



Recursos Educativos para Professores

## Módulo: CUIDADOS EM FIM DE VIDA

Sub-Módulo: PRINCÍPIOS DOS CUIDADOS PALIATIVOS



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# Introdução

<b>Módulo</b>	CUIDADOS EM FIM DE VIDA
<b>Sub-módulo</b>	PRINCÍPIOS DOS CUIDADOS PALIATIVOS
<b>Lição nr.</b>	#1
<b>Duração</b> (minutos)	300
<b>Data</b>	19 de março de 2022 – 26 de março de 2022

# Objetivos da Lição

- Compreender os cuidados paliativos como uma abordagem holística do sofrimento e o papel do cuidador nesse processo
- Desenvolver capacidades em ações de cuidado voltadas ao atendimento das necessidades individuais
- Promover a compreensão e prática de técnicas para controle de sintomas em pacientes
- Compreender os aspectos éticos, legais e espirituais no cuidado em fim de vida
- Identificando os diferentes tipos de perdas e seus impactos nas famílias e o papel do aconselhamento do luto

# Tópicos

1. O impacto da doença terminal no paciente e na família
2. Atitudes em relação à morte e ao fim da vida
  - a. Valores relacionados com o percurso de vida
  - b. O fim da vida e a morte
3. Princípios e filosofia dos cuidados paliativos
4. Organização dos cuidados paliativos nos sistemas de saúde
5. Interface de Cuidados Paliativos com certas doenças e condições específicas
6. Capacidade de comunicação e abordagem sistêmica: gestão de más notícias, reuniões familiares

# Introdução

- O diagnóstico de doença terminal/avançada tem um efeito profundo até mesmo nas famílias mais próximas e amorosas.
- A crise psicossocial/espiritual que cria é grave tanto para pacientes, famílias e profissionais de saúde

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

“Desde que a vida começa, há cuidado, porque é preciso “cuidar” da vida para que ela permaneça.”

## SÉCULO XIX

O Cuidado aos doentes terminais era:

- negligenciado pela sociedade
- providenciado por religiosos e caridosos

## SÉCULO XX

- avanços científicos e tecnológicos
- mudança no curso das doenças
- aumento da longevidade

**As pessoas vivem mais anos, mas não vivem necessariamente melhor...**

## **Ainda existe um modelo biomédico tradicional dominante:**

A ciência ao serviço de um ideal de cura → **Elimina Doenças**

- Diagnóstico rigoroso, baseado em exames cada vez mais rigorosos
- Tratamento mecanizado
- Cura



- Uma cultura de **negação da morte**
- **Ilusão** total sobre o controle da vida e da doença
- A morte passou a ser encarada pelos profissionais de saúde como uma **DERROTA**

## MORTE

- Individual, única e uma experiência subjetiva
- Um tabu na sociedade ocidental
- Several ways to "die"



