

G - ELNEC Staff Education
End-of-Life Nursing Education Consortium
- Geriatrics

Eliza Coffee Memorial Hospital

Aug.28-29, 2013

General Educational Objectives 2013...

Staff will improve their knowledge related to:

1. The gaps in EOLC, why PC is needed, and goals of care
2. Principles of patient & family assessment
3. **Dementia and its associated behaviors**
4. Managing pain, **delirium**, and other symptoms
5. The dying process and the special care required during the final days of life

...EOLC Staff Education 2013

6. The legal and ethical aspects of EOLC
7. The cultural considerations in EOLC
8. Communication techniques
9. Loss, grief and bereavement
10. Achieving quality care at the EOL and for those with delirium and the agitation of dementia

REMINDERS

- Mute/vibrate cell phones & pagers
- Potty breaks
- Ask questions at any time

G - ELNEC Staff Education *[End-of-Life Nursing Education Consortium]*

Eliza Coffee Memorial Hospital

I. Goals & Gaps in Care as EOL 'Approaches'

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Palliative Care Service & OASIS

Aug. 28/13

Objectives

- Describe the current state of dying and contrast this with how people wish to die
- Describe why Palliative Care is needed
- Describe goal-focused care and using the Palliative Medicine Prognostic Tool
- Describe A.N.D.

How Americans aged & died in the past

- Early 1900s
 - average life expectancy 50 years
- Prior to antibiotics, people died quickly
 - infectious disease
 - accidents
- Medicine focused on caring, comfort
- Sick cared for at home

Cause of Death/Demographic

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases/ Communicable Diseases	Chronic Illnesses
Death rate	1720 per 100,000 (1900)	800 per 100,000 (2004)
Average Life Expectancy	50	77.7
Site of Death	Home	Institutions
Caregiver	Family	Strangers/ Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

Administration on Aging, 2010; Kochanek et al., 2011; Minino et al.,

Medicine's shift in focus

- Potential of medical therapies
 - “fight aggressively” against illness, death
 - prolong life at all cost – Death is the Enemy
- Improved sanitation, public health, antibiotics, other new therapies
 - increasing life expectancy
 - 2000 avg 76.9 y (F: 79.5 y; M: 74.1 y)

End of life in America today

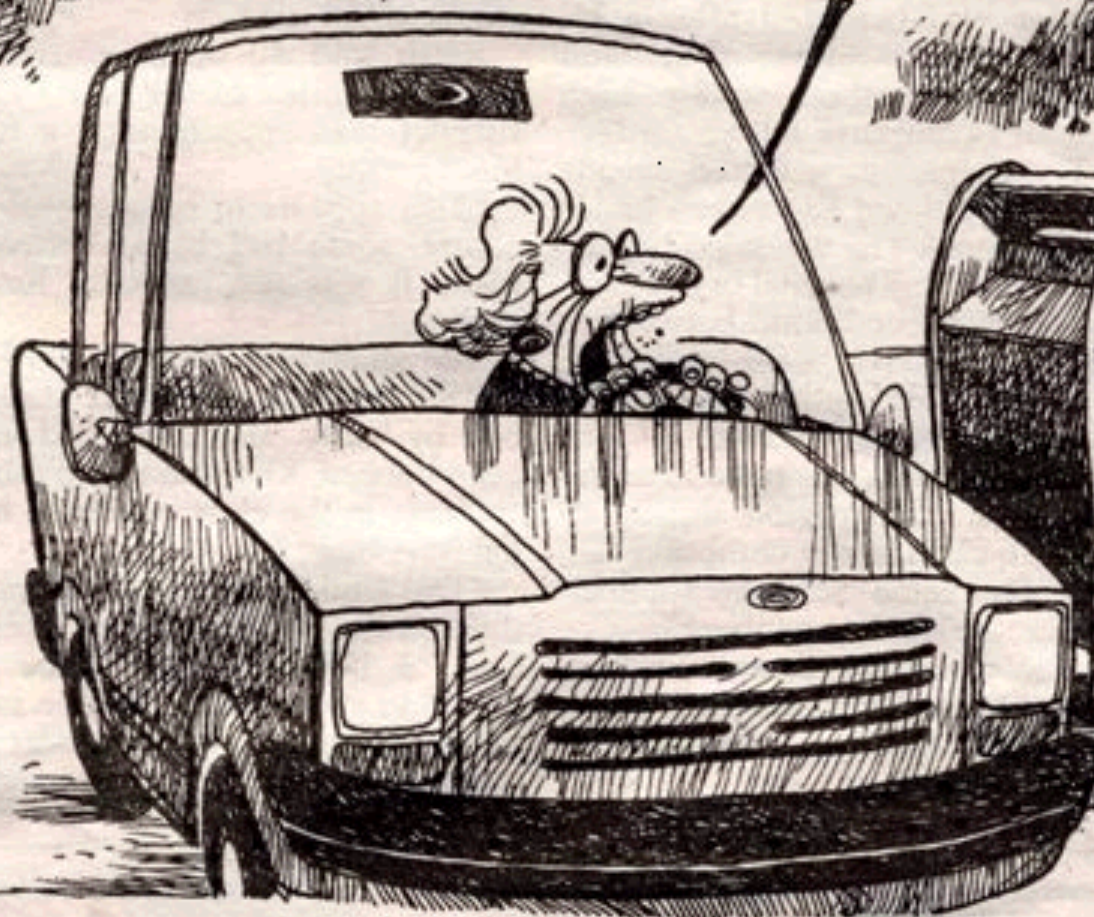
- Modern health care: only few cures
 - live much longer with chronic illness
 - dying process may be prolonged
 - Only 10% die suddenly
 - 90% die slowly
 - short “terminal” phase – e.g. cancer
 - slow decline punctuated by periodic crises

