Palliative Care: what, why, & when to use it !

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Why PC? Life is too short !

Why PC??

Do you see patients with chronic or incurable diseases? and:

- Desire a quality of life for them that focuses on living as comfortably as possible
- Want to avoid causing/prolonging suffering
- Feel it's important to avoid bankrupting Medicare

Then, consider offering PC and/or using principles of PC …!

Outline

1. Purpose of PC – what is it
2. Why we need PC
   = Avoiding Futile Care & Suffering
3. Who's eligible – when to screen
4. Financial implications for Medicare entitlement: Stewardship *[soapbox]*
5. Summary & Pearls

1. Palliative Care:

- **Improves quality of life / living**
  - Isn't that "motherhood" ?
  - Don't all medical services do that?

    Reality: Most specialties trained to focus on curing/treating specific disease, whereas…
- Uses 'holistic' process to achieve:
  - Goal-focused care – informed choice
  - Symptom soothing – comfort for as long as living
  - Peaceful death with dignity

Definitions

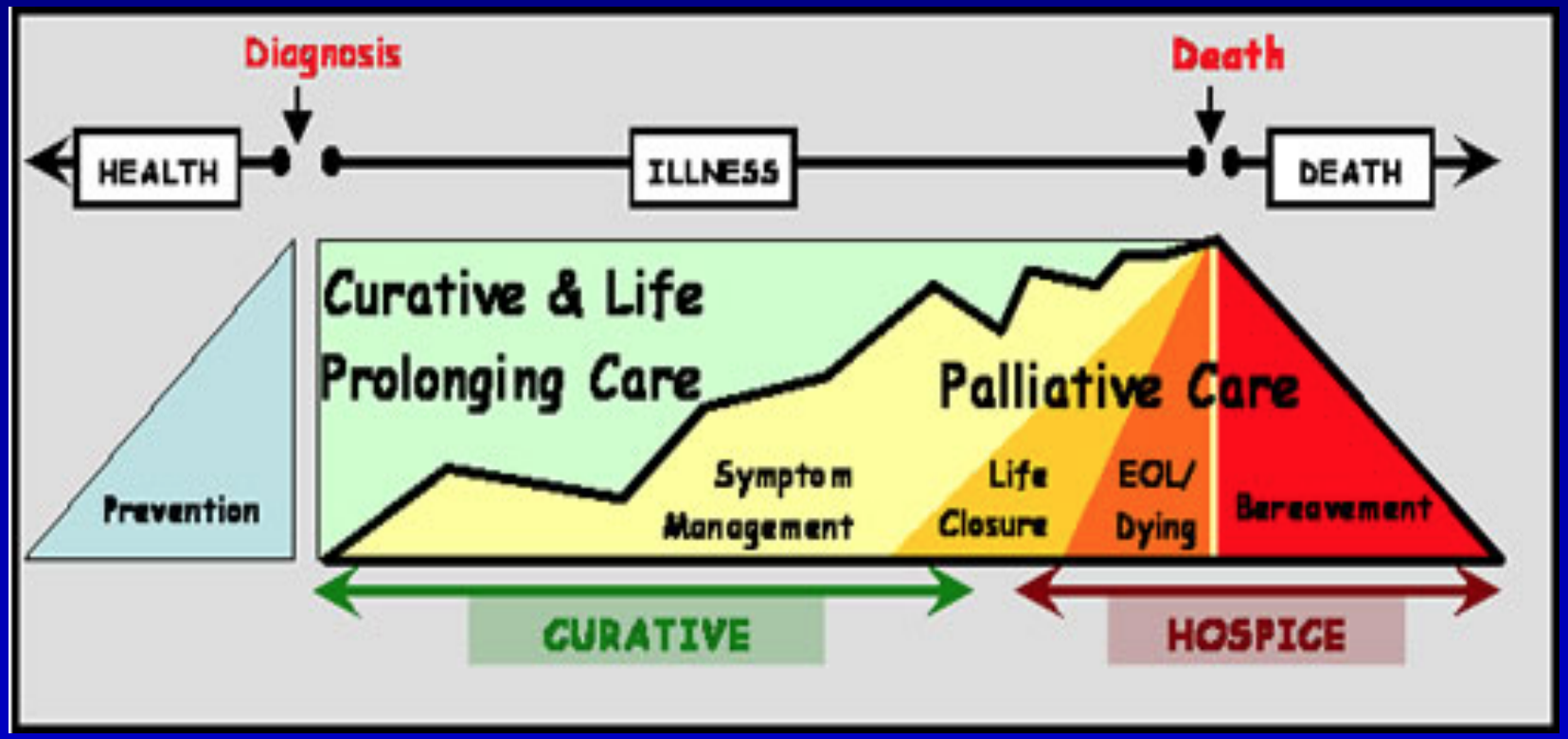
Palliative care: interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families.

