ALMDA Mid-Winter Conference
Birmingham, AL

Preparing & Caring for the Dying

[ELNEC based]

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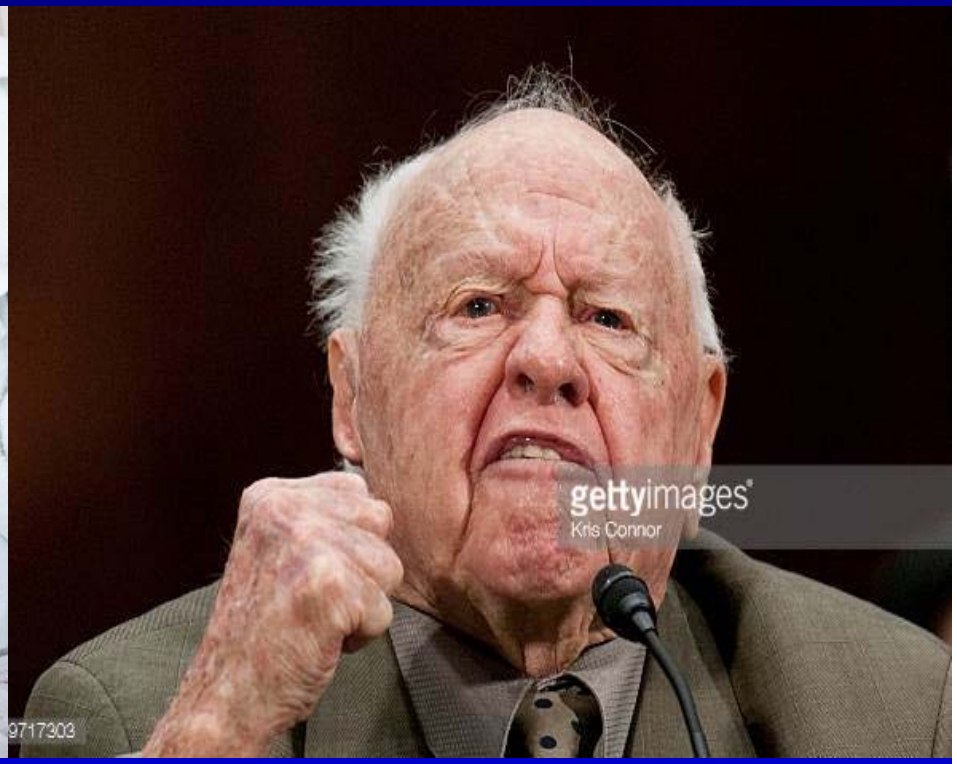
Are they suffering??...

…suffering…

…Give in or fight suffering?



Some don't enjoy living in LTC

Objectives

- Know how to assess and manage the symptoms & pathophysiologic changes of dying, including the common EOLC myths, and how to prevent and relieve suffering.
- Understand the concept of "*Two roads to death*"
- Understand how to communicate with families regarding preferences, including the principle of palliative sedation, as the EOL approaches
- Be aware of what constitutes good EOLC in LTC

Reminder – Evidence-based Care

- Evidence-based medicine means use only those treatments which have been demonstrated to control symptoms and help reach the patient's goal.
  - Corollary: ***First, do no harm!!*** i.e. Don't do those things which have shown no benefit.
- Doctors cannot really 'prevent' death – only delay it while ***prolonging suffering !***

Outline

1. The Last Days: two roads to death
   - Preparing family & staff
   - Physiological processes & Determining death
   - Anticipating problems [avoiding the wrong road]
2. Determining Resident/Family Preferences
   - Expectations and choices *before* the EOL
   - Options of Last Resort – Palliative Sedation
3. Pillars of Good EOLC
4. Summary & Pearls

1. The last days of living

- 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
  - *The Last Hours of Living: Practical Advice for Clinicians* (Medscape Internal Medicine, 2010-02-11)

Things to consider/do [death < 3wks].

