EOLC Education

Managing the Dying Process

ALMDA Annual Meeting
Sandestin, FL

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Objectives

- Know how to assess and manage the pathophysiologic changes of dying, including the common EOLC myths
- Understand the concept of “Two roads to death”
- Know how to determine death
- Understand how to communicate with families regarding preferences, including the principle of palliative sedation
- Be aware of what constitutes good EOLC in LTC

Outline

1. The Last Days: two roads to death
   - Preparing family & staff
   - Physiological processes & Determining death
   - Anticipating problems
2. Determining Resident/Family Preferences
   - Options of Last Resort – Palliative Sedation
3. Pillars of Good EOLC
4. Summary & Pearls

Evidence-based Care Reminder

- 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 – and thereby avoid harm.

1. Last days of living:

Points to remember

- Everyone will die
  - < 10% suddenly
  - > 90% prolonged illness
  - Nothing good occurs if we pretend one isn't dying !
- Last opportunity for life closure
- Little experience with death
  - exaggerated sense of dying process

Grim Reaper in LTC

Preparing for the last hours of life

- Time course unpredictable
  - From 1 to 12 days
- Private room/setting if possible
- Educate & involve family !!
- Anticipate need for medications, supplies
- Regularly review the plan of care
- Move from patient-centered to family-centered care

. . . Preparing for the last hours of life

- Caregivers
  - awareness of patient choices [e.g.]
  - knowledgeable, skilled, confident
  - rapid response – comfort crisis pack
  - "what could go wrong" preparations
- Likely events, signs, symptoms of the dying process

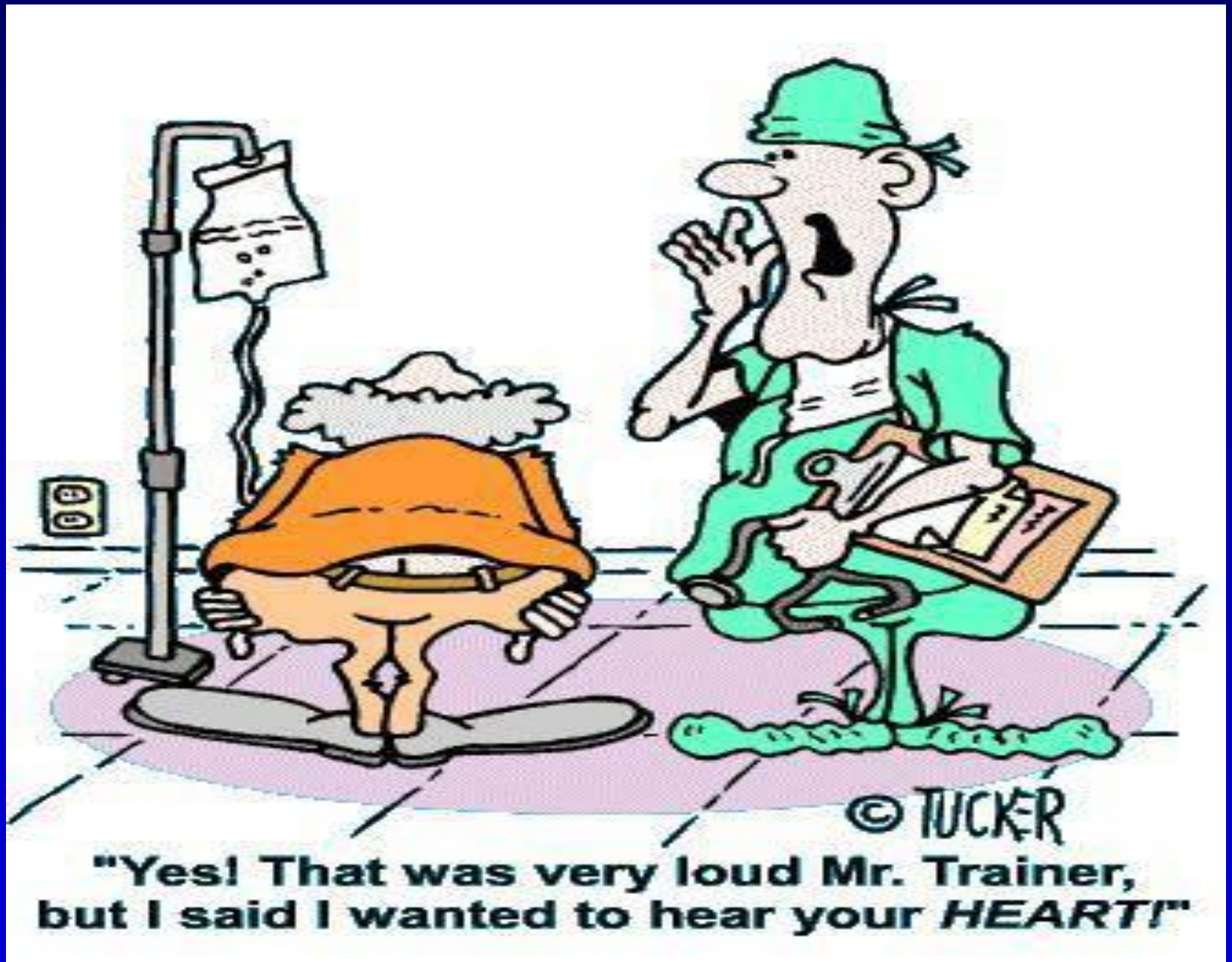
Things to consider/do [once we accept death coming in 1-2wks]. .