- It can be offered while receiving usual appropriate medical curative therapies, and
- is NOT only for those who are dying [that's *hospice*]

Hospice: A Medicare benefit providing palliative care for those certified with a terminal disease and less than 6 mo. to live if the disease "runs its usual course".

– It is "palliative care for the last 6 mo. of life."

The *New* Model for Medical Care: Palliative Care from the Beginning & Even more @ the End



Palliative = Comfort-focused Care

1) Helps patients clarify their goals in the face of a LLD*, to make informed decisions and avoid non-beneficial treatments; which…
2) Improves their quality of life so they can live comfortably (soothing symptoms) as long as possible; and then,
3) when they are at the very end of life, PC ensures a natural death w/ comfort and dignity.

*LLD = Dementias, cancers, end-stage organ disease (e.g. lung/heart/renal/liver), ALS, AIDS

Published Evidence re PC Benefits

- PC does NOT accelerate dying
  - Cost Savings Impact Study 2009 at ECM
    - patients in both the control group (94%) and the PC consult group (100%) died in the same 12 mo. (while saving hospital $386,000)

and…

- PC improves survival & QOL in lung cancer
  - Patients receiving chemotherapy and PC lived 3mo longer (11.6mo v 8.9mo) than those on just chemoRx. *[Temel. NEJM 2010.]*

and…

…PC Benefits

- Cancer pts who discuss EOLC wishes w/ MD have better QOL and lower costs in final wk of life
  - Less aggressive care/admissions to hospital
  - Improved QOL w/ more peaceful death

  ** Zhang B. Health care costs in the last week of life. Arch Intern Med. 2009*
- Pts who choose hospice live ~29 days longer than those not in hospice

  ** Connor S. Comparing hospice & non-hospice patient survival among patients who die within a three-yr window. J Pain Symptom Manage 2007*

Why/How is PC so beneficial?

Because, when implement PC principles, we …

- Reduce or Stop all/most non-comfort tx/meds
- Aggressively control symptoms which helps them to feel better and eat/socialize/exercise more and fight illness
- Encourage patient/family-driven goals
  - Avoid futile/unnecessary treatment & hospitalizations
- Encourage EOLC planning [Advance Directives]
  - helps accept limits to life

[that confronts the *Illusion of Certainty*…]

Historically, always had PC:

Physician's Traditional Role = PC

- To cure sometimes
- To relieve often
- To comfort always

- anonymous 16th century aphorism [?Hippocrates]

2. Why Palliative Care Needed

Discuss:

- **Gaps** in EOLC
- Avoid futile care: **barriers** to good EOLC
- *Medical technology has created EOL situations that prolong dying and require decisions*
- Widespread belief in EOLC myths

EOLC Gaps: How Americans aged & died 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

