Palliative Care's Place in LTC

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Outline

1. Palliative Care & Hospice
   Definitions, differences, and benefits
2. Hospice & PC History, Regs, & Myths
   – LTC
3. Who's eligible for PC & Hospice
   - General criteria and disease-specific
4. Pillars of good EOLC in NH
5. Summary & Pearls

1. What is PC & Hospice?

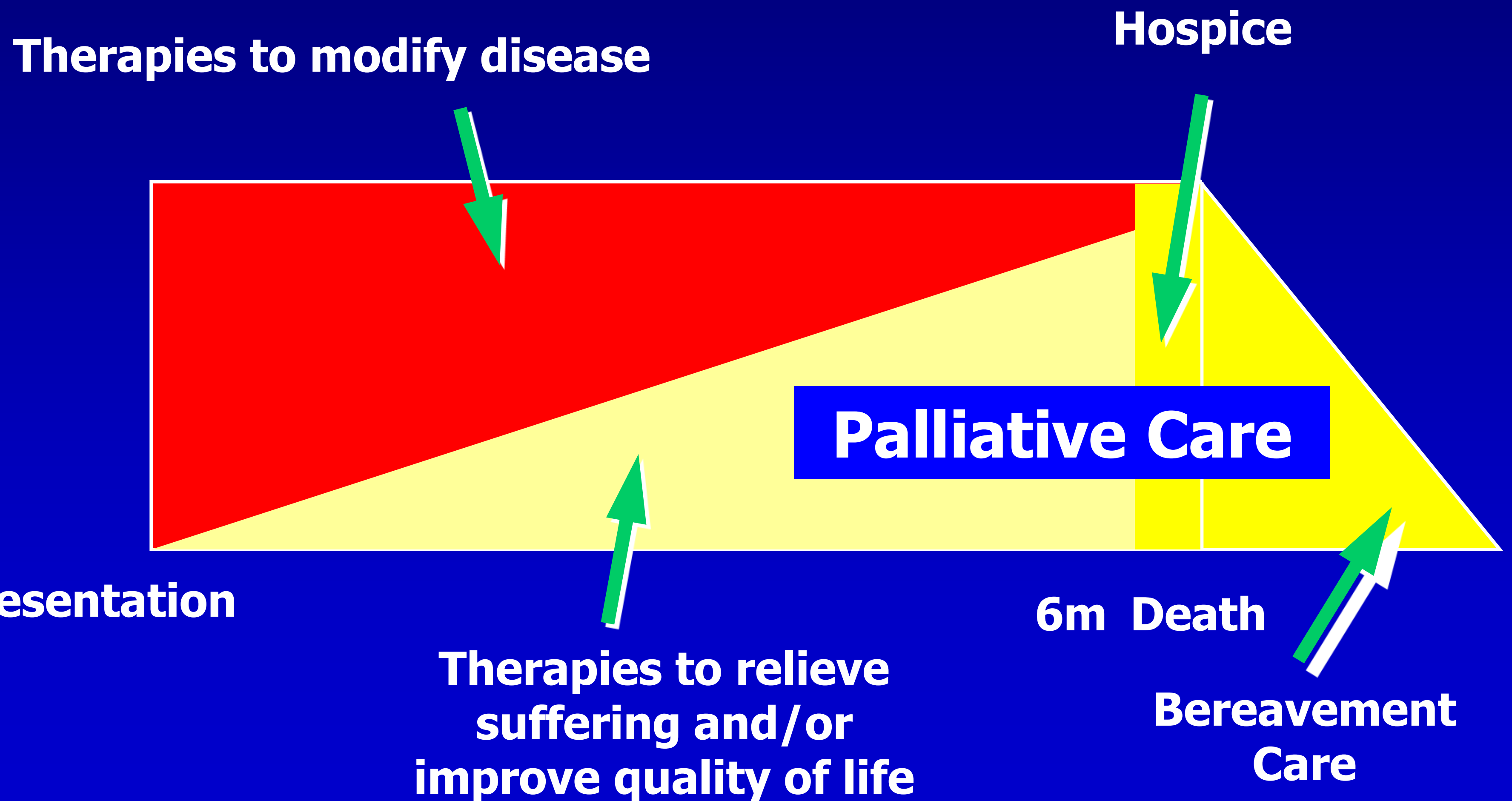
Palliative care is interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families.