- ***Stop everything not for comfort !!!***
  - Limit to essential comfort medications
    - Avoid polypharmacy !!!!
  - ***Deactivate AICD !!! [donut magnet backup – does not effect 'pacer']***
- Least invasive route of administration
  - 1st = buccal/oral mucosal; 2nd = ? rectal
  - **Subcutaneous !!!** intravenous rarely
  - intramuscular almost never

As expected death approaches . . .

- Discuss [prepare family for what's coming]
  - status of patient, realistic care goals
  - Funeral planning?
- What patient experiences ≠ what we see
  - Reinforce signs & events of dying process
- Provide information packet early
  - e.g. *Caring for the Dying*
  - *Hard Choices for Loving People* - Dunn
  - *Gone from my Sight* [the 'Blue Book']

Preparing for last days/*hours*

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

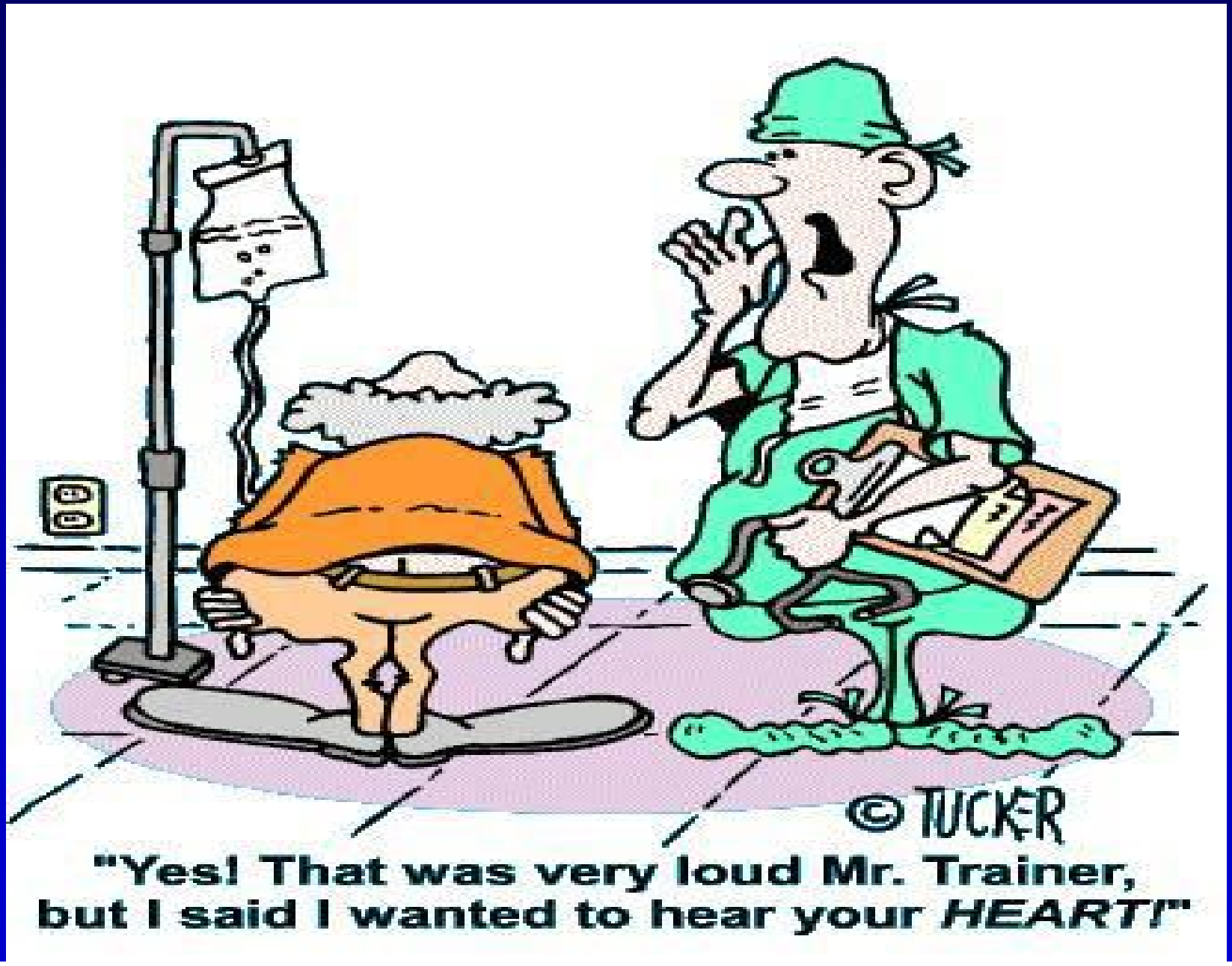
. . . Preparing for the last hours

- Caregivers/staff
  - Be aware of patient choices [e.g.]
  - Be knowledgeable, skilled, confident
  - Ensure rapid response – comfort crisis pack
    - E.g. acute dyspnea, *bleeding*, delirium
    - "what could go wrong" preparations

. . . Additional Things

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

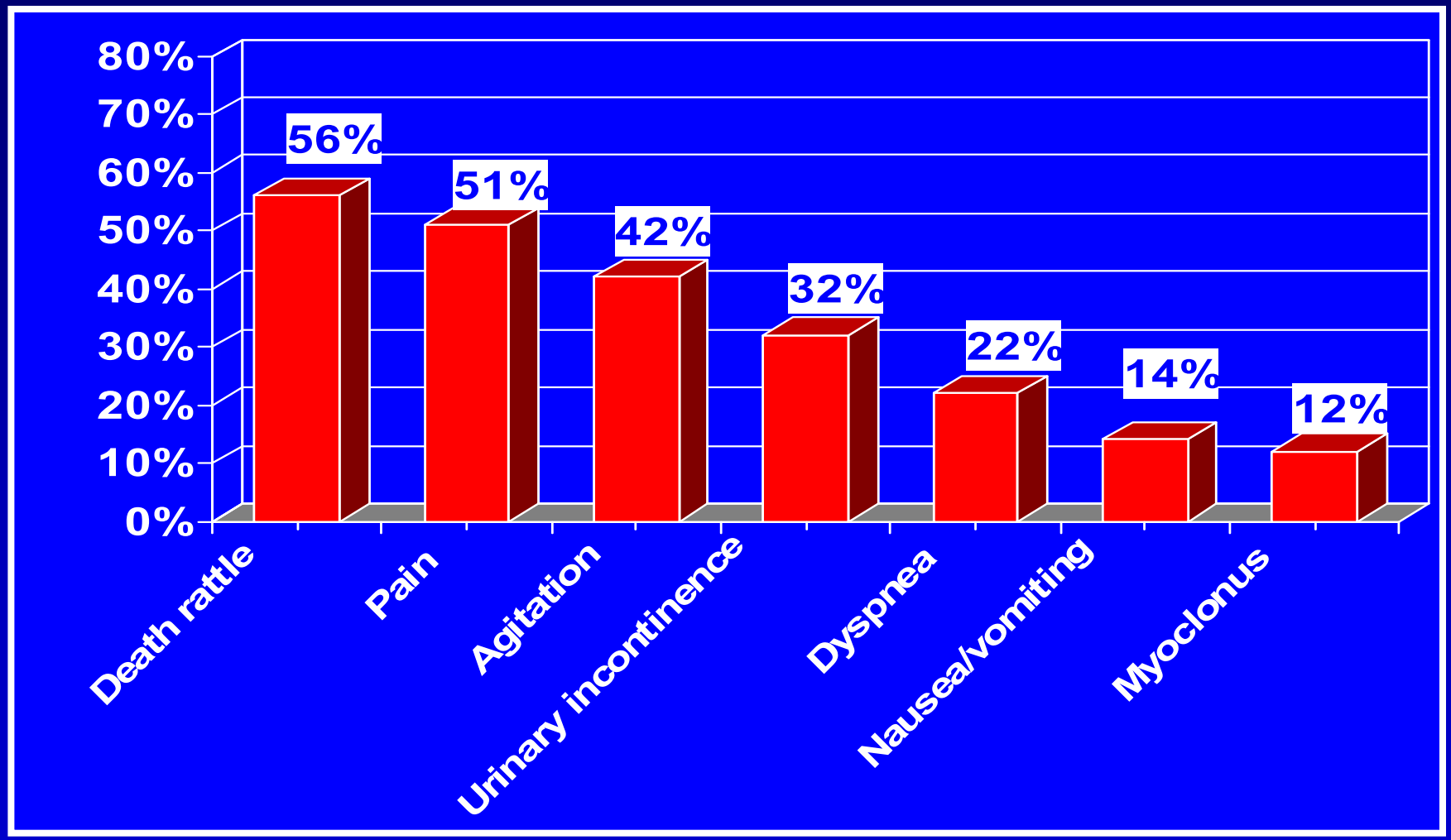
Avoid misunderstandings !



