WHAT CAN THE HOSPICE OFFER THE GENERAL PRACTITIONER?

BENONI - CPD CONFERENCE

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PALLIATIVE CARE – THE BEGINNING

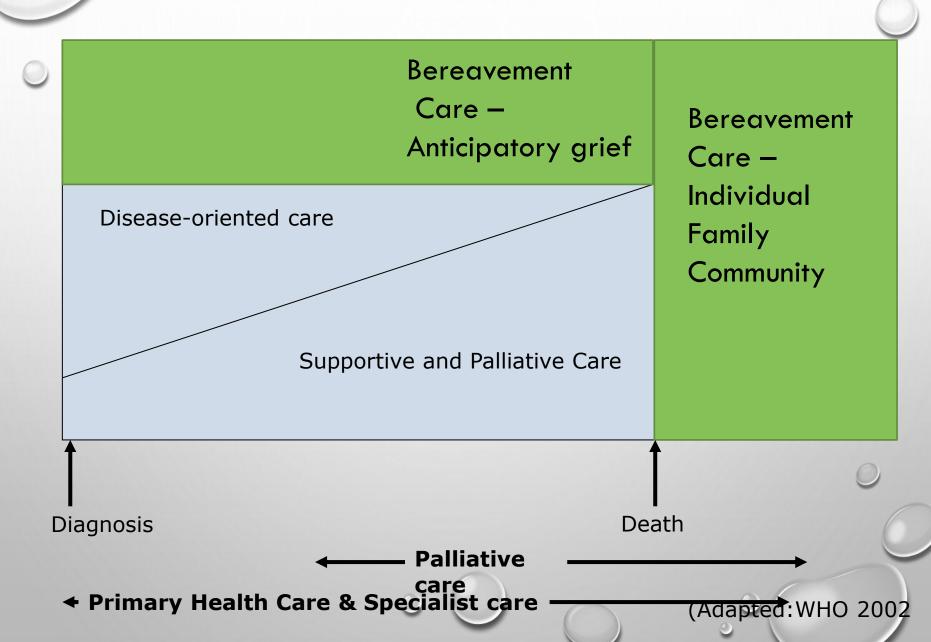
- ▶ COMFORT FOR TRAVELERS IN 4TH CENTURY
- ▶ IRELAND AND LONDON : 19TH CENTURY
- ▶ DAME CECILY SAUNDERS 1967: ST CHRISTOPHER'S
- ▶ A PLACE OR BUILDING?
- ▶ HOSPICE — "HOSPES": GUEST AND HOST.
- FOCUS IS ON CARING AND NOT CURING -EASE THE JOURNEY FROM LIFE TO DEATH.



DEFINITION OF PALLIATIVE CARE

Palliative care is an approach that improves quality of life of patients (adults and children) 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, psycho-social and spiritual.

CONTINUUM OF CARE:



PALLIATIVE CARE AND HUMAN RIGHTS

International Law Certain rights considered to be non-derogable	South African Constitution Certain rights are protected – cannot be suspended	Relevance in Palliative Care Palliative care support human rights
The right to life	Section 11- the right to life	Palliative care is about quality of life: Respect for life Recognition of whole person. Including family and loved ones
Right to be free from torture	 Section 12-the right to freedom and security including Not to be tortured Not to be treated/punished in a cruel, inhumane /degrading way 	"Failure to ensure access to controlled meds for relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment" (UN)

International law	SA Constitution	Palliative care
Free of torture (Cont)	(Cont)	Palliative care is concerned with the alleviation of suffering. "Suffering is the distress associated with events that threaten the intactness or wholeness of a person." Derek Doyle
The right to be free from slavery or servitude	The right to dignity is added Section 10 - Everyone has inherent dignity and the right to have their dignity respected and protected	Pall Care respects the dignity of patients and family members regardless of stage of illness. "You matter because you are you, and you matter to the end of your life. We will do all we can to help you die peacefully, but also to live until you die" Dame Cecily Saunders.