- 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."

Palliative Care's Place in the Course of Illness



Palliative Care is Comfort-focused

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

PC & Hospice Benefits

- PC does NOT accelerate dying
  - Cost Savings Impact Study 2009 at ECM
    - patients in <u>both</u> 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 & Hospice 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 so beneficial?

Implementing PC principles helps by:

- Stopping all/most non-comfort tx/meds
- Aggressively controlling symptoms - helps them to feel better and eat/socialize/exercise more and fight illness
- Encouraging patient/family-driven goals
  - Avoid futile/unnecessary treatment & hospitalizations
- Encouraging EOLC planning
  - helps accept limits to life

  [that confronts the *illusion of certainty*…]

A Purpose of Palliative Care & Hospice: avoid "Futile" Care!

Futile Care is:

- "when desired goals not met or desired results cannot be achieved" [qualitative], or
- "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;96:110-14.]

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 Futile Care

- Only 10% people die suddenly
- 90% need some form of terminal [EOLC] care – many are in LTC
- During EOLC, we can be primary cause of suffering or, primary cause of its relief !

- Thus, we need PC & Hospice to relieve suffering !

Historical Perspective: always had Palliative Care

Physician (& RN) Traditional Role = PC

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

- anonymous 16th century aphorism [?Hippocrates]

2. Hospice & PC 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 has reduced gov’t HC costs 6%

…History & Facts

- Incentive for patients: no cost = increase demand

  (and incentive for business – per diem payments)

  - From 1997 <500k pts, to 2007 >1million;
  - Medicare cost from $2.9B to $10B
- Increasing admissions for non-cancer dx
  - In 1998: 47% hospice = non-cancer dx
  - In 2008: 69% pts = non-cancer dx
- With increasing ALOS
  - In 2000: 62 days; in 2006: 82 days
- Alabama 2011: 184 licensed providers (121 certified) = 1 agency/37,506 pop; US = 1 / 61,401 pop.

LTC Stats

- 1.5 million residents in NH [3m by 2030]
  - 48-66% dementia [GHC = >80%]
- ALOS [2004] – 2.3yr
- MLOS – 1.3yr
- 33% die <1yr; 66% die <2yr;
- 39% hospitalized in their last 30days !
  = Medication errors, ADL decline, poor communication
- Families report inadequate pain (32%) & dyspnea (24%) control, and emotional support (50%)
- ***Therefore, <u>most</u> residents eligible*** *[or soon will be]* ***for PC &/or hospice !***

Barriers to Palliative Care in NH

- **RAI** [Resident Assessment Instrument] & **MDS** [Minimum Data Set]
  - Focus on ‘restorative’ care; PC for symptom control not recognized
  - Normal declines for EOL are indicators of inadequate care !
    - Wt.loss
    - Functional decline – increased ADL dependency
    - Dehydration
    - Decreased ability to move
    - Most of time in bed/chair

… Barriers to NH Palliative Care

- "Economics 101" = use 'Skilled' days when possible; admit to hospital x3days, then return for SNF days
- No true PC RUG's – intensive IV/PEG reimburse much better – push ANH

Attitude may be Barrier to PC ?

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Hospice Regulations

- Covered Services:
  - all meds, services, supplies re diagnosis/comfort
  - RN visits, care aides, chaplain, social worker, PT/OT/SP/Dietician, Medical Director
    - Visits based on POC + 'core' mandated unless patient/family refuse
  - Bereavement for 13mo post-death
- Should prevent hospital admissions !!
- Usually doesn't cover "non-terminal" therapies or drugs
- Reimbursed by Medicare on per diem basis

…Hospice Regs

Admissions:

- Pt must be evaluated within 48hrs of referral
- Primary doctor & medical director must sign

Certifications [i.e. that <6mo life expectancy]:

- Initial certification (90 days) by PMD & M.Director
- 2nd 90 day recert by M.Director
- 3rd recert (@ 180days, for next 60days) requires face-to-face visit by M.Director [or CRNP]
- Subsequent recerts q 60days – "unlimited"
- Must include written narrative