(Educating staff & families) Physiologic changes **prior to & during** the normal dying process

1) Increasing weakness, fatigue
2) Decreasing appetite / fluid intake
3) Decreasing blood perfusion
4) Neurologic dysfunction
   - Decreased LOC and neurotoxicities
5) **Pain – *e.g. hyperesthesia***
6) Loss of ability to close eyes

Frequency of Symptoms in Last 48 Hours



Harlos, 2010; Lunney et al., 2002

1) Weakness / fatigue

- Progressive & all patients have it !!
- Decreased ability to move
- Joint position fatigue
- Increased risk of pressure ulcers
- Increasing need for care in preceding months
  - activities of daily living
  - turning, movement, massage

2) Decreasing appetite / food intake

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

Decreasing fluid intake . . .

- Remind families (re "myths"):
  - Dehydration not distressing – actually 'protective'
- Parenteral fluids usually harmful *
  - breathlessness, cough, secretions, bladder fullness
  - Convert peaceful 'dry' death into miserable 'wet' death [*the road less desired*]
- Mucosa / conjunctiva care
  - Lip balm, mouth sponges [?favorite drink]

* *Bruera E, et al. J.Clin Oncology 2012*

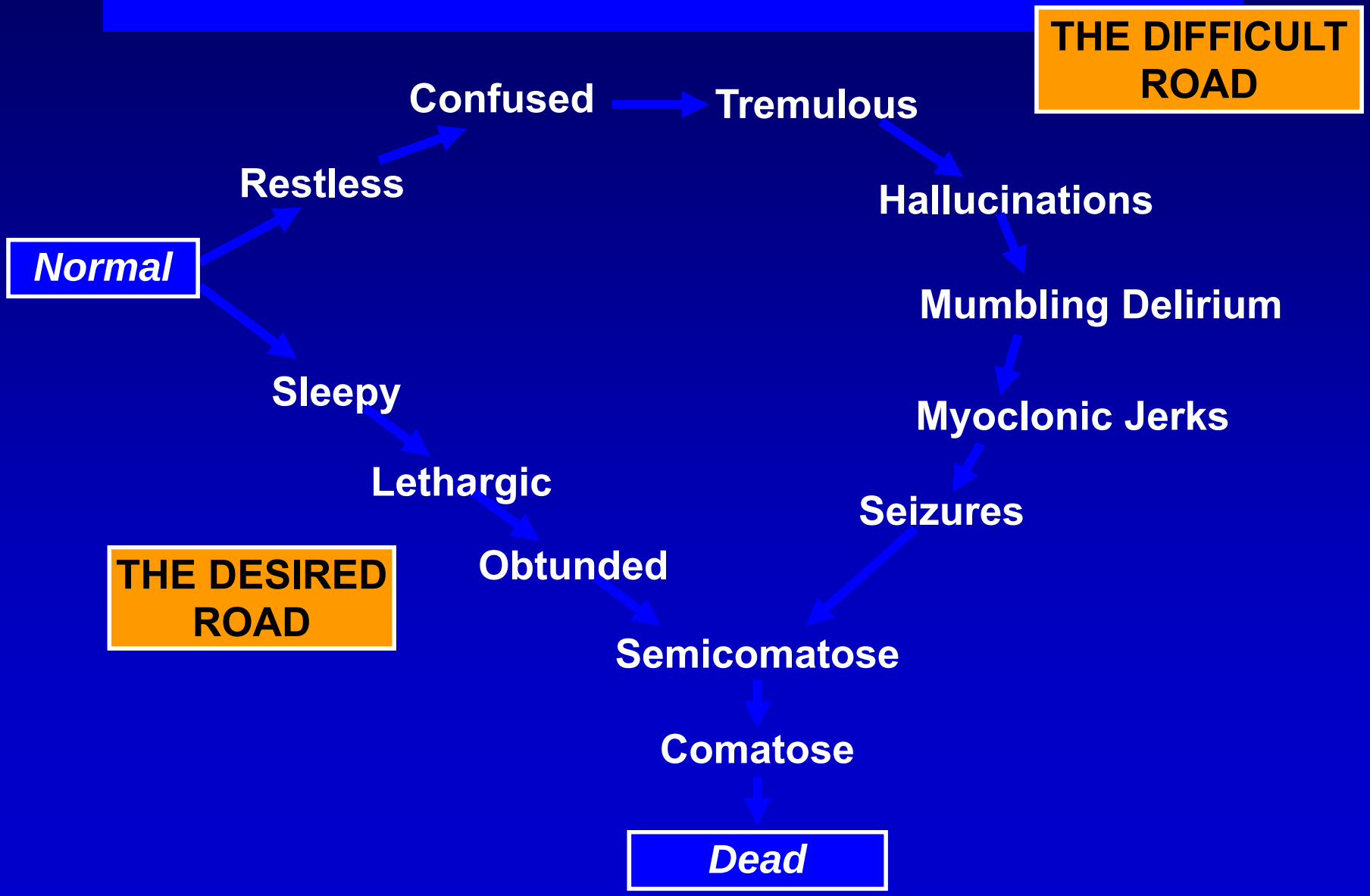
3) Decreasing blood perfusion

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

4) Neurologic dysfunctions…

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

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] – 0.5mg q30min subQ until controlled; ? then 2mg q6h plus prn [max = 100mg/day]

- Thorazine [chlorpromazine] – 25mg q30min prn until controlled, then 100mg q6h; [max = 2000mg/day] – can do continuous IV infusion – or IM or supp 100mg [not subQ]

…T. Delirium & Drug Toxicity

