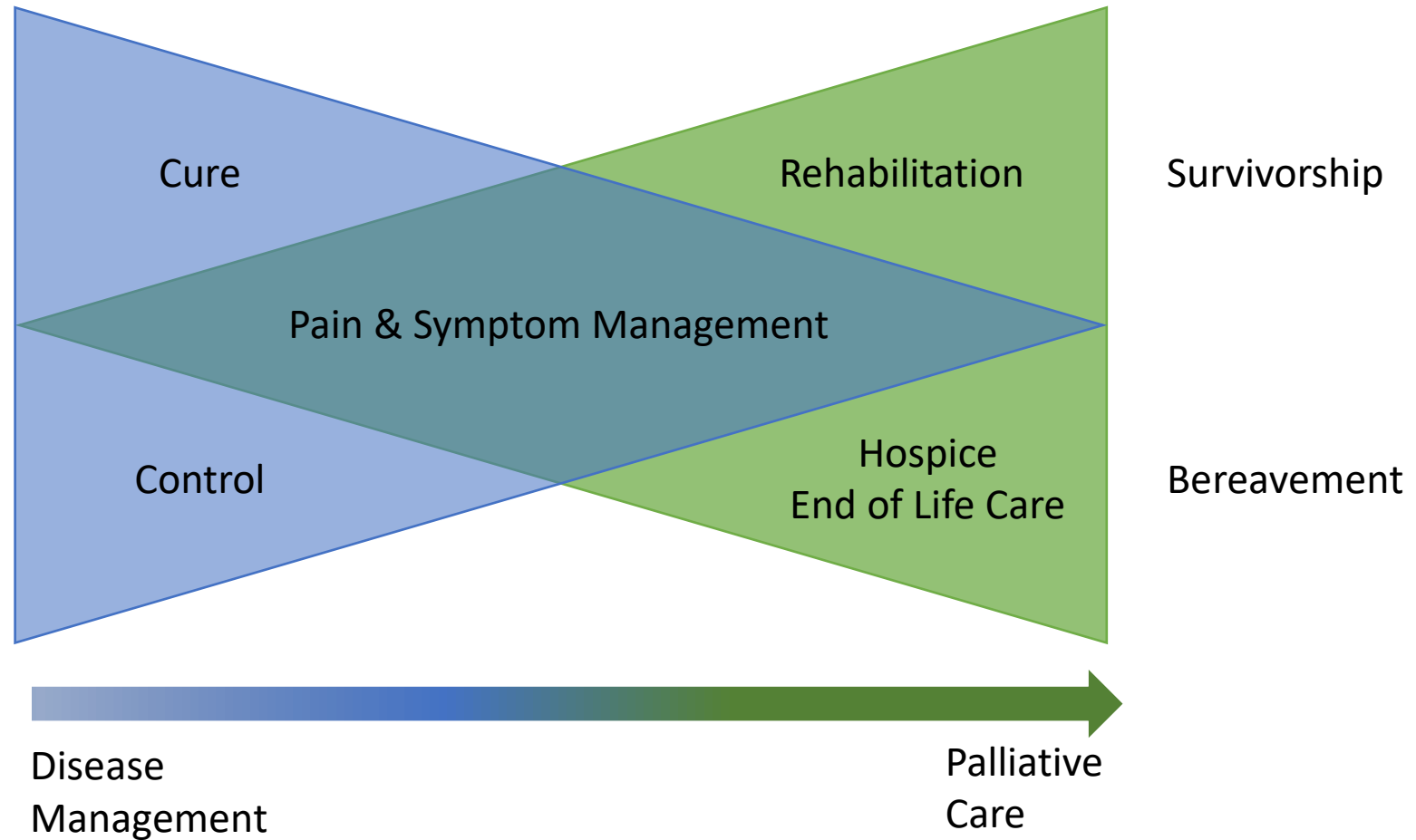
Gaining Access to Palliative Care

- Referral from PCP
- Referral from specialist
- Referral from care team member
- Hospitalization
- Self-referral
- Hospice