…Hospice Regs

Discharges:

- Patient must be discharged if not declining or not likely to die in next 6mo.
  - Patient/family can appeal discharge [AQAF]
- Patient can ‘revoke’ hospice at any time
  - To go with another hospice; or moving;
  - To resume ‘curative’ therapies

Conditions of Participation
[to be a hospice agency]

- There are 24 general C.o.P.
  - Revisions 1992, 2008
- Sctn 418.112 refers to Hospice in SNF/NF
  - 6 subsections [13 pages]
- 2008 Revision – significant implications for LTCF relationships w/ hospices

2008 Revision Highlights

- Hospice responsible for determining care
- ***Hospice Medical Director assumes oversight of patient care***
- Hospice provides care which would normally be provided in patient's home
- Hospice must ensure NH staff oriented to hospice

Should Hospice be in LTC

- Benefits of hospice to LTC residents
  - 1996 Study – Outcomes & Utilization for Hospice and Non-Hospice Nursing Facility Decedents = better QOL
- And:

  Shouldn't every NH = PC center of excellence??

  Is hospice in LTCF redundant? Conflicts?

Myths about Hospice

Myths:

i. There are ‘two’ kinds of hospice
ii. Patient must have DNR [AND]
iii. They cannot be admitted to hospital
iv. Patients must be discharged if they don’t die in <6mo.

Hospice Realities/Facts

i. Only 'one' kind of treatment hospice
   - there are "Not-for-profit" & "For-profit" businesses
ii. Patients do not need a DNR/AND
   - But, mixed messages - false hope - ?fraud
iii. Patients can be admitted to hospital
   i. Hospice related dx
   ii. Non-hospice problem
iv. After the initial 6 mo. certification, if the doctor believes death will still occur within the next six months, patients can continue in hospice

3. Hospice & PC Eligibility

Hospice General Eligibility:

- Medicare beneficiary, entitled to Part A;
  - Or: have another insurance contract; indigent
- Certified as having life expectancy <6mo "if illness runs its normal course." [Prognosis by PMD and hospice Medical Director]
- Patient waives rights to all curative care for the terminal illness

* Guidelines for Determining Prognosis taken from NHPCO

How good is prognostication?

- Factors affecting prognosis
- Measurements: prognosis/performance scales
  - Karnofsky score
  - Palliative Performance Scale
  - ECOG [Eastern Cooperative Oncology Group]
  - Disease specific scales
- Physician accuracy & judgment
  - "would you be surprised if this patient were still alive in 6-12 months?"

Factors affecting Prognosis:

Comorbid conditions:

- Age, ADL's, CV disease, DM2, nutrition

Tempo – speed of progression

Agendas – non-acceptance, mistrust, costs

Will to live vs 'given up' ?

Family expectations – 'cure' vs 'comfort only'

Intuition

PALLIATIVE PERFORMANCE SCALE (PPS)

<table>
<tr><th rowspan="2">%</th><th rowspan="2">Ambulation</th><th rowspan="2">Activity level
Evidence of disease</th><th rowspan="2">Self-care</th><th rowspan="2">Intake</th><th rowspan="2">Level of consciousness</th><th colspan="3">Estimated median survival in days</th></tr>
<tr><th>(a)</th><th>(b)</th><th>(c)</th></tr>
<tr><td>100</td><td>Full</td><td>Normal
No disease</td><td>Full</td><td>Normal</td><td>Full</td><td rowspan="3">NA</td><td rowspan="4">NA</td><td rowspan="5">108</td></tr>
<tr><td>90</td><td>Full</td><td>Normal
Some disease</td><td>Full</td><td>Normal</td><td>Full</td></tr>
<tr><td>80</td><td>Full</td><td>Normal with effort
Some disease</td><td>Full</td><td>Normal or reduced</td><td>Full</td></tr>
<tr><td>70</td><td>Reduced</td><td>Can't do normal job or work
Some disease</td><td>Full</td><td>As above</td><td>Full</td><td>145</td></tr>
<tr><td>60</td><td>Reduced</td><td>Can't do hobbies or housework
Significant disease</td><td>Occasional assistance needed</td><td>As above</td><td>Full or confusion</td><td>29</td><td>4</td></tr>
<tr><td>50</td><td>Mainly sit/lie</td><td>Can't do any work
Extensive disease</td><td>Considerable assistance needed</td><td>As above</td><td>Full or confusion</td><td>30</td><td>11</td><td rowspan="3">41</td></tr>
<tr><td>40</td><td>Mainly in bed</td><td>As above</td><td>Mainly assistance</td><td>As above</td><td>Full or drowsy or confusion</td><td>18</td><td>8</td></tr>
<tr><td>30</td><td>Bed bound</td><td>As above</td><td>Total care</td><td>Reduced</td><td>As above</td><td>8</td><td>5</td></tr>
<tr><td>20</td><td>Bed bound</td><td>As above</td><td>As above</td><td>Minimal</td><td>As above</td><td>4</td><td>2</td><td rowspan="2">6</td></tr>
<tr><td>10</td><td>Bed bound</td><td>As above</td><td>As above</td><td>Mouth care only</td><td>Drowsy or coma</td><td>1</td><td>1</td></tr>
<tr><td>0</td><td>Death</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
</table>