- Use only essential medications – stop all non-comfort ones
- Choose least invasive route
  - buccal mucosal or oral first, then consider rectal
  - **Subcutaneous !!!** intravenous rarely
  - intramuscular almost never

…Additional things . . .

- Discuss
  - status of patient, realistic care goals, how long will this take [‘ask’, ‘tell’, ‘ask’ again]
  - role of physician, interdisciplinary team
- What patient experiences ≠ what onlookers see
- Provide information packet early – e.g.
  - *Caring for the Dying* handouts [ccc website]
  - *Gone from my Sight* [the ‘Blue Book’]

Avoid misunderstandings !



. . . Additional Things

- Reinforce signs, events of dying process
- Personal, cultural, religious, rituals, funeral planning
- Family support throughout the process
- Document, Document, Document !!!
- All staff "on same page"
  - RT, RN, Dietary, MD

Physiologic changes during the normal dying process

1) Increasing weakness, fatigue
2) Decreasing appetite / fluid intake
3) Decreasing blood perfusion
4) Neurologic dysfunction
   - Neurotoxicities
5) Pain
6) Loss of ability to close eyes

1) Weakness / fatigue

- Decreased ability to move
- Joint position fatigue
- Increased risk of pressure ulcers
- Increased need for care
  - activities of daily living
  - turning, movement, massage

2) Decreasing appetite / food intake

- Fears: “giving in,” starvation
- Reminders
  - food may be nauseating
  - anorexia usually protective
  - risk of aspiration
  - clenched teeth express desires, control
- Help family find alternative ways to care

Decreasing fluid intake . . .

- Oral rehydrating fluids
- Fears (“myths”): dehydration, thirst
- Remind families, caregivers
  - dehydration does not cause distress [myth to be discussed]
  - dehydration may be protective

. . . Decreasing fluid intake

- Parenteral fluids may be harmful
  - fluid overload, breathlessness, cough, secretions, bladder fullness
- Mucosa / conjunctiva care

3) Decreasing blood perfusion

- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Mottling of skin – late [if at all]
- Diminished urine output
- Parenteral fluids will not reverse

4) Neurologic dysfunction…

- Decreasing level of consciousness
  - Progresses from increased sleep to non-responsive
- Communication with the unconscious patient
- Terminal delirium & Two roads to death !
- Changes in respiration
- Loss of ability to swallow, sphincter control

Communication with the unconscious patient . . .