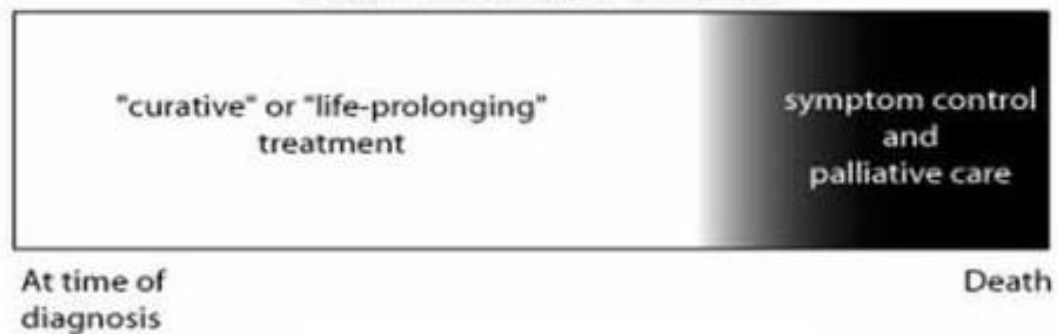
Locations for Palliative Care

- Patient's home
- Nursing home
- Assisted living
- Hospital
- Ambulatory practice/clinic
(Primary Care and Specialty Care)
- Community-based facility