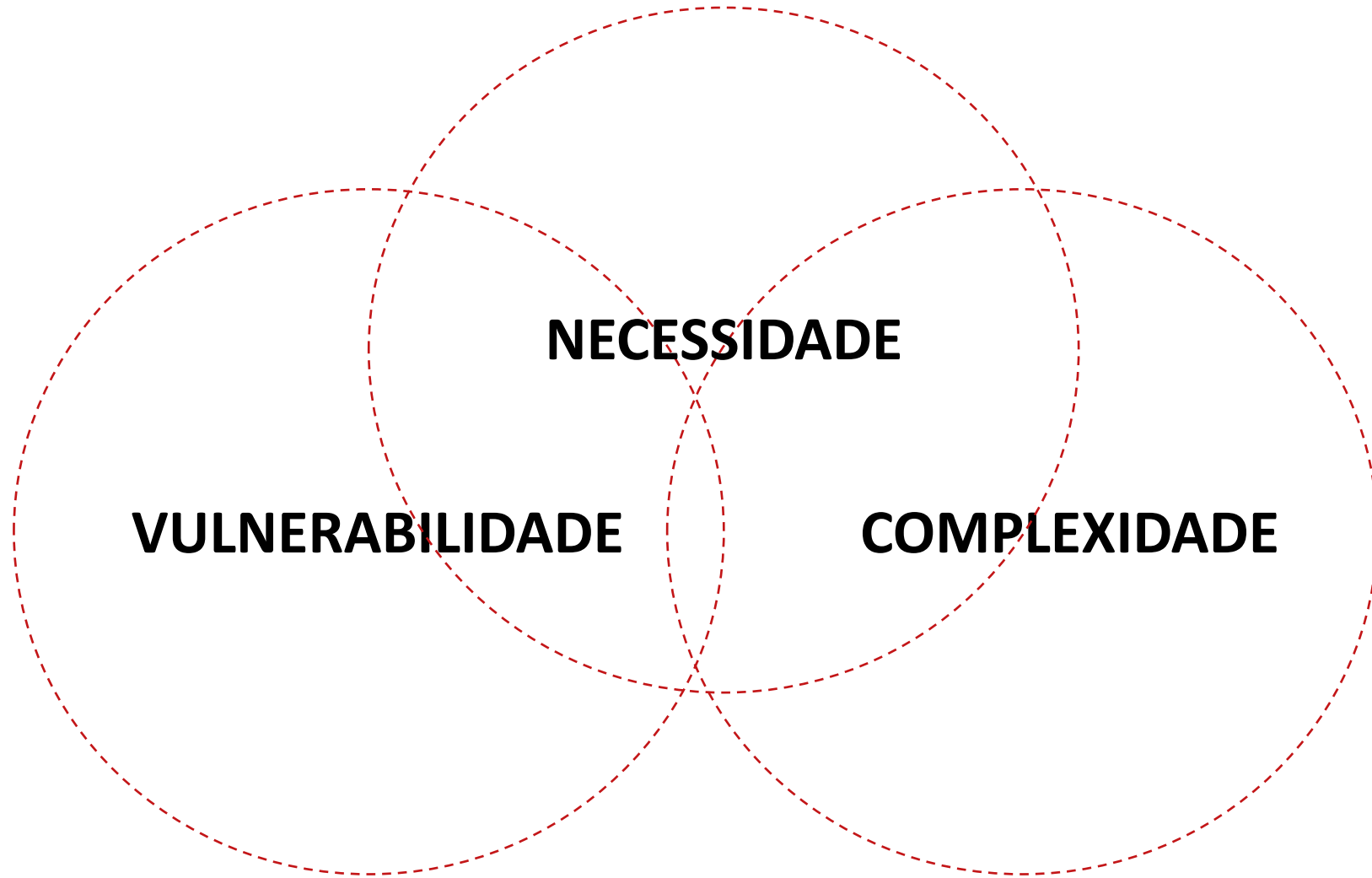
## Morte

- Tópico difícil de abordar
- Conceito complex e obscuro
- Experiência única e irrepeditível
- Tendência para procurar nos mitos ou na religião alguma maneira de explicar ou atribuir significado
- Inexoravelmente ligado à vida

## Transformação do processo que conduz à morte

- Tornou-se mais longo
- Medo do sofrimento associado a doenças terminais
- Transferência do local da morte
- Desenvolvimento técnico-científico que trouxe novas possibilidades (cura, mas também morte por solicitação)







**Dame Cicely Saunders** (Enfermeira, Assistente Social, Médica)  
(1918 – 2005)

Ela alertou para a necessidade de oferecer cuidados científicos, rigorosos e de qualidade às pessoas com doenças incuráveis, progressivas e avançadas, para quem muitas vezes se dizia 'não há mais nada a ser feito'.



St. Christophers Hospice, Londres, UK



Cicely Saunders Institute, Londres, UK



ELSEVIER

Patient Education and Counseling 41 (2000) 7–13

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Patient Education  
and Counseling

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[www.elsevier.com/locate/pateducou](http://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

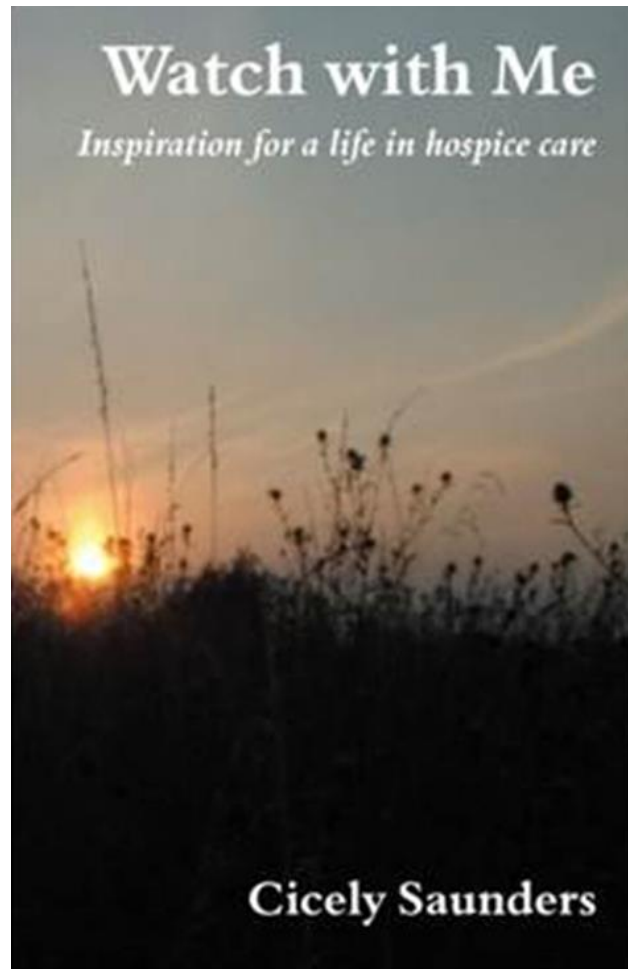
Cicely Saunders OM DBE FRCP

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*J R Soc Med* 2001;94:430–432

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*Assiste Comigo. Inspiração para uma vida em cuidados paliativos*

- Como morremos?
- Mortalidade
- A experiência do sofrimento
- A ética do cuidado
- Procurando por um significado(...)