- Distressing to family
- Awareness > ability to respond
- Assume patient hears everything
- Create familiar environment
- Remove all "unnatural" paraphernalia
  - Telemetry, IV, foley?, O2, monitors

. . . Communication with the unconscious patient

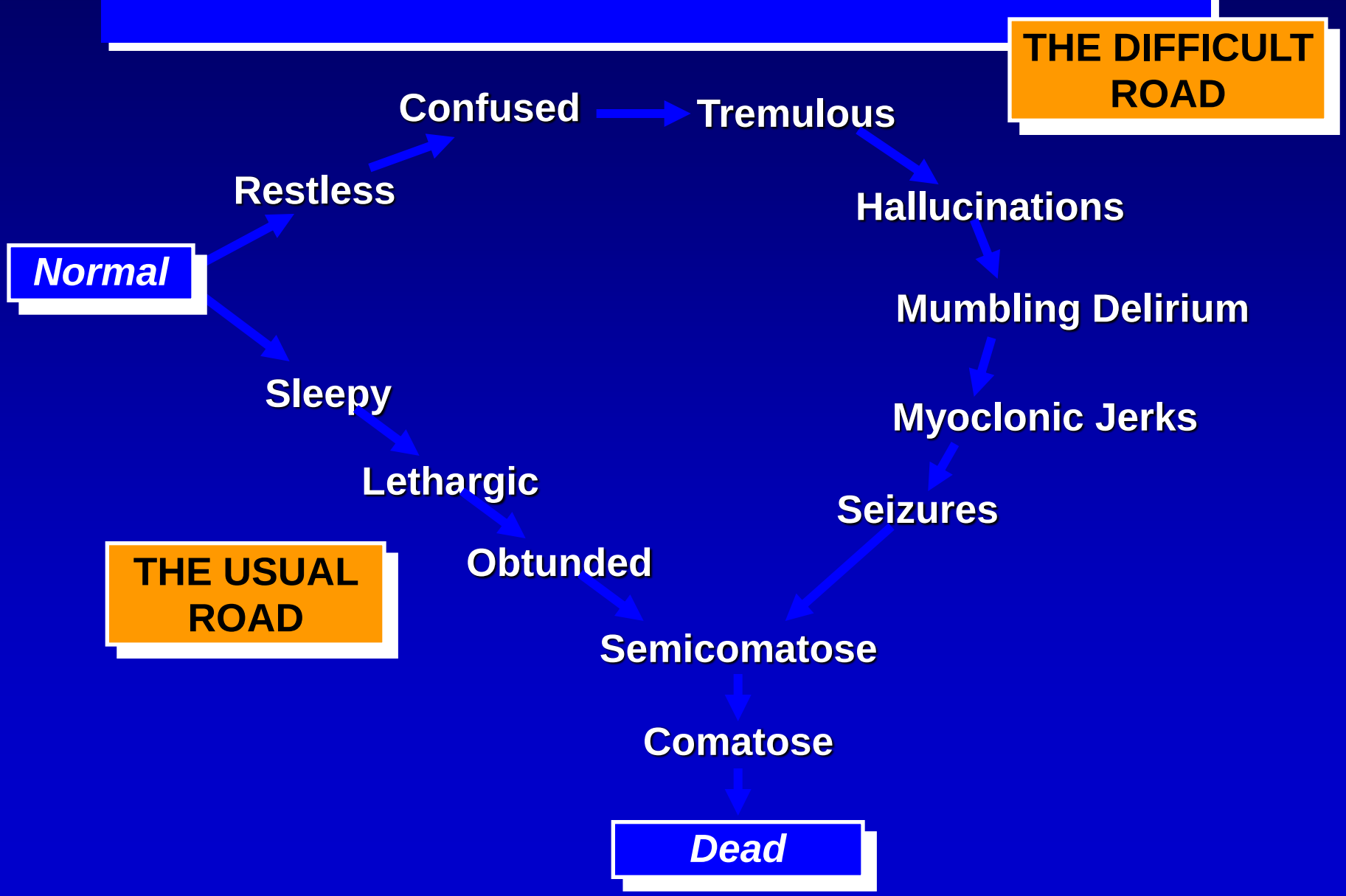
- Include in conversations
  - assure of presence, safety
- Give permission to die
- Touch
- Watch for "Nearing Death Awareness"
  - *Final Gifts [Callahan]*
- Encourage closure [5 statements]