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

Opioid-Induced Neurotoxicity…

Criteria:

- Increasing pain w/ 2+ dose escalations, prolonged use, in presence of reduced urine
  - Especially if >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 [Morphine Equivalent Daily Dose]

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]

Communicating with unconscious patient

- Unconsciousness = distressing to family
- Assume patient hears everything
  - Awareness > ability to respond
  - Include in conversations
- Remove "unnatural" paraphernalia – O2
- Watch for "Nearing Death Awareness"
  - *Final Gifts*. Callanan 1992
- Give permission to die … closure…

Statements Needed for Closure

- *Forgive me. **
- *I forgive you. **
- *I love you. **
- *We'll meet again. **
- *Goodbye.*
- *We'll be ok!*

**Ira Byock in "Dying Well"*

[Neurologic] Changes in respiration . . .

- Stop O2? – often irritating [shorten prongs]
  - **may prolong dying process**
    - **Base decision on observed dyspnea, not SaO2**
  - Suffocation sense?
- Altered breathing patterns
  - Apnea & agonal breaths & last reflex breaths
  - Cheyne-Stokes respirations
    - Not always associated w/ active dying

Loss of ability to swallow

- Loss of gag reflex
- Buildup of saliva, secretions
  - Scopolamine/glycopyrrolate/atropine drops - dry secretions
  - postural drainage
    - **Positioning – "position of safety" *** !!**
    - **Trendelenberg !!!!!**
  - Suctioning (generally avoid it)

Position of Safety

Loss of sphincter control

- Incontinence of urine, stool
- Cleaning, skin care - daily
- Turn q4h *** (prevent breakdown)
  - Document when family refuse !
- Urinary catheters, absorbent pads, surfaces

5) Pain . . .