ECOG Staging (Cancer only)

- Metastatic [i.e. Stage IV] and failed chemoRx
- Eastern Cooperative Oncology Group
  - Stg I - ambulatory, active, mild symptoms
  - Stg II - in bed <50% of day, more symptoms
  - Stg III – in bed >50% of day [= 3-6mo. survival]
  - Stg IV – bedridden, total care [= <3wks avg survival]
- III & IV: usually have symptoms: losing wt, dysphagia, anorexia, dyspnea, dry mouth

Prognosis Accuracy Poor

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

Why? - fear of withholding hope
- death is the ‘enemy’
- lack of experience = *uncomfortable*

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

"There's no easy way I can tell you this, so I'm sending you to someone who can."

Hospice Eligible Diseases

- Cancers
- Non-Cancers:
  - ALS [Amyotrophic Lateral Sclerosis]
  - CVA [Stroke & Coma]
  - Dementia
  - General Debilitation
  - Heart
  - HIV/AIDS
  - Lung
  - Liver
  - Renal

Eligibility: Cancers

- When to begin hospice, determined by individual cancer prognosis, and by speed of decline in ADL's
- More accurate than for non-cancer dx

Cancer Prognosis <6mo if:

- Malignant hypercalcemia [S. Ca++ >11]
- Extensive liver mets/failure
- Malignant pleural effusion
- Brain mets [usual = <8mo]
  - Rx steroids only = 1-2mo
  - Rx WholeBrain Rtx = 3-6mo
  - Rx Surg + RTx = 10-16mo?

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Three common cancers

Cancer	5 year survival
• Lung	1% (distant mets)
•	13% (overall)
•	35% (localized)
• Breast	18% (distant)
•	75% (overall)
•	90% (early stage)
• Prostate	31% (distant)
•	73% (overall)
•	85% (localized stage)

[Davita]

Eligibility: Non-Cancer Diagnoses

Important factors for <6mo:

- ADL's – progressive debilitation
  - Assistance for all ADL's
- Recurring hospitalizations
- Disease-specific considerations
  - Less accurate than with cancers

Need to adhere to national guidelines/ criteria

- Avoid potential OIG investigation and charges

Eligibility: ALS (Lou Gehrig's Disease)

Must fulfill 1, 2, or 3.

1) Impaired breathing [all present in prior 12mo]
   - VC <30%; - declined ventilator
   - Dyspnea at rest; - O2;

2) Rapid progression of ALS & nutrition [all present]
   - From independent walk & ADL's to w/c or BB + assist
   - Normal speech to barely intelligible
   - Normal diet to pureed
   - Oral intake insufficient to sustain life - no PEG
   - Continuing wt loss
   - Evidence of dehydration/hypovolemia

ALS cont'd

3) Rapid progression of ALS [above], and Life-threatening complications [1 of]:
   i. Recurrent aspiration pneumonia
   ii. Pyelitis
   iii. Sepsis
   iv. Recurrent fever after antibiotics

Eligibility: Stroke & Coma (acute)