EOL Symptoms, suffering . . .

- **40% worry about “being a burden”**
- **Multiple physical symptoms**
 - pain, nausea / vomiting, constipation, breathlessness
 - related to
 - **primary illness & intercurrent illness**
 - **adverse effects of medications, therapy**
 - AGING ! Leads to many problems!**

I'LL HAVE A
CHEESEBURGER,
LARGE FRIES,
BLACK COFFEE...

I'M STARTING TO
THINK RETESTING
SENIORS FOR
DRIVING ISN'T A
BAD IDEA!



Place of Death shifted...

Site of Death 2007

- Hospital 35.3%
- **Home 23.7%**
- Nursing Home 27.9%
- Other 8% (includes hospice)
- ED/Outpt 2%

Site of Death by Age

- Nursing Home 33% ages 75+
- Nursing Home 42% ages 85+

. . . Place of death

- 90% of NHO Gallup survey want to die at home
- Majority of institutional deaths could be cared for at home
 - death is the expected outcome
- Generalized lack of familiarity with dying process, death, bereavement
 - Families are afraid, don't know what to do
 - Have developed *learned helplessness*
 - Which has prompted development of ...

Hospice & Palliative Care . .

- Hospice started in US in late 1970's
- Percentage of total US deaths in hospice
 - 11% in 1993
 - 17% in 1995
 - 25% in 2000
 - 54% in 2007

[Dartmouth Atlas]

. . . Role of hospice, palliative care

- **Palliative care services evolving**
 - earlier symptom management expertise
 - impact on life expectancy
 - **PC integrated w/ std oncology care in lung cancer: lived 3 mo. longer; less depression**
 - Temel JS, et al. NEJM 2010
 - **Those in hospice live ~29days longer than non-hospice cohort**
 - Connor SR. J Pain Sympt Manage.2007

Barriers to good end-of-life care . . .

- Lack of acknowledgment of importance
 - introduced late, funding inadequate
- **Fear of addiction**, exaggerated risk of adverse effects
 - restrictive legislation – DEA regs for LTC
 - **Fear – “I can’t take morphine. Last time it gave me rigor mortis.”**

...Barriers...

- A need to put dying in context
 - We will all die
 - Fear, hope, distress, suffering, peace are all determined by both the disease and the whole person/family
 - Suffering can be relieved by a bond w/ a caring physician/other provider – much can be done to support the whole person through a crisis

... Barriers to good EOL care ...

- Discomfort communicating “bad” news
 - Misunderstandings and avoiding patients
- **Lack of skill negotiating goals of care, treatment priorities**
 - Can lead to futile or non-beneficial therapy

... Barriers to good EOL care

- Does dependency on modern medicine:
 - Lead to ‘learned helplessness’,
and frequent futile care ?
 - resulting in our ‘abandoning’ loved ones to
medical care ?