- Fear of increased pain
- Anticipating EOL – Rx inj. Morphine
- 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: dosing

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

  (Po as long as swallowing?)

  - Decrease dose ? as dehydration evolves
- 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 (from dehydration)

= Conjunctival exposure

  - increased risk of dryness, pain
  - maintain moisture [Lacrilube, Natural Tears]

DEATH: Signs . . .

- Absence of heartbeat, respirations, pupils
- *Color waxen pallor* as blood settles [livor mortis]
- Body temperature drops [algor mortis]
- Muscles, sphincters relax [initial flaccidity]
  - release of stool, urine; trickling fluids internal
  - eyes stay open; jaw falls open
- Rigor mortis concerns? [onset 0-8hrs]

What to do when death occurs

- Notify: MD, PMD, funeral home; hospice? sitters?; DME?
- RN "determines" death, calls MD to "pronounce" death
- Body preparation; Organ donation ?
- Traditions, rituals; who takes valuables?
- Care shifts to family / caregivers

2. Expectations & Preferences

Role of doctors/nurses/all staff

- Help the patient and family [before EOL]
  - clarify values & dispel misconceptions
  - decide about life-sustaining treatments
- Understand & reemphasize goals of care
  - e.g. goal = not prolong dying; relieve & prevent suffering !! [*Goal of Medicine*]
- Facilitate decisions, reassess regularly
  - ***Adjust drugs prn when family perceives inadequate control !!***

. . . Expectations/Preferences

- Discuss alternatives
  - including palliative and hospice care
- Document preferences, medical orders
- All staff informed
  - 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

Common concerns

- Legally required to "do everything?"
- Is withdrawal / withholding artificial fluids or nutrition = euthanasia?
- Does *turning* patient trigger death?
- Is the use of opioids euthanasia?
  - always be a "last" dose of morphine !!
  - Important to *adjust* morphine !!!!!!
  - Nurses do not cause death w/ "last" dose

Linking goals of care w/ Treatments

- Confirm overall goal: prevent suffering
  - Gwande's ***Being Mortal***
  - ***What is Suffering? How do we prolong it?***
- Will artificial interventions help achieve these goals?
  - What's considered "life sustaining"?...

What intervention is a Life-sustaining treatment?

- Resuscitation
- Elective intubations
- Surgery
- Dialysis
- Blood transfusions, blood products
- Opioids ?
- Diagnostic tests
- Artificial nutrition, hydration
- Antibiotics
- Cancer screening * *[This test will not help you live longer]*
- Future hospital, ICU admissions
- Pacer/AICD

Talking w/ Families: Goals of Care

1) Discuss status of conditions and prognosis
2) *Determine goals – comfort v longevity*
   - *Relieve/prevent suffering*
3) Clarify all options with family
4) Recommend one 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