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*“ 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.”*

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*“Assiste comigo”. Acho que a palavra “observar/assistir” diz muitas coisas em muitos níveis diferentes, todas importantes para nós.*

*(...) Significa olhar bem para ele, saber como é esse tipo de dor, como são esses sintomas e, a partir desse conhecimento, descobrir a melhor forma de aliviá-los.”*

***‘Não apenas habilidade, mas também compaixão’***

*Estes pacientes não procuram piedade e indulgência, mas sim que olhemos para eles com respeito e expectativa de coragem”.*

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

## Associações Internacionais de Cuidados Paliativos



**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/>

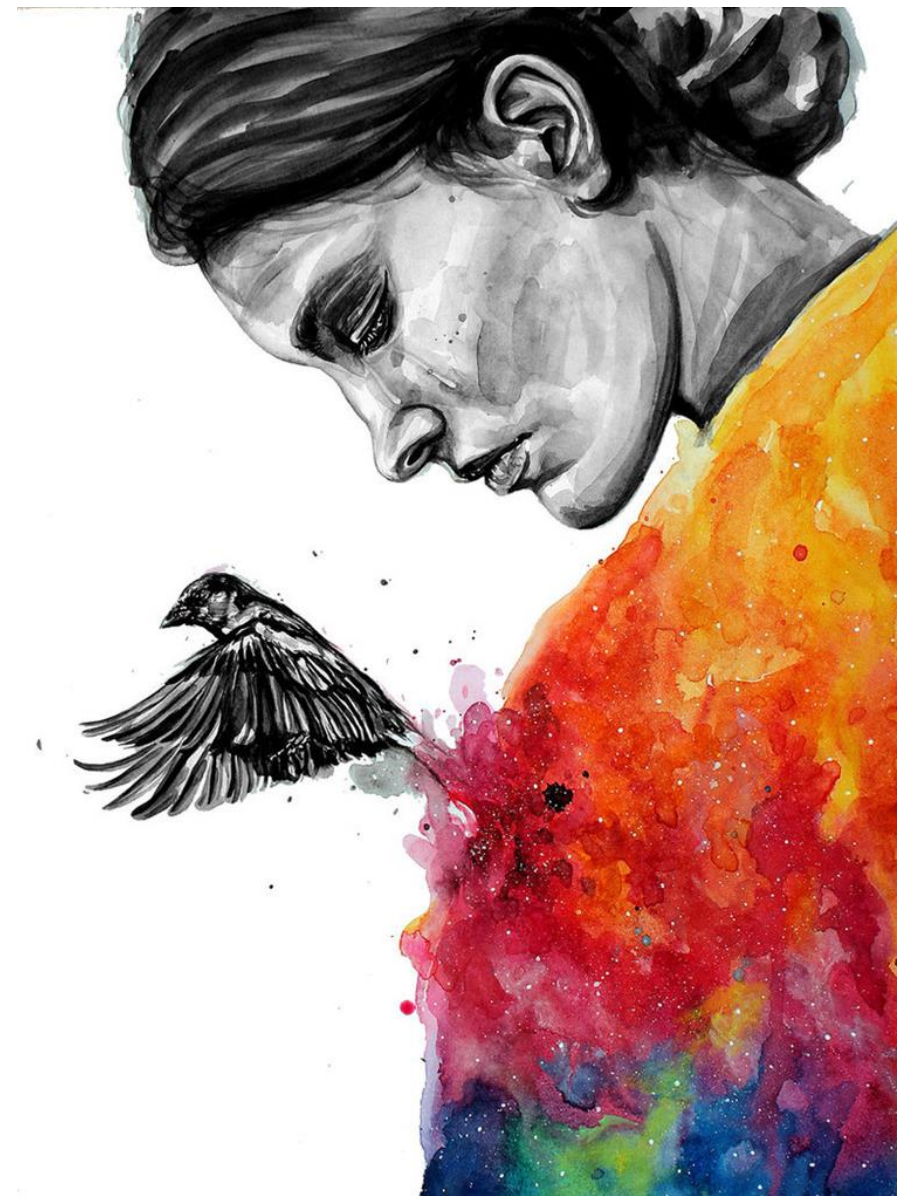
## O que são Cuidados Paliativos?

- Os Cuidados paliativos são cuidados ativos e totais a pacientes cuja doença não responde ao tratamento.
- Os cuidados paliativos têm uma abordagem holística: cuidados físicos, psicossociais e espirituais, incluindo o tratamento da dor e outros sintomas.
- Os cuidados paliativos são interdisciplinares na sua abordagem e englobam o cuidado do paciente e da família e devem estar disponíveis em qualquer local, incluindo hospital, hospício e comunidade.
- Os cuidados paliativos afirmam a vida e consideram o morrer como um processo normal; não apressa nem adia a morte e procura preservar a melhor qualidade de vida possível até à morte.