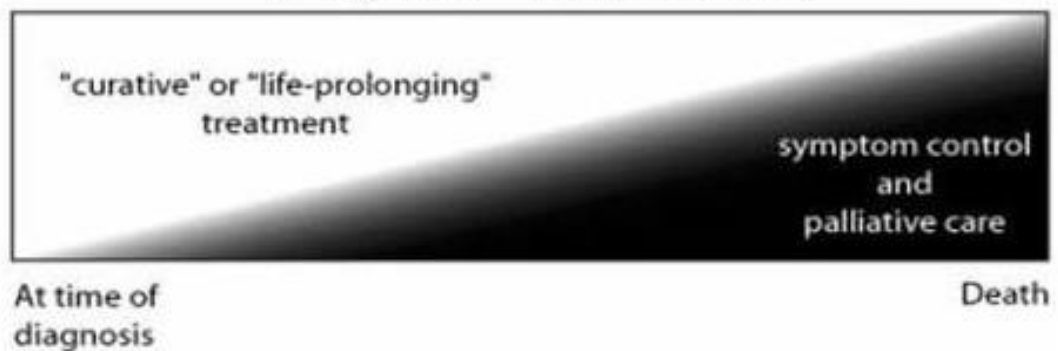
Palliative Care Enhanced Care Model



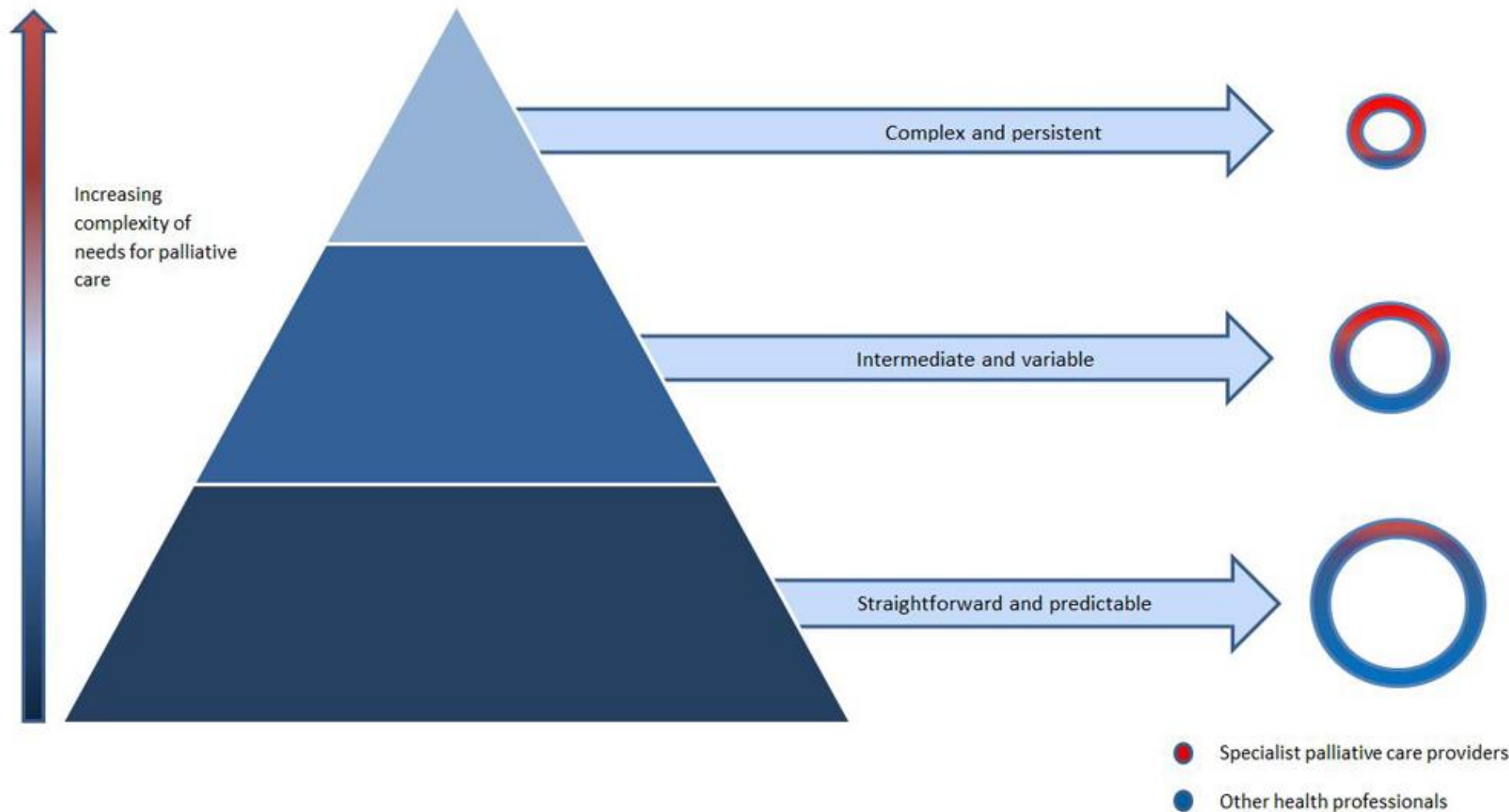
Current Care Model



Proposed Care Model

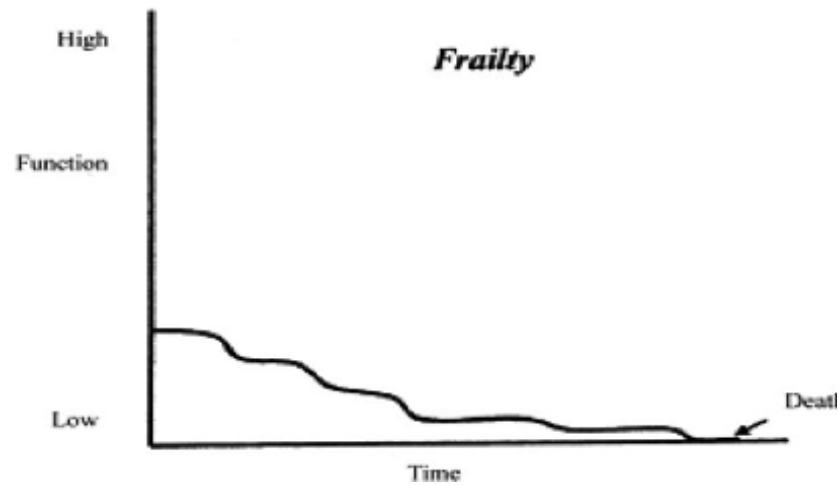
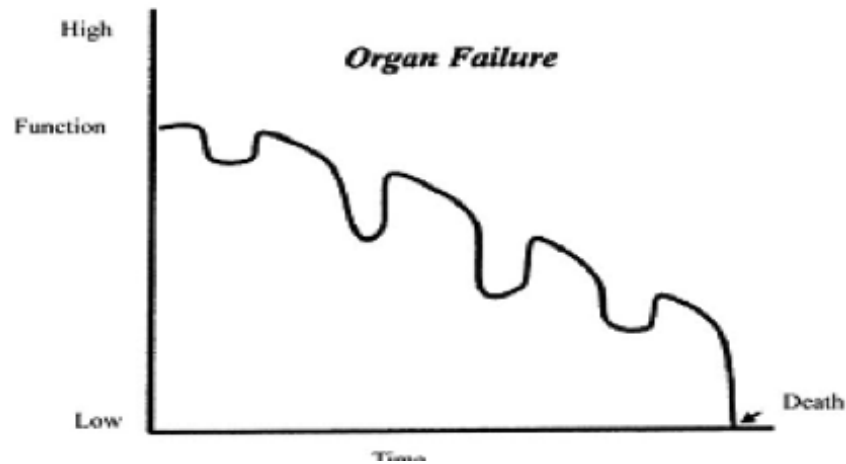
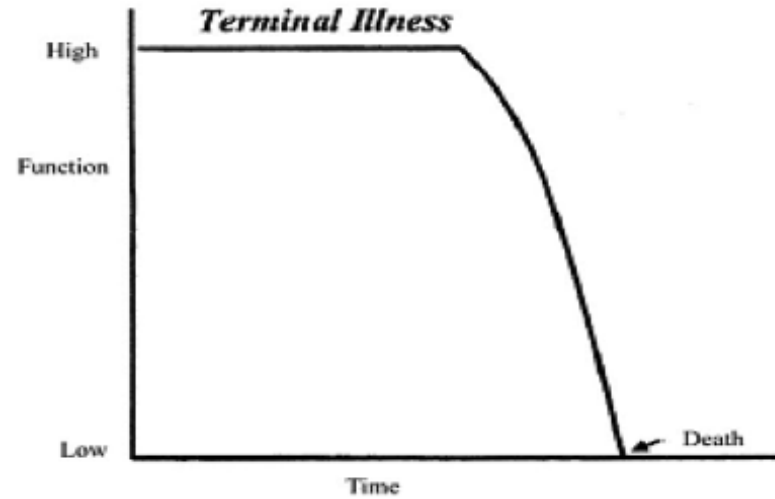
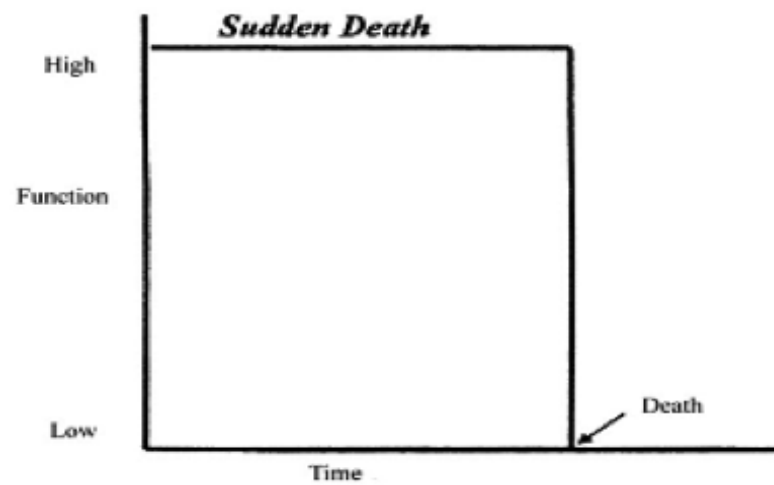


Person's Needs vs. Relative Workforce Involvement



Palliative Care interface with
certain specific diseases and conditions

Proposed Trajectories of Dying



Lynn & Adamson (2003), *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*

the **gold standards**
framework[®]
4th Edition
October 2011

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to
support earlier recognition of patients nearing the end of life

**RC
GP** Royal College of
General Practitioners

- More than prognosis, anticipating NEEDS
- Being proactive allows you to act at the right time.

the **gold standards**
framework

4th Edition
October 2011

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to
support earlier recognition of patients nearing the end of life



Royal College of
General Practitioners

3 ways to recognize that the patient is at the end of life:

1. **The surprise question:**

"Would you be surprised if this patient died in the next few months, weeks or days?"

2. **GENERAL indicators of decline:**

Progressive deterioration, Increased needs, having chosen to suspend active treatments.

