EOLC [EPEC/G–ELNEC] Staff Education

[End-of-Life Nursing Education Consortium - Geriatrics]

Eliza Coffee Memorial Hospital

V. Preparing & Caring for Death

Robert J. Webb, MD Medical Director

Palliative Care Service & OASIS

June 10, 2015

Objectives

- Know how to assess and manage the pathophysiologic changes of dying, including “positioning”, “paraphernalia”, and the common EOLC myths
- Know how to determine death
- Understand the concept of “Two roads to death”
- Understand the principle of palliative sedation
- Know what’s involved in withdrawing life support

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: Don't do those things which have shown no benefit.
- Doctors cannot really 'prevent' death – only delay it by prolonging suffering

1. <u>**The final few days**</u>

- 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)

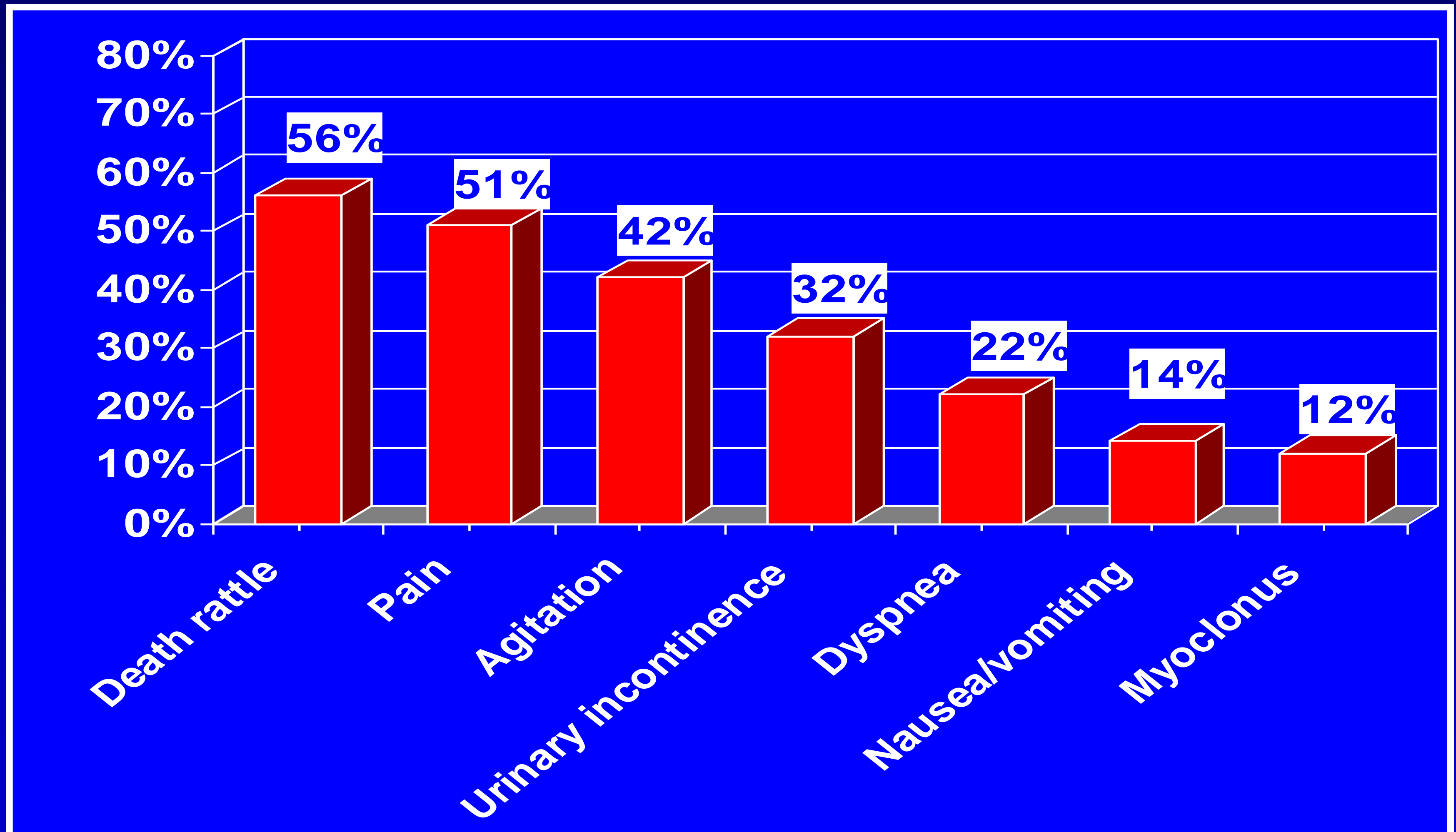
Preparing for the final days

- Time course ‘unpredictable’
- Any setting that permits privacy, intimacy
- Anticipate need for medications, equipment, supplies
- Regularly review the plan of care
- Move from patient-centered to family-centered care

. . . Preparing for the final days

- Caregivers & staff
  - awareness of patient choices
  - knowledgeable, skilled, confident
  - rapid response – comfort crisis pack
  - “what could go wrong” preparations
- Common events, signs, symptoms of the dying process

Frequency of Symptoms in Last 48 Hours



Harlos, 2010; Lunney et al., 2002

Physiologic changes during the normal dying process

1) Increasing weakness, fatigue
2) Decreasing appetite / fluid intake
3) Decreasing blood perfusion
4) Neurologic dysfunction
   - Decreased LOC
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 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 . . .