- Coma, persistent vegetative state >3days
- Severe myoclonus >3days
- Persisting Coma after 3 days, w/ any 4 of:
  - Abnormal brain stem response
  - No verbal response and No response to pain
  - S.Creatinine >1.5mg/dl
  - Age >70
- Dysphagia sufficient to not sustain life
  - PEG declined or not a candidate
- MRI/CT suggesting decreased survival
- NIHSS helpful re prognosis

Stroke & Coma (chronic)

- Karnofsky <50 [PPS <50]
- Wt loss >10% in 6 mo; or, Albumin <2.5
- Meets criteria for Dementia
- Age >70
- Medical complications
  - Aspiration pneumonia
  - Pyelitis/sepsis/fever after abx
  - Refractory Decubiti stg 3-4

Eligibility: Dementia

FAST [Functional Assessment Staging Scale] = 7c

- 7a – speaks < 6 intelligible words /day
- 7b – speaks only 1 word clearly/day
- 7c – bed-bound (2 person max. assist OOB)
- 7d – cannot sit unsupported
- 7e – no longer smiles
- 7f – cannot hold head up

AND…

…Dementia eligibility

AND, at least one of following in prior 6mo:

- COPD
- CHF
- Recurrent aspiration pneumonia
- Decubitus ulcers Stg.3-4
- Age >70
- Serum albumin <2.5
- Progressive wt loss >10% previous 6mo
- Recurring fever after antibiotics; septicemia; pyelitits

Eligibility: General Debilitation

- Have a life-limiting condition
- Patient accepts comfort focus only
- Documented clinical deterioration in ADL, or

  Documented wt loss >10% in prior 6mo.

  – may be supported by albumin <2.5gm/dl]

Eligibility: Heart Disease

- Class IV by NYHA
  - Symptoms at rest [angina, dyspnea]
- Supportive documentation
  - SaO2 <89%/RA
  - EF <20%
  - CP.Arrest
  - V.arrhythmias
  - Unexplained syncope
  - cardiogenic brain embolism
- Receiving optimal treatment
  - ACE inhibitors
  - Diuretics/vasodilators
  - nitrates

Eligibility: HIV/AIDS

- CD-4 count <25, or viral load >100,000copies/ml
- Karnofsky score <50 [PPS <50]
- Chronic diarrhea, albumin <2.5, age >50; CHF
- Plus [one of opportunistic conditions]
  - CNS lymphoma
  - Wasting worsening
  - Persistent MAC bacteremia
  - Systemic lymphoma, failing chemoRx
  - Visceral Kaposi unresponsive to treatment
  - Cryptosporidium or toxoplasmosis

Eligibility: Liver Disease

- Not liver transplant candidate
- PT >5sec above control [INR >1.5]
- Albumin <2.5
- One of:
  - Refractory ascites or noncompliance
    - [to furosemide & spironolactone]
  - Spontaneous bacterial peritonitis
  - Hepatorenal syndrome
  - Refractory hepatic encephalopathy/noncompliance
  - Recurrent variceal bleeding despite tx

Eligibility: Pulmonary Disease

- Dyspnea at rest; HR 100+/min; wt loss
  - Bed-to-chair existence, fatigue, cough
- FEV1 <30% post-bronchodilator
- Increasing ER visits/hospitalizations or decreasing FEV1 >40ml/yr
- Cor pulmonale [RHF]
- PO2 <55mmHg [SaO2 <89% on O2]
  - Or CO2 >50

Eligibility: Renal Disease

- Patient decided to stop/forego dialysis
- S.creatinine >8mg/dl [>6 if DM]
- Creat.clearance [~GFR] <10cc/min
- Clinical signs of: uremia [confusion, n/v, pruritus, restlessness]; oliguria; hyperkalemia; uremic pericarditis; HR Synd; fluid overload

Why offer a prognosis in NH?

- Having general prognosis specific to resident [not based necessarily on tissue dx]…
  - Should spur practitioner into having EOLC planning discussion
- Knowing prognosis affects goals of care and decision-making
- Improve QOL, QOC, avoid futile treatment/hospitalizations

…why offer prognosis

- Improve resident/family/staff satisfaction in care
- The ‘Right to Know’ - Ethical principles of autonomy, beneficence, nonmaleficence
  [First, Do No Harm]

When to ask for Hospice?

