

# End of Life Care. The Importance of Positive Relationships.

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# First Day on the Job

July 1982



# **Dame Cicely Saunders**



**1918 - 2005**

# Identified suffering.

- “Go study medicine ...it’s the doctors who desert the dying.”
- St Christopher’s Hospice 1967

Modern Hospice Movement.

Philosophy not a place...wherever the patient happens to be.

*“You matter because you are you and you matter to the end of your life”*

# Palliative Care.

- Palliative Care is an approach that improves the quality of life for patients and their families facing the problems associated with life limiting 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.

WHO 2002

# Palliative Care.

Enhances quality of life and may also positively influence the course of illness.(TEMEL .NEJM.2010)

Applicable early in course of illness, in conjunction with other therapies that are intended to prolong life.

WHO 2002

Palliative Care....End of Life Care...

# End of Life Care.

The term used to describe care that is provided during the period when death is imminent and life expectancy is limited to a short number of hours or days.

HSE National Clinical Programme in Palliative Care.

# Relationships

- The state of being connected.
- The way in which two or more groups regard and behave towards each other.



# Relationships and End of Life Care.

- When we consider relationships at end of life the patient and family are the primary focus, supported by an effective and competent team of care givers.

N.B.

Past events have a major influence on present interactions.

# Aim in EOLC

- Enhance the quality of living and relationships for patients and families for whatever time is left.
- Create opportunities for meaningful interaction, reconciliation, gratitude and an opportunity to say goodbye.
- Supporting family to improve the experience in bereavement.

# Quality

- Quality is enmeshed in a web of elusive and intrinsic characteristics of care givers such as knowledge, skill , insight , tact , judgement , moral sensitivity, motivation and morale as well as more concrete dimensions such as physical comfort and environment.

Tierney

# Grief...patient and family

- Loss of control
- Loss of independence
- Loss of privacy
- Loss of role and function
- Loss of identity
- Vulnerability and fear
- Anxiety
- Loss of a future

*Grief can be destructive or creative*

# Approaching End of Life ?

- Deteriorating functional status
- Increased frequency of Illness exacerbations.
- Attempts at reversibility proving futile
- Ceiling of Care?

# What matters in EOLC?

- Patient feedback impossible.

One opportunity.

Pressure to “get it right”

Practice informed by professional standards of caregivers and feedback from families after death.

# What matters?...families re EOLC

- Pt comfort and symptom control
- Emotional support
- Information and education
- Communication
- Competence

Care provider response time, and time with pt.

Interactional approach

Consistency ,flexibility.

Personalised care. Environment.

# EOLC and Relationships...effective practitioner at End of Life?

- Get to know the Patient and Family.
- Knowledge and skills.
- Establish links to professional colleagues to seek guidance and expertise.
- Multidisciplinary working..who is my team?
- Get to know yourself.
- Be open to learn/ take advice.

*Expertise offered in a setting of mutual trust and clear communication.*



# *(Palliative)* Medicine

- Medicine is fundamentally concerned with people
- The study and practice of medicine demands both a willingness and an ability to engage with people on a variety of different levels
- The creation of healing and therapeutic relationships require mutual trust, honesty and respect.
- We can start by allowing people to tell their story in a calm and unhurried fashion.

O'Brien T.2010

# The First Meeting.

Please tell me your story.

*I have read your notes so I am familiar with what has gone on but I would love to hear it from you, your experience of this illness from the beginning.*

Seated, phone on silent. Undivided attention  
Joint assessment ideally.

*Being present with silent attention*

*M Kearney*

# The First Meeting.

Multidimensional assessment.

Physical....symptom burden

Social...tell me about your family? Past losses?

Genogram.

Psychological... how are you coping with all this? Are there things you worry about?

Spiritual.. what keeps you going? What are you hoping for? Beliefs?

*That which makes you uniquely you*

# The First Meeting...conclusion

- Is there anything else you want to tell me ...or anything you want to ask me before we finish up?
- What is causing you most concern?
- What are you hoping for?
- Explanation of symptoms, outline treatment plan and expectations.

# Diagnosing Dying.

- Medical and nursing assessment.  
Offer information to patient...gently  
“ A bit worried about you...”  
“ Am I dying?”  
Explore fears.  
Seek permission to speak to family?

- Aim for good symptom control so patients and families have an opportunity to focus on non physical aspects of their situation.

*“ Holding the space”*

Hopes, fears and opportunities.

# Explore hopes and fears.

- “Hoping for best but just supposing...”

“ What is important to you?...”wills, weddings , christenings , son in USA etc.

On call assessment...lady and cathether

# Care Plan.

Time?. Rate of recent change often key to time left?

Ceiling of care. Anything reversible? Ethical decision making..."hold the window open "

Symptoms. Identify and anticipatory prescribing

Psychosocial .. Clear information to

family..opportunities to plan, reconcile, address practical concerns eg will etc..Answer honestly and explain treatment plan.