What's Best?

“... they saw finally that in their attempt to help they had not helped but only complicated his disease beyond their power to help. ... Loving him, wanting to help him, they had given him over to “the best of modern medical care”—which meant, as they now saw, that they had abandoned him.”

– Wendell Berry, *Fidelity*, 1992

Why Palliative Care Needed...

- Gaps in EOLC
- Not meeting patient/family goals
- *Medical technology has created EOL situations that prolong dying and require decisions*
- Widespread belief in EOLC myths [later]

... Why Palliative Care Needed

- 50% of terminally ill suffer pain during their last months of life [*Weiss, et al. 2001*]
- LLD Patient & family preferences!
- Poor prognostication leads to futile interventions

Dying for Care?

- “Most elderly and seriously ill patients died in acute care hospitals. Pain and other symptoms were commonplace and troubling to patients. Family members believed that patients preferred comfort, but life-sustaining treatments were often used.”

[Lynn. Perceptions by family members of the dying experience...SUPPORT Investigators. 1997]

What Do Patients & Families with Serious Illnesses Want?

- Pain and symptom control
- *Avoid inappropriate prolongation of the dying process*
- Achieve a sense of control
- Loved one's wishes honored
- *Included in decisions & to be listened to*
- *Honest information*

Singer et al. JAMA 1999;281(2):163-168.

Tolle et al. Oregon report card.1999 www.ohsu.edu/ethics

Prognosis Accuracy Poor

- Physicians are terrible prognosticators
 - Accurate only 20% of the time
 - 63% overly optimistic

Why?

- fear of withholding hope
- lack of experience
- death is the 'enemy'
- not an exact science!

[Christakis. BMJ 2000;320] [Benkendorf. Prehosp EmCare 1997]

Palliative Care – formal definition

The medical specialty focused on relief of the pain and other symptoms of serious illness. The goal is to prevent and ease suffering and to offer patients and their families the best possible quality of life.

It is offered simultaneously with all other appropriate medical treatment.

- [CAPC}

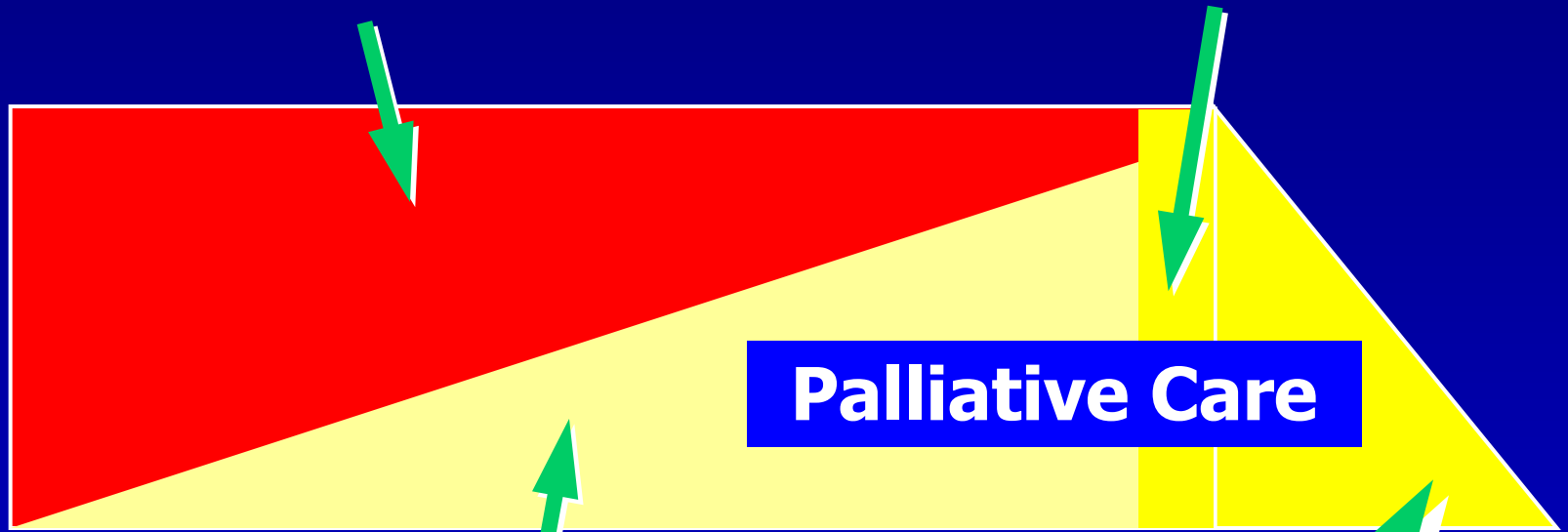
What PC is & is not:

- It is NOT care only for those nearing death or the end of life !
- It is NOT the same as Hospice; which provides PC only for the last 6 mo. life
- PC is a philosophy of care available to anyone with a chronic/incurable illness, at any time in their life, who wants mostly to be comfortable

Palliative Care's Place in the Course of Illness

Therapies to modify disease

Hospice



Palliative Care

6m Death

Bereavement
Care

Therapies to relieve
suffering and/or
improve quality of life

Presentation

Palliative Care = Comfort Care

- PC helps people (and families) with a life-limiting disease live comfortably as long as possible (soothing symptoms); AND
- when they are at the very end of life, PC helps them to die comfortably.

PC Core Principles

1. Goal focused
2. Evidence-based
3. Interdisciplinary
4. Informed decision making, patient choice
5. Aggressively controls symptoms

Principle #1 - Goal-focused Care

- What are ‘goals’?
 - A result or end we want to reach.
- Why set goals of the medical care?
 - Care goals shape expectations & priorities

PC – Goals (spectrum)

“DO EVERYTHING”

- CPR
- Dialysis/transplants
- Tx all conditions
 - Even if pain worsens

COMFORT

- A.N.D. / DNAR
- Control symptoms
- Tx any discomforting symptom aggressively

MAINTAIN FUNCTION

Setting Goals Example

- Mrs. Abigail Alzheimer

- 82 yof, Alzheimer's x 4 years
- HTN, PVD, OAB, OA, OP, GERD
- TIA's, CAD w/ stents, CHF
- Taking many prescriptions
- Widow, in ALF, 3 kids

The Role of the HC Professional

- To plan for the future – the when, not if
- To communicate bad news
- To help establish goals of care
- To provide treatments that meet these goals
 - Life prolonging/curative
 - Pain & symptom management
 - Psychological, emotional, spiritual support
- Withdraw tx no longer meeting these goals
- To negotiate conflict around tx and goals

Setting Goals Process Summary

- 1) Must ask the pt/family what's their goal !!
E.g. "Given your current condition, what's important to you?"
- 2) Explain goals may change once given more info or as disease progresses!
- 3) People need to know, if LLD present, cure no longer reasonable expectation
- 4) Should result in appropriate adv. directive

Care Goals

- **Global goals** - e.g. Cure v Comfort
 - General or philosophical guide
 - Can change as illness progresses
- **Specific goals** - e.g. antibiotics for UTI
 - Discuss as need arises
 - Change with situation
 - **Anticipate situations and plan response** (e.g. wt. loss, not eating - ?PEG)

Palliative Medicine Prognostic Tool (PMPT)

- Use the Tool to help clarify goals
 - Take note if PC Screening Tool on chart:
(**Of 174 screened in 2010, w/ follow-up, if score 10+,
87% died w/in 12 months**)
 - When PC score >10 , should have EOLC discussion w/ patient/family (review of goals, etc), or consult PC Service
- * Will discuss in more detail later

Goals - Mrs. Abigail Alzheimer

What do she and her family want at this point in her life?

- What do they value most?

- “Do Everything” vs “Comfort only”

- vs “In between (stabilize function)” ?

What info will help them make decision?

- What evidence is there?

Principle #2 – Evidence-based

- Evidence-based medicine means use only those treatments which have been demonstrated to control symptoms and help reach the patient's goal.
- Corollary: Don't do those things which have shown no benefit.

Evidence to help Ms. Abigail's decision

- What tx is available for Alzheimer's?
- What might make her memory and QOL worse?
- How do we rationalize the different choices for treating all her problems...?