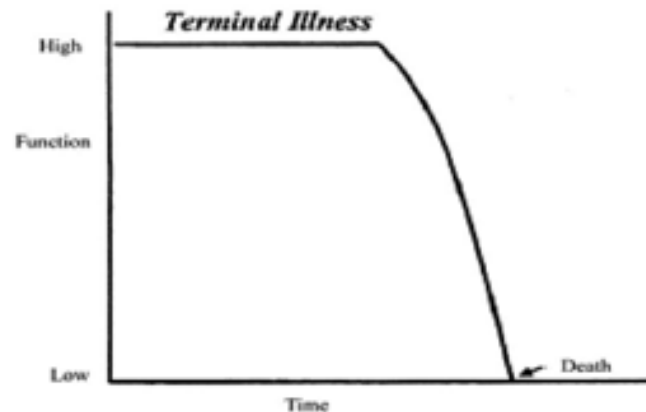
3. **SPECIFIC indicators of decline** (disease specificity).

GENERAL indicators of decline:

- Refer to the increase in health care (and other) NEEDS
- ↓ functional capacity and ↑ dependence in daily activities
- Several comorbidities (morbidity or mortality determinants)
- Advanced disease (with complex symptoms and/or progressive deterioration of health condition)
- ↓ treatment response
- Absence of treatment (by the patient's option or by medical advice)
- Progressive weight loss (>10%) in the last 6 months
- “Sentinel” events (eg frequent falls, multiple visits to the ER, repeated unscheduled admissions, transfer to a nursing home,...)

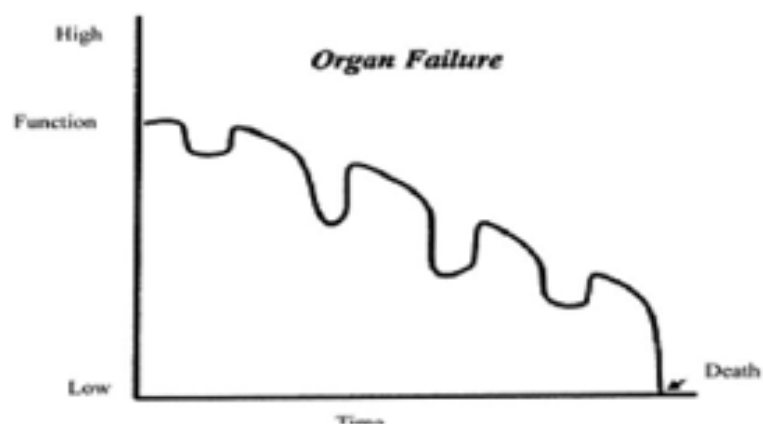
SPECIFIC indicators of decline

CANCER



- Locally Advanced Disease or Metastatic Disease: Symptomatic and Disabling
- ↓ performance and functional capacity

ORGAN FAILURE



- **RESPIRATORY | COPD**
- **CARDIAC**
- **RENAL FAILURE**
- **LIVER FAILURE**
- **NEUROLOGICAL**

YET...

Some vulnerable groups within society have unmet needs and equal access to good quality palliative care must be ensured

Socioeconomic status

People living in less affluent areas have higher death rates from some cancers, but are more likely to die in hospital and less likely to die at home.

Cultural and ethnic groups

People of all backgrounds and beliefs may experience spiritual pain and existential crises towards the EoL. Health care staff need to be able to recognize such crises and be aware of how to seek help from representatives of the range of faiths and beliefs in society.

Older people

Older people do not have access to hospice and palliative care services in the proportions that might be expected. There is considerable evidence of undertreatment of symptoms in hospitals and nursing homes, which are the setting for much care that is provided to older people in the last years and months of life.

Children and adolescents

Children and adolescents are a special group, as their death has a devastating and enduring impact on families. Care often needs to be provided in a range of settings, including the home and inpatient and respite care.

Skills of communication and systemic approach

Active listening as it is the key to effective communication

Greeting and seating

- Be hospitable, allow the patient to take his/her comfortable position in a private area
- Sit next to the patient at a reachable distance without any 'barrier', if possible.