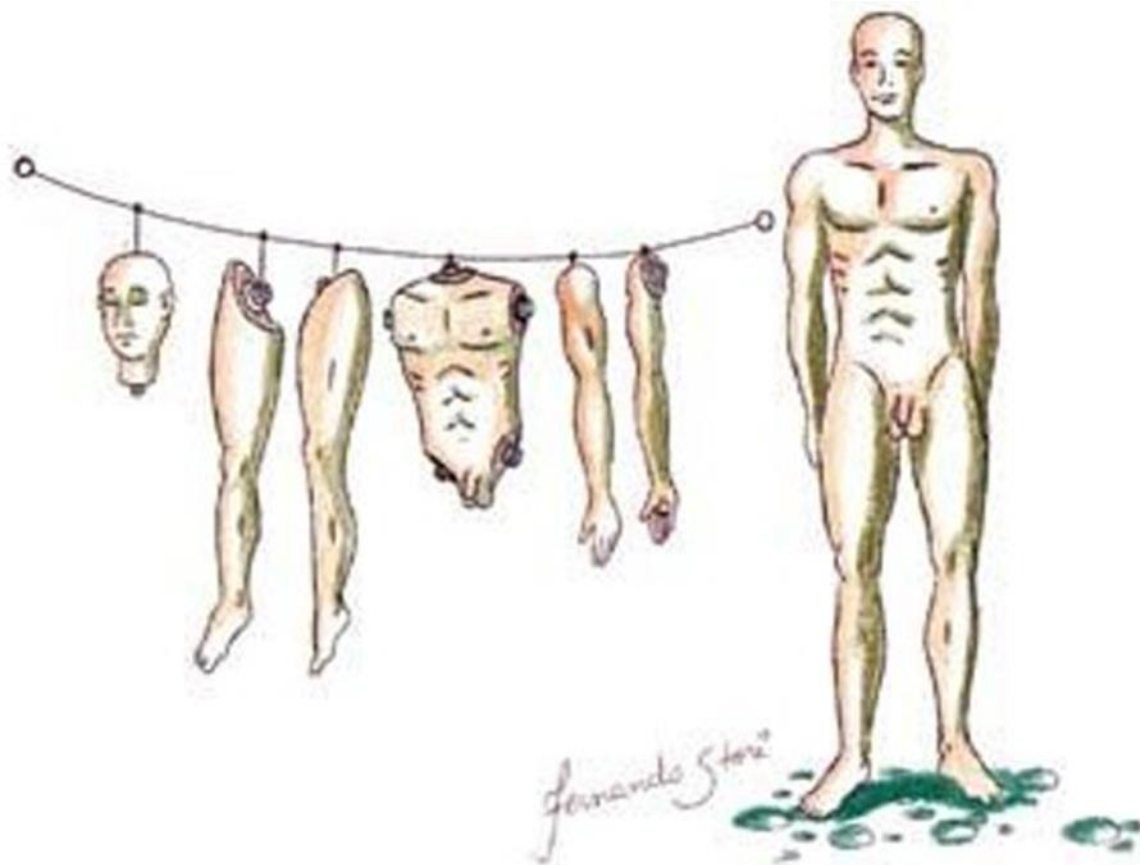
Definição EAPC

# NECESSIDADES

(mais do que diagnóstico ou prognóstico)







## **PESSOA**

Abordagem holística





Seguir  
**SUPOORTE**

**CURA**

**ALÍVIO**

| por vezes | doenças crónicas |

**CONFORTO**

| sempre | cuidado paliativo |

## Princípios e Filosofia

- Afirma a vida
- Promove qualidade de vida
- Trata a pessoa
- Apoia a família



## 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)

## ÁREAS FUNDAMENTAIS/ PILARES

- Gestão de sintomas
- Trabalho em equipa
- Comunicação
- Apoio familiar (incluindo no luto)



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*

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## Comparação entre Cuidados Paliativos e Cuidados em Hospício

VS

### Cuidados Paliativos

Alívio físico e psicossocial

Foco na qualidade de vida

Abordagem de Equipa Multidisciplinar

*Em qualquer estágio/fase da doença*

*Pode ser concomitante com um tratamento que leve à cura*

### Cuidados em Hospício

Alívio físico e psicossocial

Foco na qualidade de vida

Abordagem de Equipa Multidisciplinar

*Prognóstico de 6 meses ou menos*

*Exclui tratamento curativo*

[https://www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare\\_VS\\_Hospice.pdf](https://www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare_VS_Hospice.pdf)