WHA67.19

 In 2014, the first ever global resolution on palliative care, world health assembly resolution WHA67. 19, called upon WHO and member states to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care.

HTTPS://APPS.WHO.INT/GB/EBWHA/PDF_FILES/WHA67/A67 R19-EN.PDF

 National policy framework and strategy on palliative care 2017 -2022

PERCEPTIONS

HOSPICE = DEATH

HOSPICE = CARE

DIAGRAM 1: THE NEEDS AND REACTIONS OF THE PERSON DIAGNOSED WITH A TERMINAL ILLNESS

- · Beliefs (religion/culture)
- Loss of faith/
- · Finding comfort in faith
- · Searching for meaning
- Alienation
- Losing interest in activities of daily living
- Sadness vs contentment
- Sighing
- Lack of concentration
- Forgetfulness
- Social withdrawal
- Mood swings uncharacteristic behavior change

- Loss of energy
- Increase in pain
- . Nausea, loss of appetite, and cessation of eating
- · Changes in mental status
- Increased frequency of falls or illness with poor recovery
- Increased swelling of the extremities or entire body
- . Breathing changes- Change stokes/death rattle
- Extremities cold and colour changes

- Disorientation
- Confusion
- Often sensing the presence of deceased family members/friends (Death-bed escorts)



- Numbness
- · Sadness leaving loved ones' behind
- · Sleep more than usual
- Express wish to die
- Anger
- Guilt/Regret. Unfinished business.
- Anxiety
- Loneliness
- Relief
- Gratitude
- · Longing for physical touch and comfort
- · Finances, housing, relationships

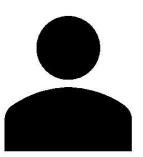
The 6 Things That Matter Most

- Please forgive me (I'm sorry)
- I forgive you
- Thank you
- I love you
- It's OK to die
- Goodbye (Ira Byock, 2004; Williams-Murphy, 2011)

PATIENT CARE

PALLIATIVE CARE

- 1.Management & Leadership
- 2.Human Resource
- 3. Admin support
- 4.Risk Management



HPCA STANDARDS

PALLJATJVE HEALTHCARE SERVICES

www.hpca.co.za

- 5.Access to care
 Pt rights
- 6.Interdisciplinary Team
- 7. Holistic
 Patient care
- 8. Medication Management
 - 9. Support Services
 - 10.Education & Research

GOLD STANDARDS FRAMEWORK (UK)

The surprise question: would you be surprised if this patient were to die in the next 6-12 months?

Patient choice or patient need: the patient with advanced illness makes a choice for comfort care only; or the patient is in special need of supportive or palliative care

Clinical indicators: general and specific indicators of advanced disease. General indicators include weight loss > 10% over 6 months, general physical decline, reducing performance status.

(HPCA. 2012. Legal aspects of palliative care.