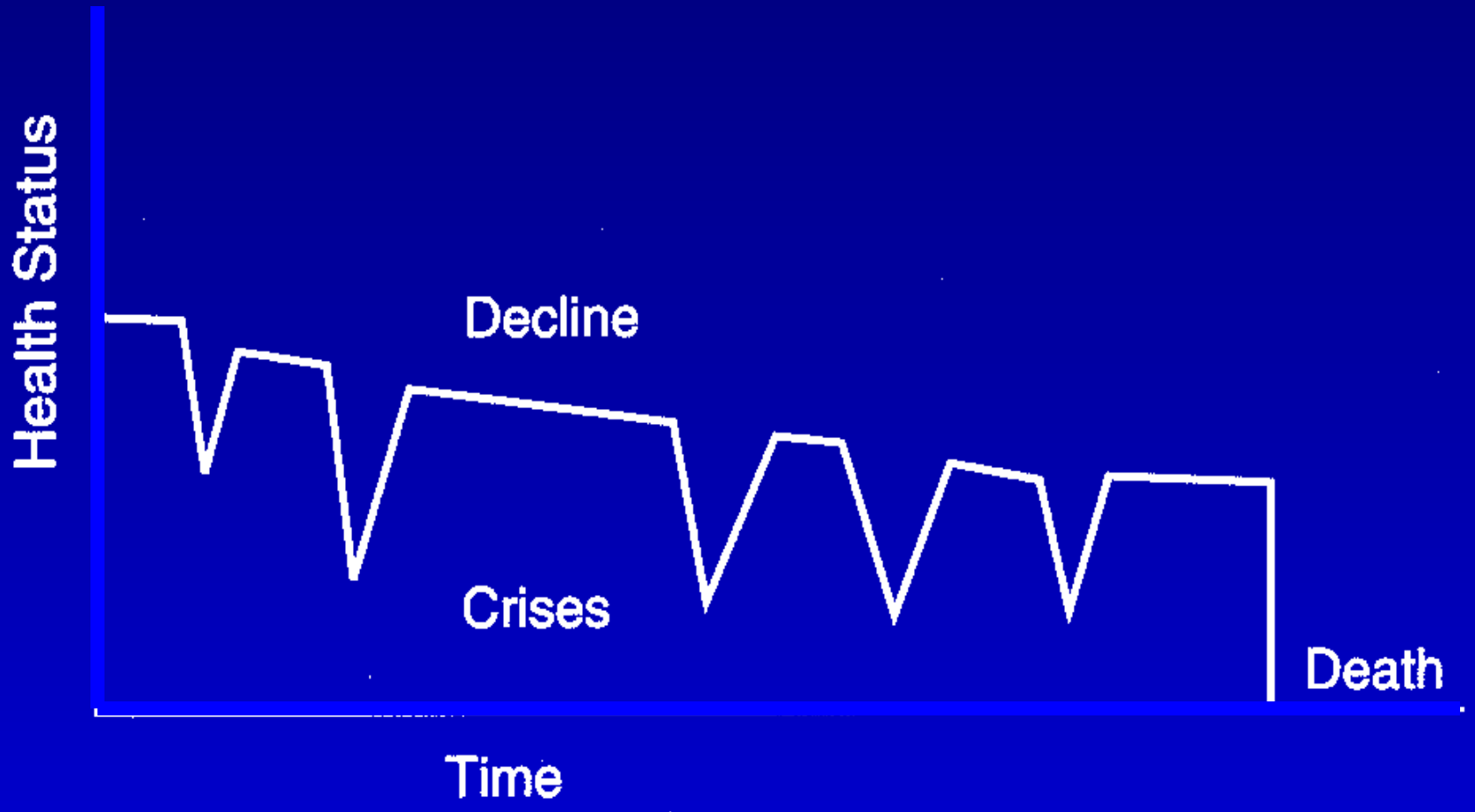
Medicine's shift in focus

- Potential of medical therapies
  - "fight aggressively" against illness, death
  - prolong life at all cost – *Death is the Enemy*
- Improved sanitation, public health, food supply, 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

Slow decline, periodic crises, sudden death



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, therapies!***
  - Now live with *chronic geriatric syndromes*!!

Place of Death shifted…

Site of Death 2007

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

Site of Death by Age

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

National Center for Health Statistics, 2011

. . . Place of death

- 90% of NHO Gallup survey want to die at home
  - But, only 23% do [2007]
- 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 …

PC & Hospice History

- Hospice = 'hospitality'; for travelers, foundlings, destitute; organized by churches
- First formal program, England 1967
  - St.Christopher's, London
  - Dame Cicely Saunders
    - 1965 - Speaks to Yale School of Nursing – begins efforts in USA to initiate programs

- Medicare Benefit since 1982 - provides palliative care to the terminally ill at "home"

…Hospice & PC History

- 1989 - LTCF recognized as 'home'
  - 22% hospice care now in LTCF [2008]
  - 78% NH have hospice care [2004]
- 2006: PC recognized as Specialty
- in 2009: 41% all deaths w/ a "terminal prognosis" in USA were in hospice, in 5000 programs [from 31 in 1984]
- Hospice reduces gov't HC costs 6%

Palliative Care helps avoid "Futile" Care!

Futile Care is:

- "when desired goals not met or desired results cannot be achieved" or
- *excessive medical intervention (effort & finances) with little prospect of altering a patient's ultimate clinical outcome.* [qualitative]
- "clinical care that has a <1 - 5% chance of survival" [quantitative]

[Davila F. The infinite costs of futile care… Physician Exec. 2006.]
[Schneiderman L. Beyond futility to an Ethic of Care. Am J Med. 1994.]
[Swetz. Ten common questions on medical futility. Mayo ClinProc.2014]

…Why PC Needed

Serious adverse outcomes for caregivers [of patients w/ LLD], compared to care at home w/ hospice:

- Patient in ICU associated w/ 5x risk of PTSD
- Hospital care associated w/ 8.8x risk of prolonged grief disorder

* *Wright A. et al. JCO.2010*.