- Estimated life expectancy less than 6 mo [per guidelines]
  - Would you be surprised if she were alive in 6-12 months?
- Cure no longer possible or decide to stop attempted cure
- Symptoms [e.g. pain, shortness of breath] not controlled and hoping to relieve suffering - "tired of fighting it"
- Don't leave it "too late"
  - 35% patients die in <7days from admission *[2008]*

…when to ask??

- Use MDS coordinator to provide score for Mortality Risk Index [MMRI-R – 10 items w/ weighted points; max score of 85]
  - Score >36 = 57% die in <6mo
  - Score >56 = 90% die in <6mo
  - Score >70 = 100% die in <6mo

MMRI-R Items [points]

- Admission to NH in past 3mo? [8]
- Lost wt unintentionally in past 3mo? [5]
- Renal Failure? [6]
- CHF? [4]
- Poor appetite? [4]
- Male? [5]
- Dehydrated? [4]
- SOB? [8]
- Cancer? [age linked – 2-9pts v 13-20pts]
- Deteriorated cognitive skills/status in past 3mo?
  [ADL linked – 0-16pts v -2 to 21pts]

When to implement PC approach !

- Resident & family want comfort care only
  - At any time – could last years !
  - E.g. Alzheimer's, ALS, severe PD
- Death likely in <1yr
- Doesn't meet hospice criteria yet

- With educated staff & MD re PC, don't need consult to implement !

When to ask for PC Consult

- Symptoms uncontrolled
- Family issues/unrealistic expectations
- Want a 2nd opinion or need support

Call Julie Archer, CRNP or

Dr. Rob Webb, MD

4. Pillars of good EOLC in NH

1) Allowing resident/family sense of control
2) Reduce burden of dying
3) Avoid prolonging dying process
4) Focus on controlling "total pain" [physical, social, psychological, spiritual]
5) Recognize and treat fatigue, depression, anxiety

… Pillars of good EOLC in NH

6) Support family during dying and bereavement
7) Attend to spiritual needs
8) Enhance communication
9) Support healthcare providers
10) Coordinate services

[Morley, JAMDA, 2011]

Grass (w/ hospice) not always greener!

5. Summary & Pearls

- PC improves QOL, being comfort-focused
- Hospice is PC for the last 6mo of life
- Hospice requires certification of <6mo survival if disease runs usual course
- Hospice doesn't require AND/DNR order
- Patients can be in hospice >6mo
- Patients can be admitted to hospital

…Summary & Pearls

- Non-cancer diagnoses now the majority of hospice patients
  - need good documentation to justify admission
- Hospice benefits patients/families more, when enrolled at least 3 mo
- Can use MDS MMRI-R for prognosis
- NH should be PC providers of excellence

Information Resources for Hospice & Palliative Care

- OneSlideProject – engagewithgrace.org
- nhpco.org [National Hospice & Palliative Care Organization]
- CAPC [Center to Advance Palliative Care]
- **Comfortcarechoices.com** [RJ Webb's website]
- The Five Wishes – agingwithdignity.org

Success & Aging

PC 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!

“Growin’ old ain’t for sissies”

- Bette Davis

THANK YOU !

Paying for Hospice in LTC

- **Room & Board**: Patient responsible for costs

  Medicaid most frequent payer in LTCF

  - Pays LTCF ~$186 per diem, less "resource" amount (Resident Liability - ~$300/mo = a "copay")

  When hospice elected, Medicaid pays hospice R&B, less an additional 5% "deductible"

  Hospice then pays LTCF for R&B

- **Hospice Service**: Hospice receives per diem from Medicare

Payment Example

Resident w/o Hospice

R&B: $156/day

= $4,836/mo

R.L.: - $ 511.

Net: $4,325/mo

**R.L. = Resident Liability*

** M.Aid deducts 5% from pay't to hospice*

Resident w/ Hospice

- $ 156/day
  = $4,836/mo [31d.]
- \- $ 511.
- = $4,325/mo
- \- $ 217 (5% ded'n)

Net: $4,108 to hospice

Hospice pays $4,325 to LTC