Ms. Allison's dilemma

- How do we rationalize the different choices for treating all her problems?
 - **GOALS, GOALS, GOALS**
- What has she told family in past ?!
- Based on info given, they choose comfort
- Therefore, reduce many meds [why?] – can always resume them – how many to stop?

On 14 \$\$\$ Medications (\$900+/mo.)

- Lipitor (\$100/mo)
- Plavix (\$120)
- Asa
- Trental (\$75)
- Altace (\$75)
- Aricept (\$150)
- Nexium (\$120)
- Lasix (\$11/mo)
- Toprol (\$25)
- Amiodarone (\$150)
- Paxil (\$79)
- Detrol (\$85)
- Vitamins, Calcium
- Fosamax (\$66)

Based on her goals, can she stop all of them?

Can she stop all/most meds?

- Will that help her reach her goals?
- Can she and her family live with the decision !!??

Principle #3 - Interdisciplinary

- Interdisciplinary Team needed
 - Physician
 - APN/CRNP
 - LCSW
 - Chaplain
 - Nursing & Caregivers
 - Pharmacist
 - Patient & family !

Principle #4 – Informed Decisions...

Should Mrs. Alzheimer have a TKA - what's the process involved to make a decision?

- To make decisions, people need credible and adequate information
- Knowledge about their condition and prognoses affects decisions
- Information combined w/ skillful guidance may avoid futile interventions and improve QOL

...Informed Decisions: A.N.D.

- What is it
- Why is it important
- What's being done to promote it

What is A.N.D.

- “Allow Natural Death” = A.N.D.
- Introduced in 2000 by Rev. Chuck Meyer*
- Acknowledges that when death approaches “the pt is dying and everything is being done...including withdrawal of nutrition/hydration...”
- “AND prevents unintentional pain and simply allows a natural death.”

* Meyer C. *Allow natural death: an alternative to DNR?*

...also, A.N.D. can be...

- chosen at any time– same as Palliative Care can – i.e. comfort focused care
 - **Was philosophy of care up to 60 years ago**
 - Non-interventionist approach
 - Take only those drugs, or offer only treatments, which reduce uncomfortable symptoms
 - Not just for the actively dying !?!

Why use A.N.D.

- **Avoid negative term “DNR”** – “Do Not Resuscitate” perceived as withholding something from patient
- Reduce undignified, inappropriate ‘Codes’
- **Avoid misinterpretations of DNR**
 - Do everything but CPR ?
 - Don’t do anything “since she’s dying” ?

CPR & “No Heroics” - Myths & Reality



CPR Myth:

- Most people recover with CPR and ‘shocking’ the heart
 - TV success rate ?

67%

CPR & “No Heroics” - Myths & Reality



CPR Reality:

- Started 1959: intended for “healthy” middle-aged
- Only 0-17% over age of 70 survive CPR
- Usually considered “heroic measures”
- Ribs break & pneumonia often develops
- Incompatible with a peaceful death

Tribble BT. DNAR: More than code or no code. AAHPM bulletin. 2008

CPR & “No Heroics” - Myths & Reality



...CPR Reality:

- Seniors' bodies have little reserve and rarely return to pre-CPR health status
- CPR in seniors often ends in traumatic death or placement on machines

Thus, A.N.D. means...

- When I start to die, do whatever is required to keep me comfortable but don't prolong dying and don't do CPR.
- Expanded choice: above plus no drugs or treatments unless they “always” have an immediate/rapid effect to make me feel better

A.N.D. Project 2007: Education re EOLC Myths

1. Dehydration is painful
2. We cannot allow someone to starve to death
3. Feeding tubes prevent aspiration
4. CPR will resurrect most patients

[*will discuss these later]

A.N.D. Project 2007: Results at ECM

- Medical staff approved use of “A.N.D.”
- Labels on charts changed
- Has led to PI project using P.M.P.T.
(Palliative Medicine Prognostic Tool)

Summary & Pearls

- 90% people will die “slowly”
- People w/ a LLD do not want to prolong dying and want symptom control
- Palliative Care offers “comfort care”
- Knowing patient goals effects priorities & improves care
- AND = Allow Natural Death
- Use AND in place of DNR

“Growin’ old ain’t for sissies”

- Bette Davis

THANK YOU !