…Why Palliative Care Needed

- 50% of terminally ill suffer pain during their last months of life [*Weiss, et al. 2001*]
- LLD Patient & family preferences!
- During EOLC, we can be primary cause of suffering or, primary cause of its relief !

Dying for Care?

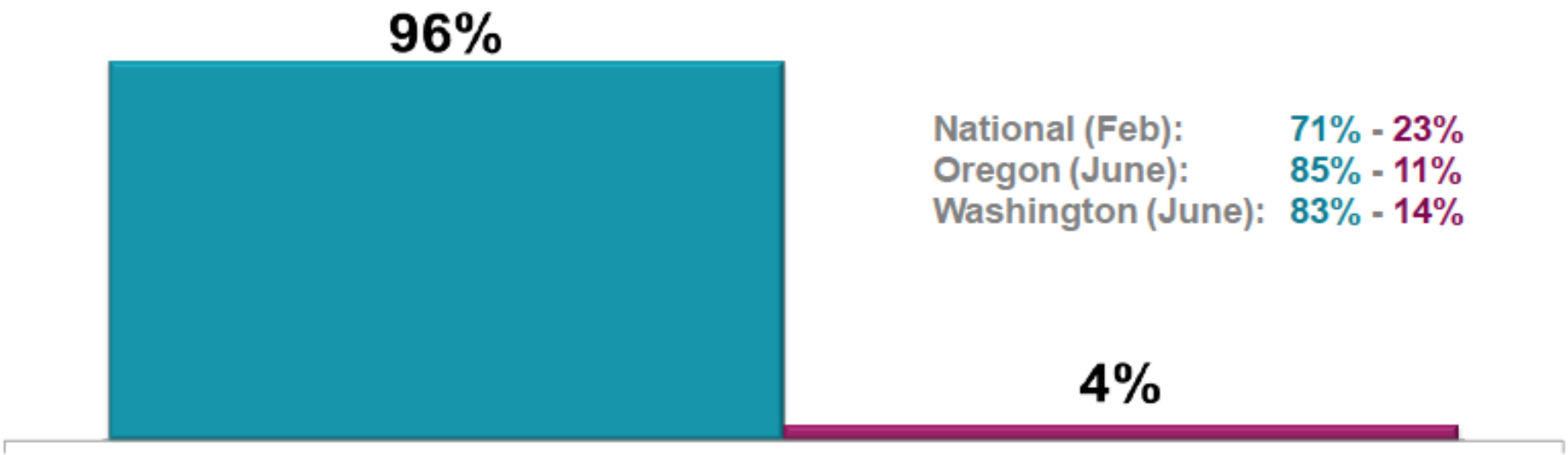
"Most elderly and seriously ill patients died in acute care hospitals. Pain and other symptoms were commonplace and troubling to patients. Family members believed that patients preferred comfort, but life-sustaining treatments were often used." *

- Which is confusing, considering doctors surveys…

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

Physicians are nearly unanimous in their belief that it is more important to enhance the quality of life versus extend life by any means.

Which statement comes closer to your point of view?



Poll #4: n=500 board-certified U.S. physicians from AMA master file; October 28-November 2 ,2011

What do Patients & Families with Serious Illnesses Want [i.e. their goals?]

- Pain and symptom control
- ***Avoid prolongation of the dying process***
- Achieve a sense of control, & Hope
- "Beat the prognosis"
- ***Included in decisions & to be listened to***
- ***Honest information***
  - Everyone wants adverse event info [1/100,000 - Ziegler. Arch Intern Med 2001]

* *Singer et al. JAMA 1999;281(2):163-168.*
* *Tolle et al. Oregon report card.1999 www.ohsu.edu/ethics*

Avoiding Non-beneficial Care

- "To continue to fight for a cure when there is no reasonable hope for one may cut off the true growth and comfort that can come from going on this journey together with those we love."

Hank Dunn. Hard Choices for Loving People. 2001

The only thing worse than "no hope" is "false hope"!

Avoiding Futility: **Barriers** to Good EOL Care

Issues that interfere in comfort care and the right to *die well***:

1) Society
   - Myths about PC
2) Health care
3) Patient
4) Family

** *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* - I.O.M. Report Sept.2014

Attitude may be Barrier to PC

Attitude: Myths of Palliative Care

1. My doctors have given up on me.
2. No more treatment .
3. Only for people with cancer.
4. Only for old people.
5. I′m very close to death.
6. They dope you up & you sleep until you die.
7. If I get morphine, I will stop breathing.
8. I will have no control if I agree to PC.