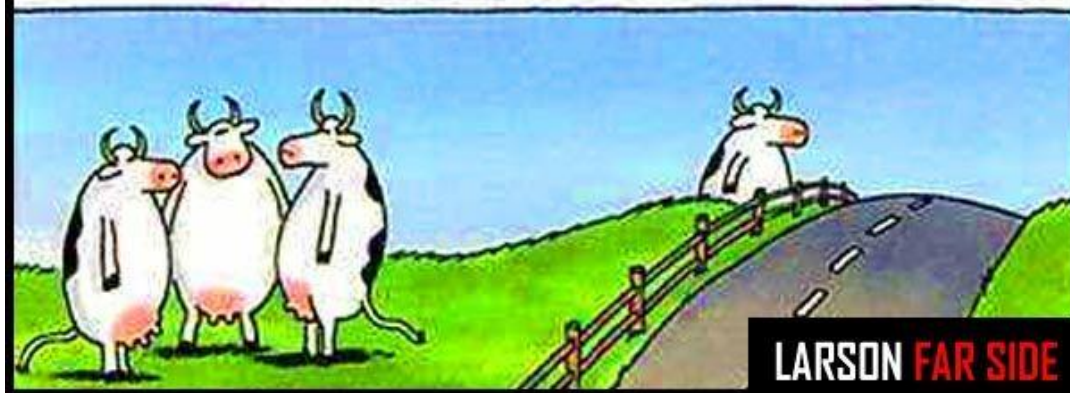
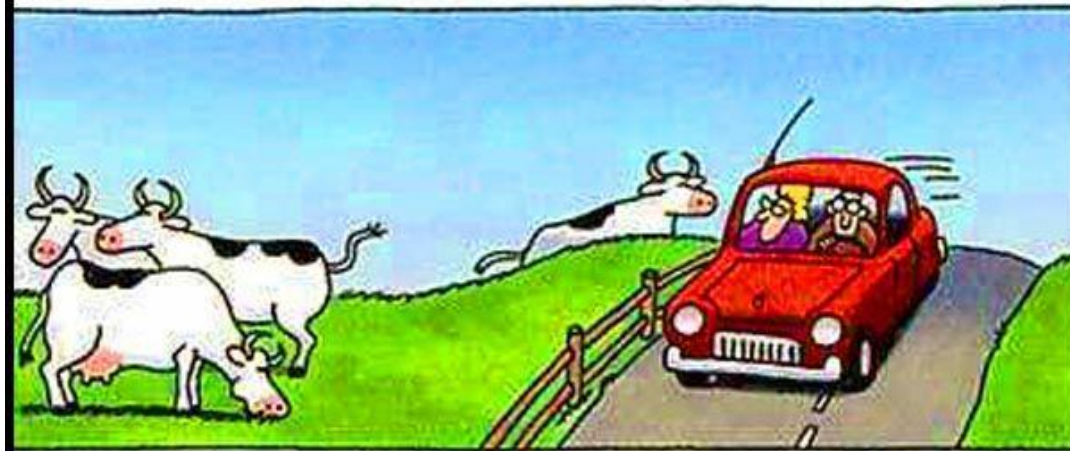


# Family...with permission

- Who? Where? Anyone of particular concern.
- Explain clearly expectations of care and avoid ambiguity.
- Involve in care
- No regrets...no right way...meaning in the waiting.
- Offer hospitality and welcome
- Encourage questions

*Formal/Informal*





# Family feedback..

- “If you are doing a study about this tell them family members need to know about the medicine and about death. Why does nobody talk when it’s clear the person only has a few days. Maybe if you are too open people will panic?”
- “One nurse said ‘you know he is going to die’ which snapped me out of my oblivion. I didn’t appreciate it at the time but in retrospect I really did..it allowed me prepare” *BMC Palliative Care 2013*

# Staff

- Ensure all staff are aware of changing status of patient.
- Plan continuity of care and communication.
- Ensure staff are comfortable with ceiling of care and treatment plan.
- Encourage advocacy based on knowledge.
- Staff should be aware of family and dynamics.
- Acknowledge impact.
- De brief

# Staff

- Consider the professional care giver as drug.  
Ballint 2001
- Who we are as persons (not just our professional persona) is our most potent medicine.
- Who we are as persons determines the quality of our relationships and the quality of care we offer.
- Our potency as healers stems from an acceptance of our own powerlessness.

Kearney M 2005

# Healing versus Curing

- Not about providing answers or solutions.
- Staying with the questions.
- Acknowledging the uncertainty.
- Staying with the silence.
- Being there...and going back..

# Our Response

- We sometimes resort to escalating medicine to fix the unfixable.

Remember...

*The cry of loss may not expect or want an answer only a silent listening.*

*C.M Saunders*



# Letter from a daughter.

“Dad said “ ‘...this place gave me my life back’  
“a dying man whose pain was so well managed and his needs so anticipated that he could actually ‘live’ during those final days. Those last few days of Dad’s life matter so much to us now , the memories are very precious.”

“You welcomed each one of us in turn as we arrived like you already knew us and we were part of the place for those last few days.”

B.R. 2014

# Power of Presence.

Watch with me...

... In watching, we should learn not only how to free patients from pain and distress, how to understand them and never let them down, but also how to be silent and how to just be there.

C.M Saunders

Thank You.