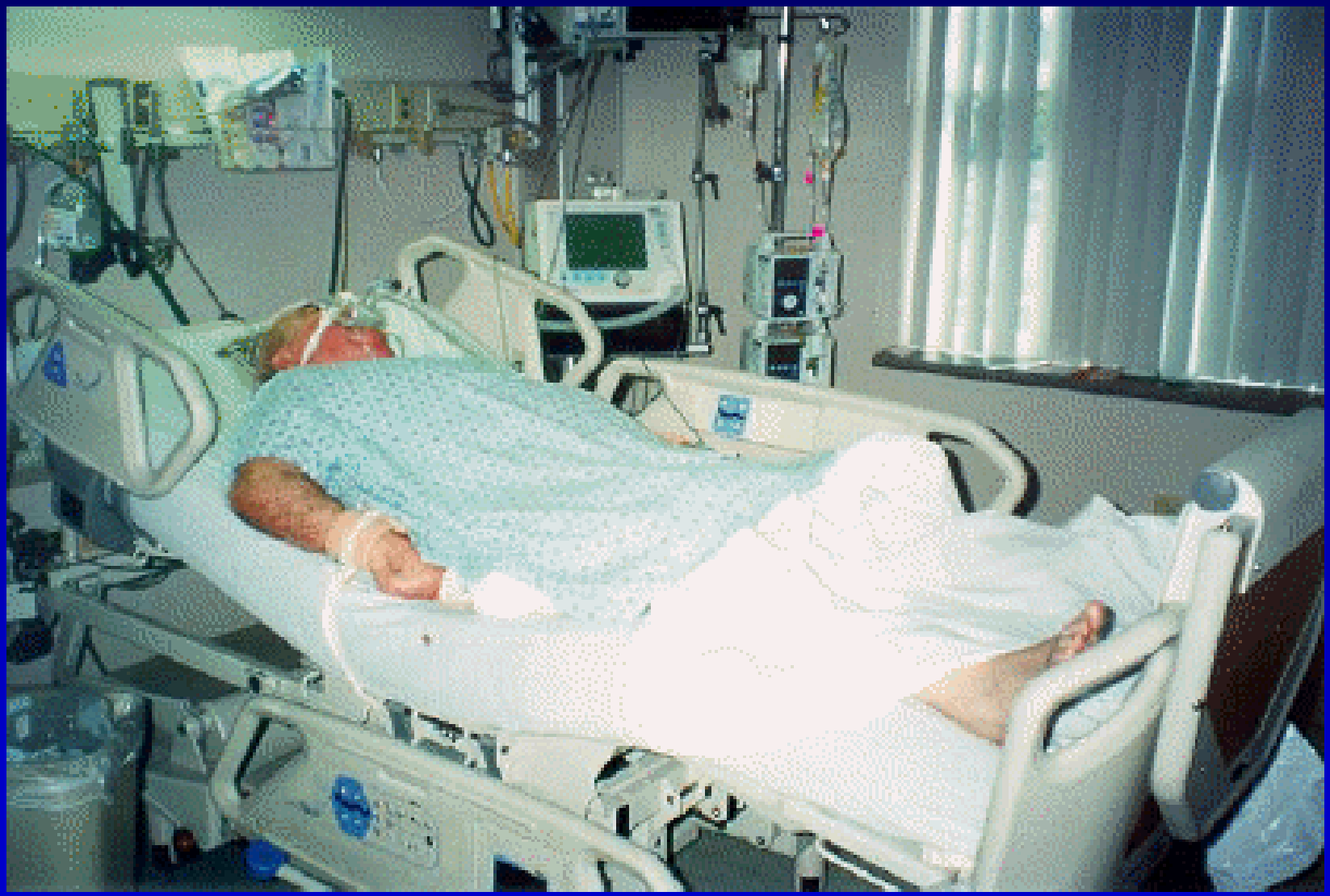
For uncontrolled symptoms:

- Accelerating opioids for pain or dyspnea
  - Anticipating EOLC – Rx inj.MS
- Stopping life-sustaining therapy
- Voluntarily stopping eating and drinking (VSED)
- Palliative sedation
- Physician-assisted death [now in 7 States, all Canada, Japan, several European countries]

Preferences – Palliative Sedation

- Symptoms uncontrolled: use morphine, haldol, phenobarb (130mg subQ, q4h) 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?

3. Pillars of good EOLC in NH

1) Allowing resident/family sense of control
2) Reduce burden of dying *[& prevent suffering*]*
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 *[and other staff!]* accept death when appropriate!
  - 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 – we should stop "interfering" in that journey!

[the memory of <u>how</u> they died will last forever !!!!]

…Help family to give care

- Identify feelings, emotional needs
- Identify other ways to demonstrate caring
  - teach the skills they need
  - Avoid perception of 'abandonment'
- Use education:
  - comfortcarechoices.com [RJ Webb's website]
  - *Being Mortal* – Atul Gwande *****
  - Hank Dunn's *Hard Choices for Loving People*
  - *END-of-LIFE* - NIA/NIH

Core Qualities of Peaceful Death

1. A peaceful mind
2. *Not to suffer*
3. Being with others and not alone
4. Family acceptance of patient's death

Masel EK, et al. Life is uncertain. Death is certain. Buddhism and PC. J pain symptom manage.2012

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 !