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.*

# Organização dos Cuidados Paliativos

## Configurações e serviços

- 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

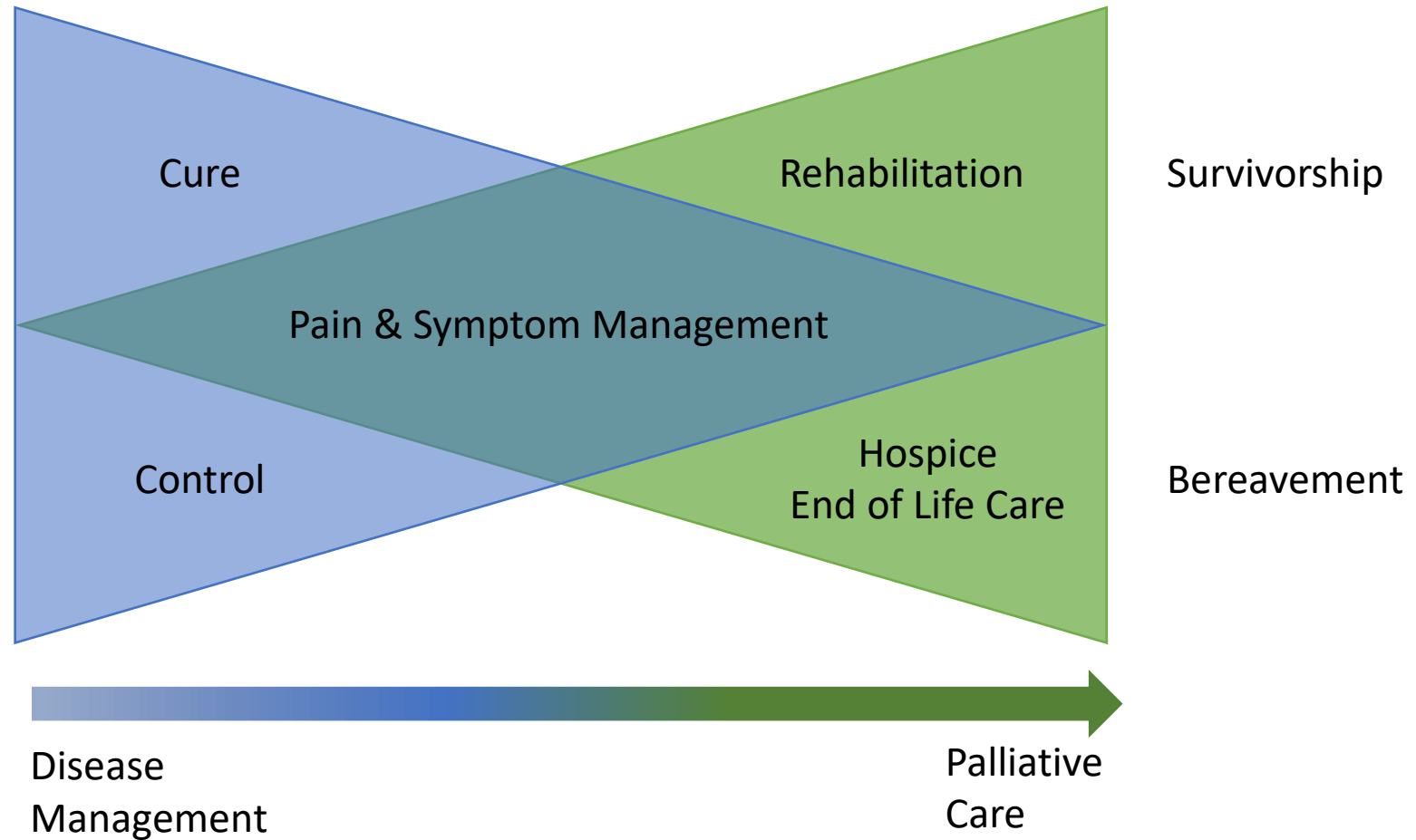
### **Gaining Access to Palliative Care**