Statements Needed for Closure

- Forgive me.
- I forgive you.
- I love you.
- We'll meet again.
- Goodbye.

- *Ira Byock in "Dying Well"*

2 roads to death



Terminal delirium

- ~85% of palliative care unit deaths!
- Hyperactive/agitated or hypoactive or mixed
- Medical management - Morphine +
  - Neuroleptics
    - haloperidol, chlorpromazine
  - Barbiturates - phenobarb
  - Benzodiazepines
    - Lorazepam [avoided usually], midazolam
- Family needs support, education

Terminal Delirium

Neuroleptics:

- DOC = Haldol [haloperidal] – 1mg q30min subQ until controlled, then 2mg q6h x 24h, then prn [max = 100mg/day]

- Thorazine [chlorpromazine] – 25mg q30min prn until controlled, then 100mg q6h; [max = 2000mg/day] – can do continuous infusion – or supp 100mg

…T. Delirium & Drug Toxicity

- R/O Opioid-Induced Neurotoxicity (OIN)
  - Relatively dehydrated = increase concentration of opiate
  - Abnormal sensitization of pain receptors

[MEDD = Morphine Equivalent Daily Dose]

Opioid-Induced Neurotoxicity

Criteria:

- Increasing pain w/ 2+ dose escalations, prolonged use, in presence of reduced urine
  - Consider when >25mg/hr morphine or MEDD
- delirium [cognitive failure]
- allodynia (normally non-painful movement is painful)
- Hyperalgesia (exaggerated pain response) or hyperesthesia [painful to touch skin]
- Myoclonus & even seizures

OIN Treatment

1. Calm the CNS:

   Ativan – 1-2 mg IV/subq q1h prn

2. Opioid Rotation:

   Stop current opioid or reduce to 25%

   Begin Methadone or other at 25% MEDD

3. Opioid-Sparing Adjuvants – Lidocaine, Ketamine

4. Hydration? – 24hrs of hypodermoclysis 50ml/hr

[Harris JD. Clin J Pain. 2008. De Stoutz, et al. J Pain Sympt.Mgmt. 1995]

Changes in Respiration . . .

- Altered breathing patterns
  - diminishing tidal volume
  - apnea
  - Cheyne-Stokes respirations
    - Not necessarily associated w/ active dying
  - accessory muscle use
  - last reflex breaths - agonal

. . . Changes in respiration

- Fears
  - Suffocation [have crisis plan in place]
- Management
  - family support
  - **oxygen may prolong dying process**
  - breathlessness

Loss of ability to swallow

- Loss of gag reflex
- Buildup of saliva, secretions
  - Scopolamine/glycopyrrolate [0.4mg q4h SQ] to dry secretions
  - postural drainage
    - **Positioning – "position of safety" *****
    - **Trendelenberg**
  - Suctioning (avoid it)

Position of Safety

Loss of sphincter control

- Incontinence of urine, stool
- Family needs knowledge, support
- Cleaning, skin care
- Turn q4h *** (prevent breakdown)
- Urinary catheters – patient/family choice
- Absorbent pads, surfaces

5) Pain . . .