1) Society Barriers

- "McDonald's medicine" attitude
  - Fast, cheap, easy access, quality
- Obsession with medical technology and health perfection – *can cure everything*?
  - Medicalization of society [read *Limits to Medicine: **Medical Nemesis**, the Expropriation of Health. Ivan Illych*]
- Lack of experience with EOLC
- Unrealistic expectations
  - "pill for every ill" [TV & big *Pharma*]

Why do we take so many pills? Tonight's program is sponsored by pills: red pills, blue pills, green pills, purple pills, pills and more pills!! Ask your doctor if pills are right for you? [? George Carlin-ism]

2) Healthcare Barriers

- MD "death anxiety"
  - Lack of training, experience; personal discomfort
  - Misunderstandings and avoiding patients
  - EOLC myths
- MD reimbursements
  - 'interventions' > bedside communications EOL
  - No incentives to have 'the talk' [e.g. *death panels* !!]
- Business model > medical model
  - Keep alive so able to continue services??
  - *Maximize services even if no evidence of benefit*
- Fraudulent practices/businesses

3) Patient Barriers

- Spiritual anxiety – existential
  - If believe in heaven, why delay it & prolong suffering
- 'Why me' – too much to do yet?
- My family – "who will look after them"
- Myths – fears that dying painful, EOLC, etc

[not as common or significant as family related issues…]

4) FAMILY Barriers…!

- Myths – fears of pain, addiction, starvation, EOLC
- "Selfishness" – loneliness, 'be orphaned'
  - *Mom can't die before me??!!*

    Can't let go of memory of once 'healthy parent'??
- Financial – need mom's SS check
- Drug diversion [narcotics !]
- 'Entitled' to max care regardless of cost
- Guilt & unrealistic expectations…

…Family [unrealistic] Expectations

- Technology today can cure everything? So don't give up!!
  - *Death anxiety*
    - *Doctors just as anxious – "can't die on my watch"*
  - Expect doctor to 'do something'
    - Dr. trained to "rescue" everyone
  - Children's guilt – not available? Regrets?
- Danger is now have many toxic 'somethings' available for treatment
  - Need to use least toxic – *First, do no harm!*
  - OR, choose comfort focus goal

…More Barriers…

- A need to help family put dying in context
  - We will all die [seniors can accept this!!]
  - 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

. . . More Barriers to good EOLC

- MD: Lack of skill negotiating goals of care, treatment priorities
  - Can lead to futile or non-beneficial therapy
  - Treatment or technological imperatives – *reflex use because it's there – the need to "do something"*
- 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 PC: The Role of the Doctor

- To help 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

Process of Setting Goals : Summary

1) Must ask the pt/family what's their goal !!

   E.g. "Given your current condition, what's important to you?" - comfort v. longevity?