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

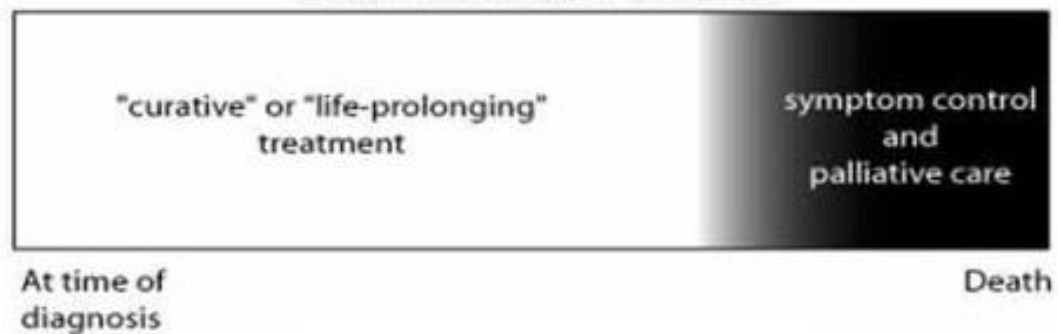
### **Locations for Palliative Care**

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

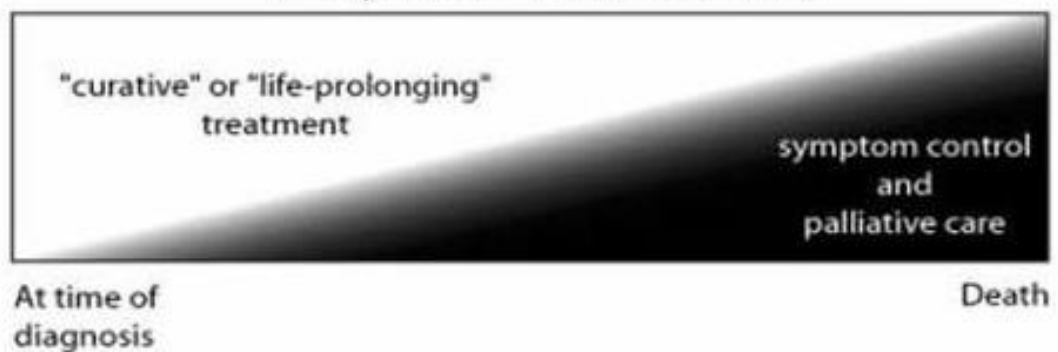
# Palliative Care Enhanced Care Model



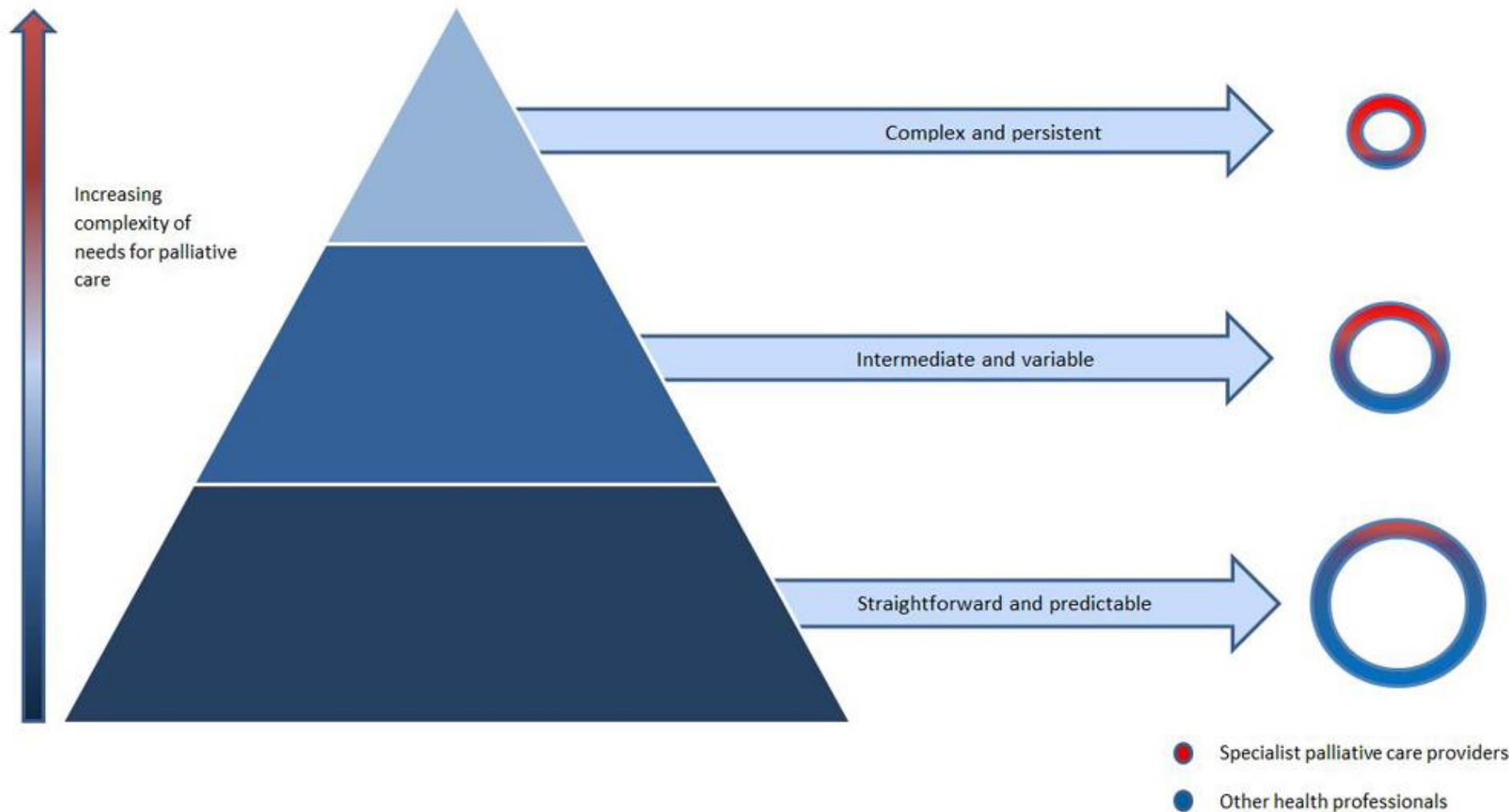
## Current Care Model



## Proposed Care Model



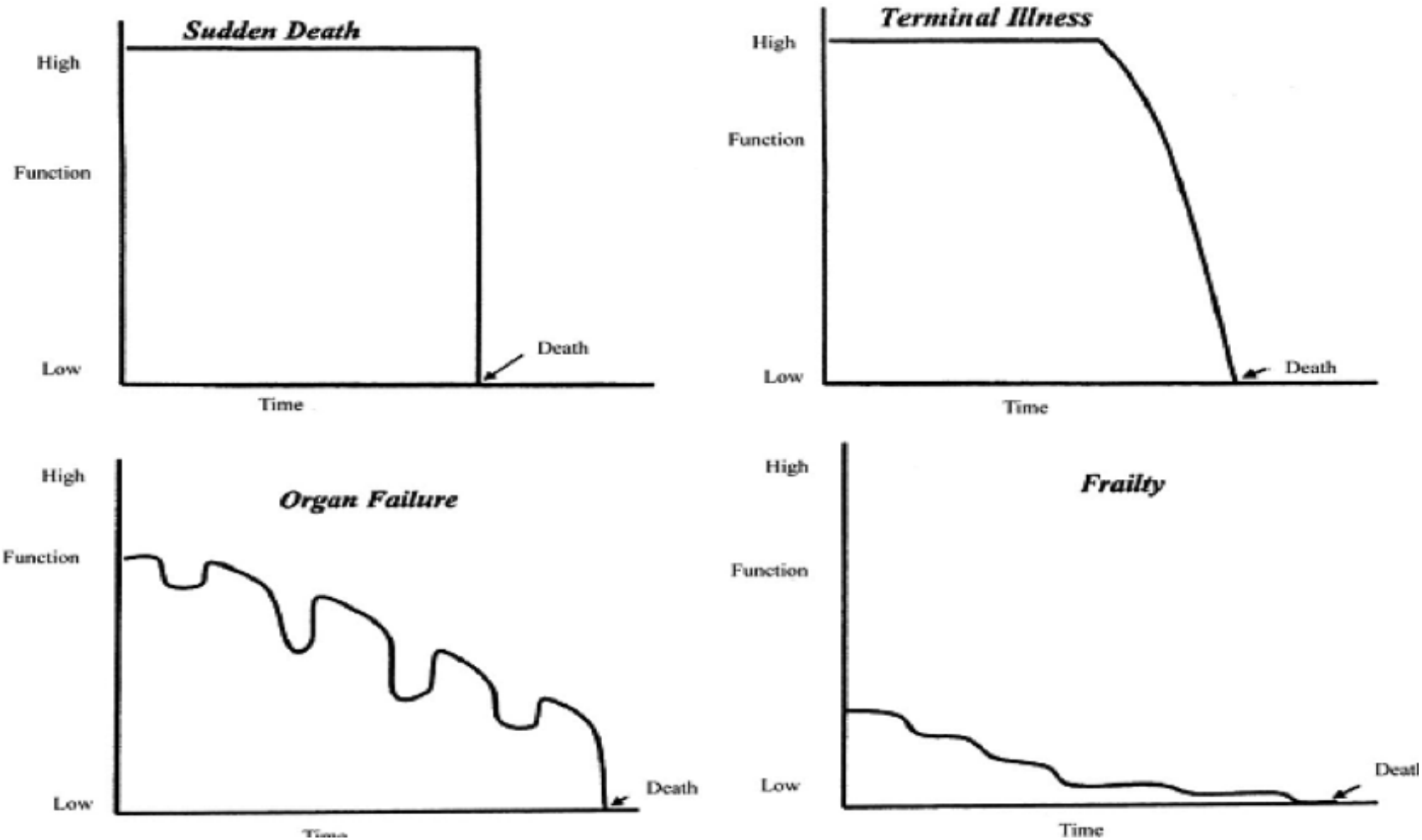
## Person's Needs vs. Relative Workforce Involvement





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**<sup>®</sup>  
4<sup>th</sup> 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**

4<sup>th</sup> 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.

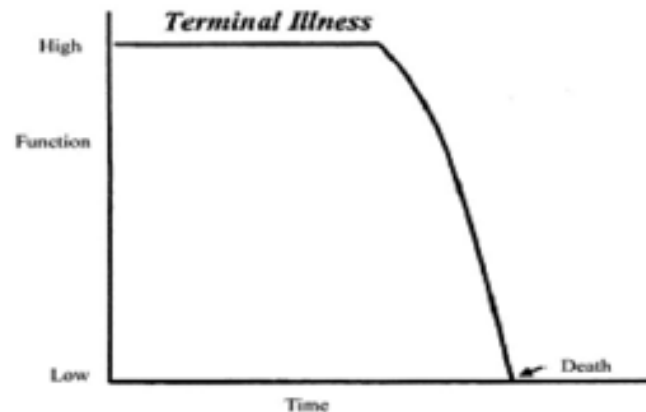
**3. SPECIFIC indicators of decline (disease specificity).**