- Fear of increased pain
- Assessment of the unconscious patient
  - persistent vs fleeting expression
  - grimace or physiologic signs
  - incident vs rest pain
  - distinction from terminal delirium
  - groaning/moaning not always ‘pain’

. . . Pain

- Management when no urine output
  - stop routine dosing ?, infusions of morphine?
  - breakthrough dosing as needed (prn)
  - least invasive route of administration
    - SubQ
    - SubLing /buccal

Pain Management: dosing

- Morphine
  - 3-10 mg SQ q4h + 3mg q1h prn pain/dyspnea

  (Po as long as swallowing?)
- Dilaudid [hydromorphone]
  - 1 mg SQ q4h + 0.5mg q1h prn
- Methadone
  - 5mg q8h SQ/**SL** + 2.5mg q3h prn

6) Loss of ability to close eyes

- Loss of retro-orbital fat pad
- Insufficient eyelid length
- Conjunctival exposure
  - increased risk of dryness, pain
  - maintain moisture [Lacrilube, Natural Tears]

Signs that death has occurred . . .

- Absence of heartbeat, respirations
- Pupils fixed
- Color turns to a waxen pallor as blood settles
- Body temperature drops

. . . Signs that death has occurred

- Muscles, sphincters relax
  - release of stool, urine
  - eyes can remain open
  - jaw falls open
  - body fluids may trickle internally

What to do when death occurs

- Who to call – physician
  - Family +, Hospice if involved
- No specific "rules"
- RN "determines" death, calls MD to "pronounce" death
- Organ donation
- Traditions, rites, rituals

After expected death occurs . . .

- Care shifts from patient to family / caregivers
- Different loss for everyone
- Invite those not present to bedside

. . . After expected death occurs

- Take time to witness what has happened
- Create a peaceful, accessible environment
- When rigor mortis sets in
  [15min to few hrs, lasting 24-48hrs]
- Assess acute grief reactions

Moving the body

- Prepare the body
- Choice of funeral service providers
- Wrapping, moving the body
  - family presence
  - Transport w/ flowers on/around ?
  - intolerance of closed body bags !

Other tasks

- Others to notify of the death?
  - stop services [hospice? DME?]
  - arrange to remove equipment / supplies
- Secure valuables with executor
- Dispose of medications, biologic wastes
- Post-death debriefing for STAFF ??
  - Chaplain's role?

2. Patient Preferences. . .

EOL Role of the physician/nurse

- Help the patient and family
  - elucidate their own values
  - decide about life-sustaining treatments
  - dispel misconceptions/myths
- Understand & reemphasize goals of care
  - e.g. goal = not to prolong dying
- Facilitate decisions, reassess regularly

. . . Role of the physician/nurse

- Discuss alternatives
  - including palliative and hospice care
- Document preferences, medical orders
- Involve, inform other team members
  - Have unified approach
- Assure comfort, non-abandonment

Avoiding ‘Abandonment’

“… 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

Preferences - Common concerns . . .

- Legally required to "do everything?"
- Is withdrawal / withholding = euthanasia?
- Are you killing the patient when you treat pain and sedate them?

. . . Common concerns

- Can the treatment of symptoms constitute euthanasia?
- Is the use of substantial doses of opioids euthanasia?
  - There will always be a “last” dose of morphine !!
  - Nurses do not cause death w/ “last” dose

Linking goals of care w/ Treatments

- Re-Establish overall goals of care
- Will artificial feeding, hydration, or other life sustaining tx help achieve these goals?
  - What's considered "life sustaining"?

What's a Life-sustaining treatment?