Active listening as it is the key to effective communication

Ask open questions

- Open ended questions give freedom to the patient to decide what and how much he/she should tell

Active listening as it is the key to effective communication

Encourage talking

- Generally we talk more and the patients are forced to listen, unable to clear their doubts and uncertainties.
- It is good to encourage the patient to talk about his concerns.
- bring the patient back to the discussion when he/she deviates from the central theme.

Active listening as it is the key to effective communication

Maintain eye contact

- It gives confidence to the patient that he/she is being attentively listened to

Active listening as it is the key to effective communication

Tolerate 'brief' silence

- HCPs tend to get impatient when patients slow down their narration and become silent.
- It has to be understood that patients can become emotional as they narrate their past and describe a sensitive event or situation.

Active listening as it is the key to effective communication

Avoid unnecessary interruption

Summarize & prioritize the agenda

- Tell them the plan of treatment.

Empathize & give realistic hope.

SPIKES Protocol for Breaking Bad News

S – SETTING up the Interview

Arrange for privacy

Involve significant others

Sit down

Make connection with the patient by maintaining eye contact, touching as appropriate

P – PERCEPTION

How does the patient perceive the medical situation

“What have you been told about your medical situation so far?”

I – INVITATION

Assessing preferences for information disclosure

K – Giving KNOWLEDGE and Information to the Patient

Include a warning shot (e.g., “Unfortunately I have some bad news to tell you...”)

Use non-technical words

Avoid excessive bluntness

Give information in small chunks and periodically check for understanding

E – Assess the Patient’s EMOTIONS with Empathic Responses

Observe for any emotion

Allow for silence

Use empathic statements (e.g., “I know this isn’t what you wanted to hear. I wish the news were better”)

S – STRATEGY and SUMMARY

Check for understanding

Make a plan for the future

Family: Members of the Care Team

Central to the delivery of care are family members and/or caregivers:

- Provide insights into progression, improvement, and quality of life
- May advocate for patient needs, wishes and desires
- Source of emotional support and reliability for patients in ever-changing circumstances
- Provide long-term, 24 hour care with minimal emotional and psychological support

Family members benefit from the support of the palliative care team:

- Experience physical, emotional, and mental stress caring for family member or friend
- Prone to social isolation and caregiver burden
- Benefit from support of the overall palliative care team in the form of information, counselling, or practical assistance and training

Family Related Challenges

- Family Functioning
 - May have less than optimal relationships
- Incongruent patient and family member needs
- Communication process barriers
- Impaired concentration
- Timing and amount of information
- Family members not wanting to bother the health care team
- Family members' rejection of support
- Cultural issues and provider comfort level

Family conference or meeting

- A family conference (FC) is an opportunity for the family and HCP to share their knowledge and concerns about the physical and psychosocial-spiritual dimensions of care.
- Appropriate communication principles and practice are both important for an effective FC.

- When possible, the patient should determine who they would like to be present
- Identify the health proxy
- Helpful to have members of the care team available to the patient to aid in decision making
- Ensure an environment where patients and families feel comfortable sharing information

Shared Decision Making

- Engages patients and families in decisions about their care
- Increases their involvement and satisfaction
- Helps patients and families clearly communicate their goals and needs
- No “one right way” to intervene