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

…What to discuss…

Specifics: Four Questions*

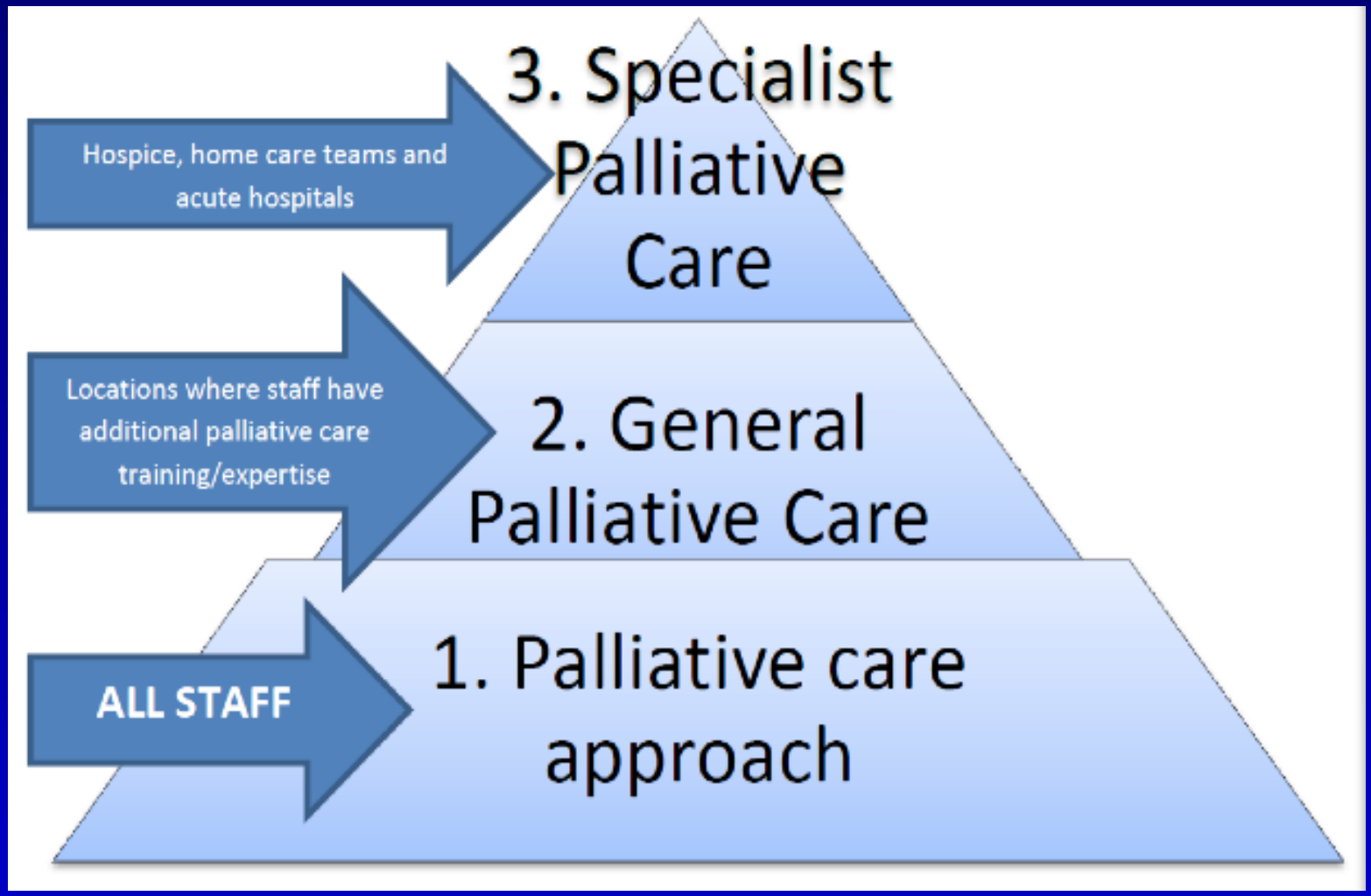
1. *What is their understanding of condition?*
2. *What are their goals if health worsens?*
3. *What are their fears?*
4. *What trade-offs are they willing/not to make?*

* Atul Gawande. The Best Possible Day. NYT Oct.5/14. [*Being Mortal: Medicine and What Matters in the End*.]

3. Who's Eligible for PC?

- Any LLD [Life Limiting Disease]
  - Alzheimer's/dementias
  - Stage IV cancers
  - End organ disease [CHF/COPD/CKD4-5/etc]
  - Neuro-degenerative diseases [ALS, PD, etc]
- An acutely serious or life threatening illness
- LTCF resident or advanced age or frailty
- Doctors write "Poor Prognosis"
- **Anyone who is 'suffering' & wants a 'comfort' focus !**

Levels of palliative expertise: **everyone** can be a little palliative



Eligible patients: Screening for PC

- DGPT – ***"Discussion of Goals & Prognosis Tool"***
  - From CAPC tool [Center to Advance PC]
  - Was called Palliative Medicine Prognostic Tool [handout]
    - Avoiding term "palliative" for now !?
- Six Sections/components – point scoring
  - I. Poor prognosis already
  - II. Prognosis 6-12 mo.
  - III. Diseases
  - IV. Symptoms uncontrolled
  - V. Functional Status anticipated
  - VI. Psychosocial issues

…Screening for PC

- Coordinator and/or case mgr make daily rounds in all critical care units and place tool on appropriate charts for MD to see
- Score 10+ = likely die <6-12mo.
  - Encourages MD to have goals and EOLC discussion w/ patient/family [??];
  - or can consult PC

Using DGPT to screen for PC

- 2013 Total Consults: 318
  - Consults w/o DGPT: 272 [86%]
  - Consults from DGPT: 46 [14%]

- PMPT screenings: 164
  - Resulted in consult: 46 [28%]
  - No consult [i.e. control group]: 118

More consults requested before DGPT placed—because staff more knowledgeable??