## 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,...)

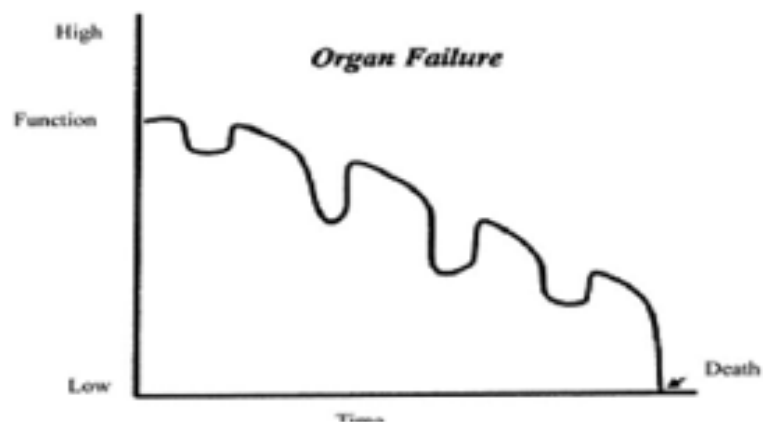
# SPECIFIC indicators of decline

## 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.

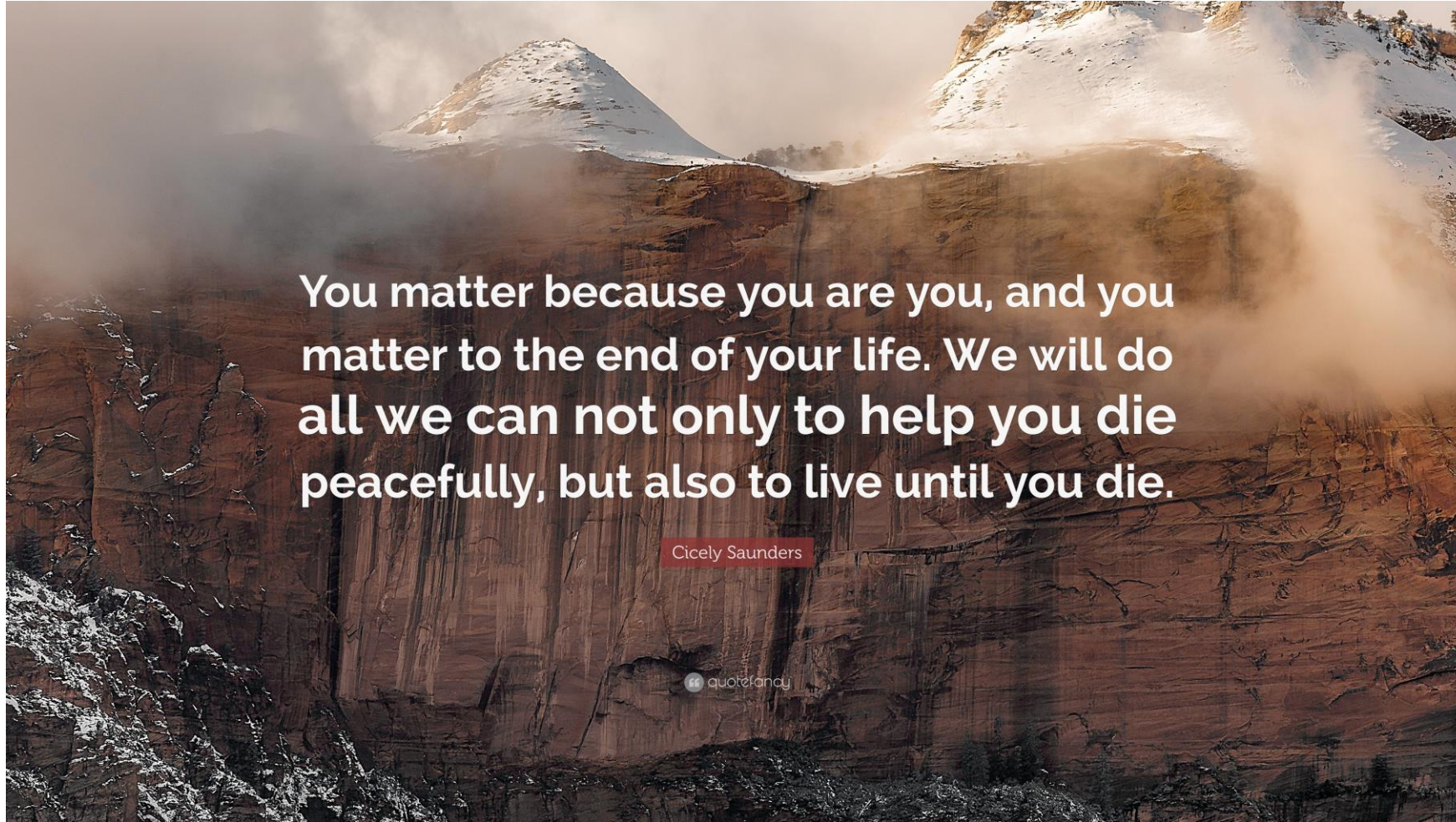
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- Value family statements
- Acknowledge family emotions
- Listen to the family
- Understand the patient as a person
- Elicit family questions



## 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



# Obrigado!

Prof. Carlos Pinto

Prof. Catarina Simões

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19 de março de 2022 – 26 de março de 2022