Family conference

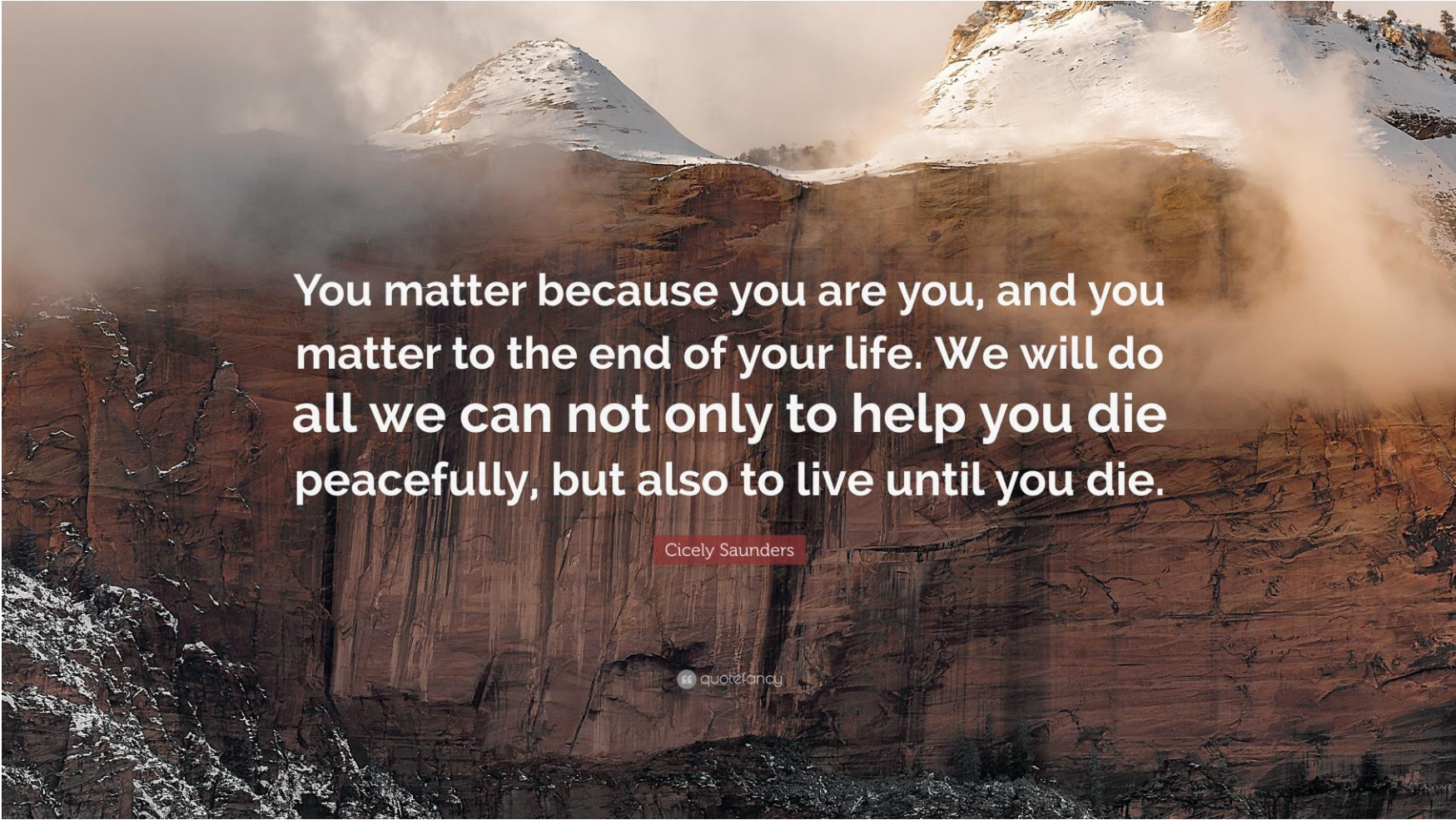
- The FCs guided by common sense principles and sound clinical practice (good structure, content, and process) have beneficial outcomes.
 - (1) Creation of a therapeutic partnership so the family and medical team collaborate in the difficult task of sophisticated medical and psychosocial care of a complex illness.
 - (2) Enhanced therapeutic management through education and support of the patient and primary caregiver (and other family members) to facilitate self-efficacy and convey realistic hope with careful sequencing of key messages.
 - (3) Easier patient transitions from cure- to care-oriented management, with a formal (yet thoughtful and gentle) introduction to the principles and practice of modern palliative medicine.

V.A.L.U.E.

- Value family statements
- Acknowledge family emotions
- Listen to the family
- Understand the patient as a person
- Elicit family questions

Family conference in 9 steps

- Preparation
- Establish the proper environment
- Introductions and relationship building
- Pt/family understanding of condition
- Medical review/summary
- Reaction/questions
- Set goals and negotiate options
- Translate goals into care plan
- Wrap up and document



You matter because you are you, and 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.

Cicely Saunders

quote fancy



GIVINGCARE
Empowering Caregivers

Thank you!

Teachers's name

Teachers e-mail

Date of the session