…Screening for PC w/ DGPT

[Info at top of form]

Comfort focused care (Palliative care) *is appropriate at any point in a serious illness and can be provided at the same time as curative treatment for patients with difficult to control symptoms or who may be approaching end-of-life. The prognostic tool helps identify patients who may benefit from goal focused care or end of life education earlier in the course of the disease.*

[RN, Case Mgr, MD can complete this]

…Screening

1) If **one** of these are present

- Admitted to ICU from extended care facility
- Documented prognosis *grave, grim, or poor*
- Hospice patient prior to admission
- Has expressed wish not to have life prolonging treatment

Then, MD should discuss goals & AND/DNR

…DGPT Screening

2) Would you (MD) be surprised if this patient were still alive in 6-12 mo?

- Yes - Score 3 points * [*consider hospice referral*]
- No - Score 0

…DGPT Screening

3) Basic Disease Process **Score 2 points each**

a. Cancer stage IV (metastatic/recurrent) *
b. Advanced COPD (requires home oxygen) *
c. Acute CVA/Altered Mental Status [NIHSS score >16] *
d. End stage renal disease [Stage 4-5, considering dialysis] *
e. Advanced congestive heart failure [Class III-IV] *
f. >3 admits or ED visits for incurable disease in past year
g. Other terminal or incurable disease causing significant symptoms
h. Acute Anoxic Encephalopathy = 10pts
i. Dementia or Multiple medical problems [CAD/CHF/CKD/COPD/CVA]

* Hospice eligible likely

…DGPT Screening

4) Uncontrolled Symptoms/Clinical Conditions

Score 2 points each

a. Pain
b. Dyspnea
c. Nausea
d. Weakness
e. Depression/Anxiety
f. Weight loss.
g. Constipation.
h. Other

Score 1pt each

i. Prolonged vent. Support
j. Delirium
k. ICU >7days

…DGPT Screening

5) Anticipated Functional Status at Discharge

ECOG Performance Status (Eastern Coop. Oncology Group) Scale

- Fully active, able to carry on all pre-disease activities with min. restrictions = 0 pts
- Ambulatory, capable of most self-care. Up & about >50% of waking hours = 1 pt
- Capable of limited self care: confined to bed or chair >50% waking hours = 3 pts
- Bedbound = 4 pts

…DGPT Screening

6) Psychosocial issues (patient or family)

- Complex family/social issues = consider PC consult
- Spiritual distress = consider chaplain referral

Scoring :

- **If >10: use available guideline to discuss goals, AND/DNR, hospice.**
- Score >10 indicates high risk of dying in <6mo.

Alz.Dem. w/ Hip Fx + Delirium: what's her score?

- Sctn 1: [poor prognosis]
- Sctn 2: 3 [alive in 1 yr?]
- Sctn 3: 2+2 [CHF + dementia]
- Sctn 4: 2+2+1 [pain + weakness + delirium]
- Sctn 5: 3 [ADL: bed/chair >50%]
- Sctn 6: [AND + goals]

Total: 15 [core sctns 2-5]

4. Stewardship in Healthcare

- Stewardship: "A [fiduciary & ethical] responsibility to take care of something one does not own."
- Stewardship implies avoiding things which are non-beneficial/futile for another person !

[Futile Care: care which will not help a patient reach their goal.]