- Resuscitation
- Elective intubations
- Surgery
- Dialysis
- Blood transfusions, blood products
- Diagnostic tests
- Artificial nutrition, hydration
- Antibiotics
- Other treatments
- Future hospital, ICU admissions

Talking w/ Families: Goals of Care

1) Discuss status of conditions and prognosis
2) Determine goals – comfort v longevity
3) Clarify all the options and talk with family

…Goals & Avoiding Futile Care

4) Ideally, physician recommends <u>one</u> option based on Goals – "if this were my 'mom', I would do everything necessary to keep her comfortable"
5) Formulate a plan, including response to crises

Preferences – Myths of CPR

- What is the success rate of CPR on TV?
  - 67% !! *[Diem. NEJM 1996]*
- What is it in real life?
  - 0-17% ! (for those >70 years of age)
- Is CPR a dignified procedure for elders?
- Why isn't it very successful?

Why CPR is unsuccessful in Seniors

Originally created for middle-aged

- Johns Hopkins - 1959

Srs have no ‘reserve’ to combat a major event.

They often have chronic life-limiting diseases:

- CHF, CKD, ESLD
- Cancers
- Dementias

Life-limiting means no cure!

Preferences - Other EOLC Myths

1) Dehydration is painful
2) We cannot allow someone to starve to death
3) Feeding tubes prevent aspiration

Dehydration & Starvation

- Difficult to discuss
- Food, water are symbols of caring
- ANH [Artificial Nutrition & Hydration]
  - ANH is Not Food ! Is a Medical Treatment !

EOLC ***Realities***

1) Dehydration improves comfort [ketosis & endorphins]
   - Do you want to die a ‘wet death’ or ‘dry death’
2) People do not “starve to death”

   We allow them to die naturally from the disease !
3) PEG’s increase aspiration risk x 4

McCann. Comfort care for terminally ill patients. JAMA. 1994
Christakis. BMJ 2000;320][Benkendorf. Prehosp EmCare 1997
Koretz R,et al. Am J Gastro. 2007

Preferences – Potential Last Resort Options

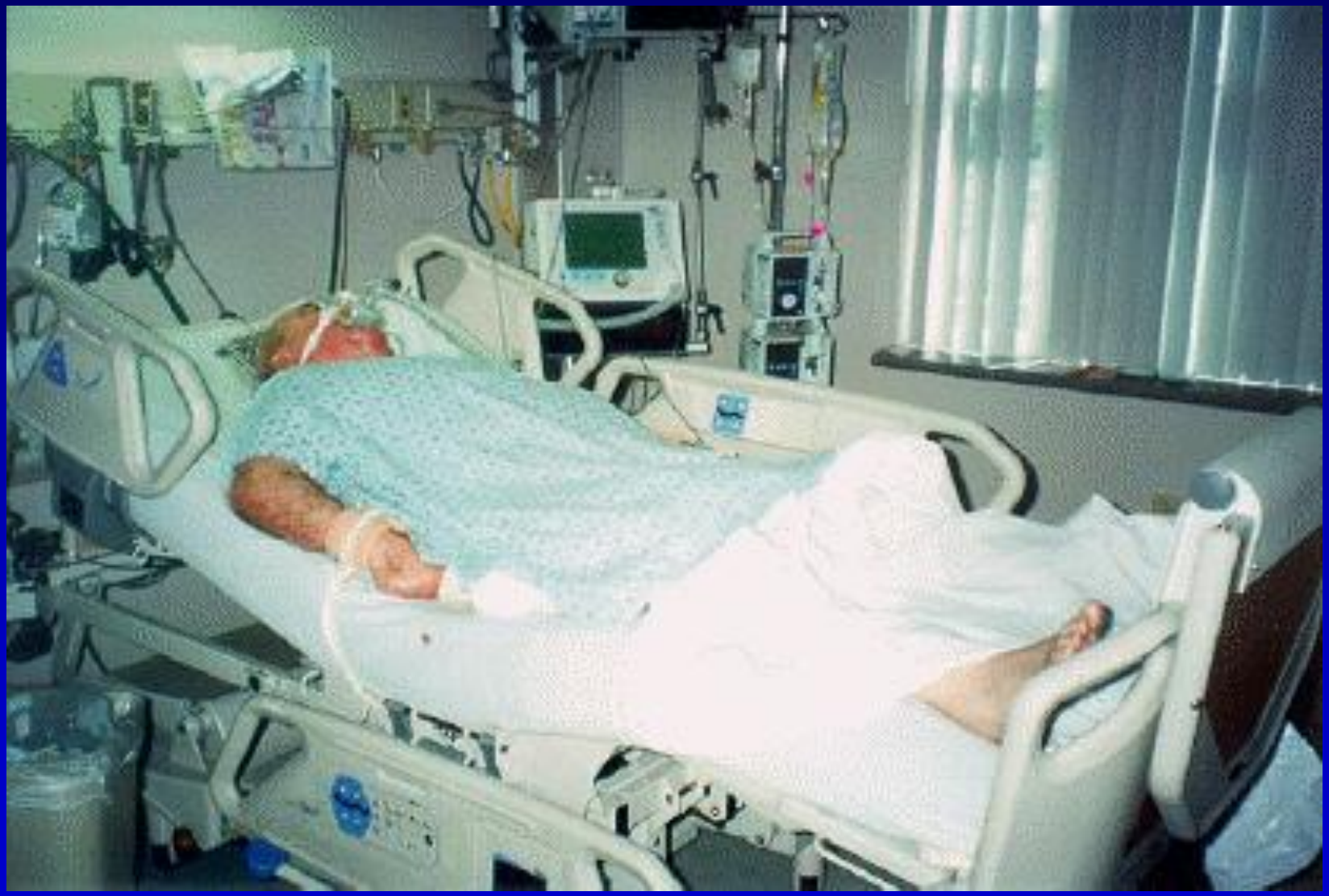
For uncontrolled symptoms:

- Accelerating opioids for pain or dyspnea
- Stopping life-sustaining therapy
- Voluntarily stopping eating and drinking (VSED)
- Palliative sedation
- Physician-assisted death

Preferences – Palliative Sedation

- Symptoms uncontrolled: give enough drug (morphine/ haldol/ phenobarb) to control symptoms or induce unconscious state
  - PPS = Proportionate Palliative Sedation
  - PSU = Palliative Sedation to Unconsciousness
- Principle of double effect and unintended consequences
- Ensure family agreement based on goals

How do you want to live/die?



How do you want to live/die?

How do you want to live/die?

3. 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) Help/support family during dying and bereavement
7) Attend to spiritual needs
8) Enhance communication
9) Support healthcare providers
10) Coordinate services

[Morley, JAMDA, 2011]

What you can do…

- Help patients & families accept death !
  - Decision to stop aggressive treatments is not a decision to end a life – only a ‘stepping aside’ to allow one to finish the journey to death – [to prevent more suffering] we should stop “interfering” in that journey!

Help family with need to give care

- Identify feelings, emotional needs
- Identify other ways to demonstrate caring
  - teach the skills they need
  - Avoid perception of 'abandonment'
- Use educational handouts
  - comfortcarechoices.com [RJ Webb's website]
  - Getpalliativecare.org [CAPC]
  - Hank Dunn's *Hard Choices for Loving People*
  - *END-of-LIFE* - NIA/NIH

Finally:

- "You need to accept that death is part of life, then when it actually does come, you may face it more easily."

  - Dalai Lama – *Advice on Dying*

* Death is not an adverse event when one is dying!!
* "Letting go" is not same as "giving up" !!

Summary & Pearls

- Prepare families for death – early!
- Anticipate crises and prepare for them
- Be knowledgeable and educate families
- Aggressively treat symptoms
  - Watch for opioid neurotoxicity
- Reinforce goals – use appropriate tx
- Develop Pillars of Good EOLC
- Create EOLC protocol/guide [CCC.com]

'OLD' IS WHEN...
An 'all nighter' means not getting up to use the bathroom.

- Maxine

THANK YOU !

Success & Aging

Hope is eternal. 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!