www.hpca.co.za/resources

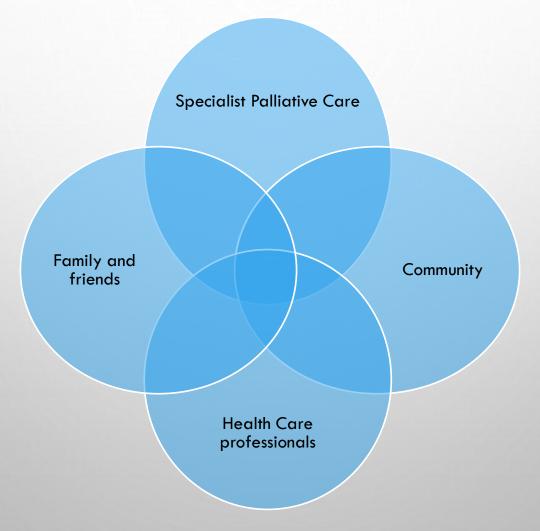
BARRIERS IN TRANSITION FROM CURE TO CARE

- INABILITY OF HEALTH CARE PROFESSIONALS TO EVALUATE THE FUTILITY OF AGGRESSIVE THERAPY
- PATIENT AND/OR FAMILY DOES NOT WANT TO STOP AGGRESSIVE TREATMENT
- A RELUCTANCE TO COMMUNICATE THE REALITY OF THE INCURABLE STAGE
- LACK OF KNOWLEDGE THAT PALLIATIVE CARE CAN BE EXERCISED IN ALL HEALTH CARE SETTINGS
- LACK OF TRAINED PALLIATIVE CARE PROFESSIONALS
- CULTURAL, LINGUISTIC AND SPIRITUAL DIFFERENCES
- HEALTH CARE PROVIDER FEARS OWN EMOTIONS

PARTNERSHIP IN ACTION

- A systematic approach to palliative care provision
- Focus on patient and family needs
- Spread knowledge and empower people
- Maximize use of existing resources: sustainability
- Enhance equity of access
- Cost effective
- Improved care outcomes

AN INTEGRATED PALLIATIVE CARE APPROACH



DEFINITION OF ADVANCE CARE PLANNING (ACP)

'Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.'

International Consensus Definition of Advance Care Planning (Sudore et al 2017)

Dr Nelia Drenth

NUMBERS MATTER

- 92% of people say that talking to their loved ones about end-of-life care or serious illness is important BUT 32 % have done so (conversation project national survey, 2018)
- 21% haven't had the conversation because they don't want to upset their loved ones, 53% would be relieved if a loved one started the conversation and 95% said they are willing or want to talk about their end-of-life wishes (conversation project national survey, 2018)
- 97% of people say it's important to put their wishes in writing BUT 37% have done it (kaiser family foundation serious illness in late life survey, 2017)

BENEFITS OF ACP

Enables greater autonomy, choice and control – respect patient human rights

Improves quality of end of life care

Greater concordance with wishes, if they have been discussed, i.e people die in their preferred place of death

Reduced unwanted/ futile invasive interventions, treatments or hospital admissions, guiding those in care to provide appropriate levels of treatment

Reduce cost

Enhanced proactive decision making reduces later burden on relative's anxiety

Enables better planning of care, including provision of care.

Greater satisfaction, reduced anxiety and depression in bereaved relatives

The process can itself be therapeutic and enables resolution of relationships

ADVANCE CARE PLANNING PROCESS

(THE GOLD STANDARD FRAMEWORK - GSF)



- 1. **Think** about the future, what is important to you. What you want to happen or not happen if you become unwell
- 2. **Talk** with family and friends, and ask someone to be your proxy spokesperson if you could no longer speak for yourself
- 3. **Record** write down your thoughts as your own ACP, including your spokesperson and store this safely
- 4. **Discuss** your plans with your doctor, nurses or carers, and this might include a further discussion about resuscitation or refusing further treatment
- 5. **Share** this information with others who need to know about you, through your health records or other means, and review it regularly

SHARED RESPONSIBILITY

- TO ENHANCE PATIENT AND FAMILY ACCESS TO PALLIATIVE CARE SERVICES
- TO REMOVE FINANCIAL BARRIERS FOR THOSE WITH A TERMINAL ILLNESS.
- TO MAXIMIZE THE APPROPRIATE USE OF SPECIALIST PALLIATIVE CARE SERVICES
- TO PROMOTE A COORDINATED SERVICE RESPONSIVE TO PATIENT AND FAMILY NEEDS
- TO INCREASE KNOWLEDGE OF HEALTH PROFESSIONALS IN PALLIATIVE CARE PRINCIPLES AND PRACTICE
- TO PROMOTE A HIGHLY EFFECTIVE WORKING RELATIONSHIP BETWEEN SPECIALIST PALLIATIVE CARE SERVICES AND THE COMMUNITY.

WHERE DO I FIND A HOSPICE?

WWW.HPCA.CO.ZA

THANK 4011!