Stewardship

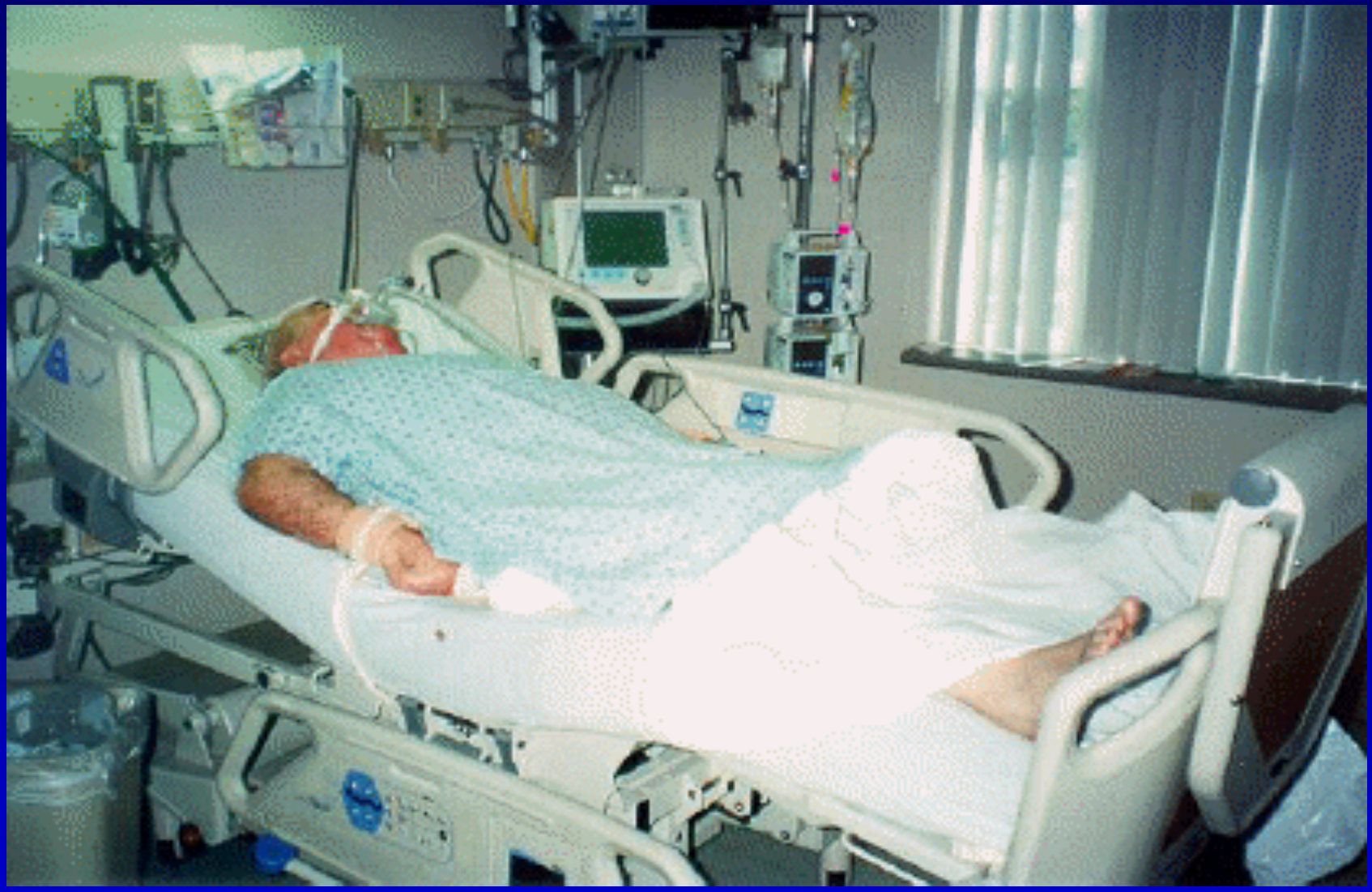
- 5% of Medicare beneficiaries die each year
- 30% of budget [total = $461B in '08] is for last year of life
- Of those dying, 50%-80% of costs spent on last 2 mo. of life [w/ no "gain in quality"]
- Do we (physicians **&** patients) not have a stewardship responsibility – to avoid futile or non-beneficial care?

* *1. USA Today; 2. J. Lubitz, DHHS, report to US Congress 2004; 3. LA Times 2010; 4. Alliance for Health Reform 2010.*

Could PC be Medicare's Salvation?

- By focusing on **quality** of life rather than quantity of years, suffering and futile care can be reduced
- Important to think about how you want to
  - **LIVE**
  - and **DIE**?

Futility – how do you want to die?



5. Summary & Pearls

- PC improves QOL and QOD [Quality of Dying] – because it's comfort-focused
- Hospice is PC for the last 6mo of life
- Nothing good comes from our denying that someone is dying !
- Do you want to 'live' or 'be kept alive'?
- Choose to be informed - base decisions on goals of care [How do you to do that??]
- Who should accept stewardship for Medicare?

Resources for Palliative Care

- Getpalliativecare.org
- *It's Ok to Die* – Dr. Monica Williams-Murphy
- You're Sick, It's Serious [aahpm]
- **Comfortcarechoices.com** [RJ Webb's website – has this slide show]
- The Five Wishes – agingwithdignity.org
- OneSlideProject – engagewithgrace.org
- Patient Decision Aids - http://www.npc.nhs.uk/patient_decision_aids/pda.php

Success & Aging

Hospice offers Hope. Like hope, definition of success changes as we age: life is a circle.

- At age 4, success is…not peeing your pants
- At age 12, success is…having friends
- At age 16, success is…a driver's license
- At age 20, it's…having sex
- At age 35, it's having money

Success cont'd

- At age 50, success is…having money
- At age 60, it's…having sex
- At age 70, it's…having a driver's license
- At age 75, it's…having friends
- At age 80, success is not peeing your pants!

As you slide down the banister of life, may all the slivers point down!

- Maxine

So, enjoy yourself while you can !

Thank You !