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

. . . Decreasing fluid intake

- Parenteral fluids usually harmful *
  - fluid overload, breathlessness, cough, secretions, bladder fullness
  - Convert more peaceful ‘dry’ death into miserable ‘wet’ death
- Mucosa / conjunctiva care
  - Lip balm, mouth sponges [?favorite drink]

** Bruera. Parenteral hydration…. J.Clin.Oncol.2012.*

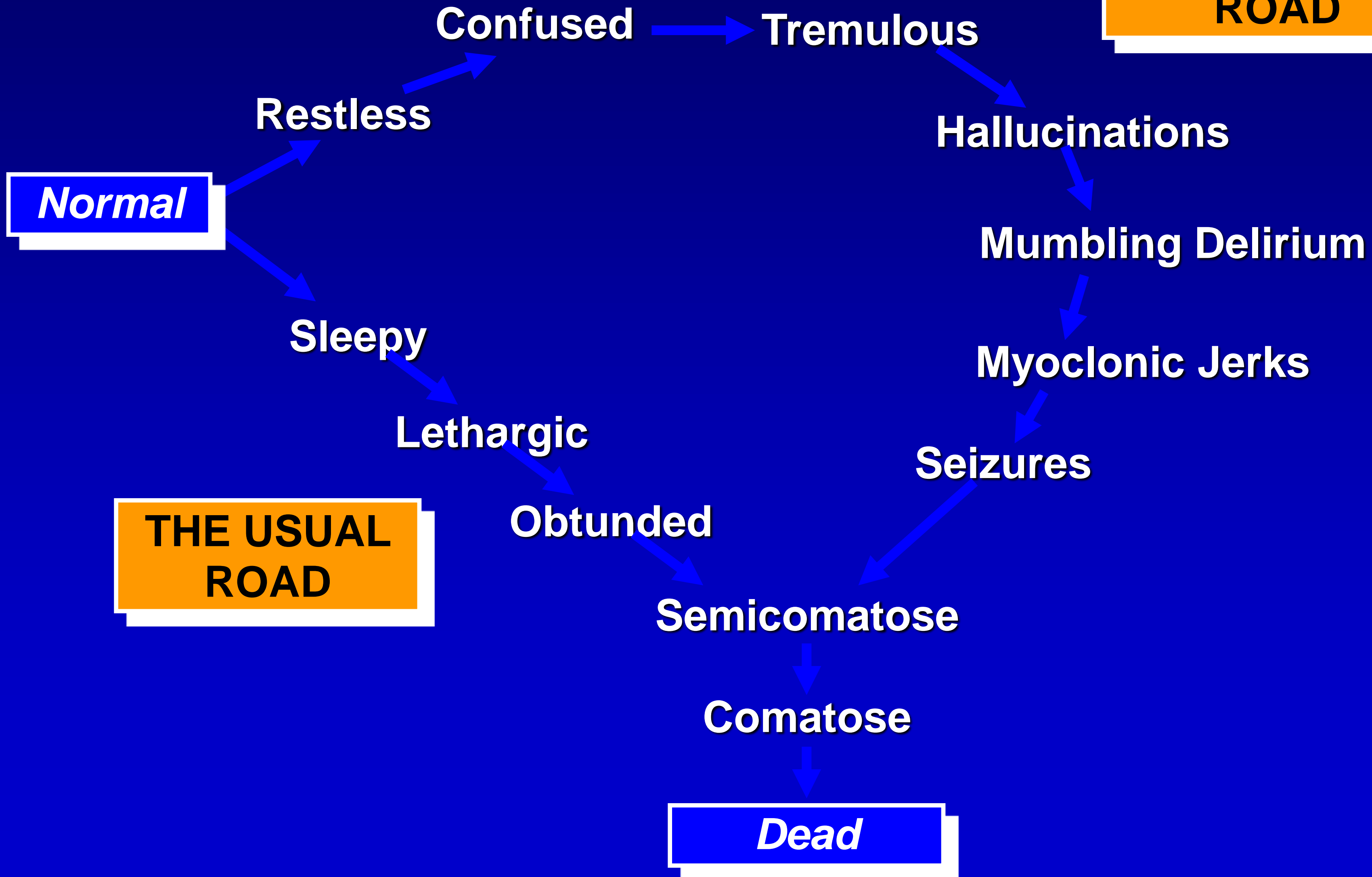
3) Decreasing blood perfusion

- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Mottling of skin
- Diminished urine output
- Parenteral fluids will not reverse

4) Neurologic dysfunction…

- Decreasing level of consciousness
- Communication with the unconscious patient
- Terminal delirium
- Changes in respiration
- Loss of ability to swallow, sphincter control

2 roads to death



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, SCD

. . . Communication with the unconscious patient

- Include in conversations
  - assure of presence, safety
- Give permission to die
- Touch
- Watch for “Nearing Death Awareness”
- Encourage closure

Statements Needed for Closure

- Forgive me.
- I forgive you.
- I love you.
- We’ll be ok.
- We’ll meet again.
- Goodbye.

- *Ira Byock in “Dying Well”*

Terminal delirium

- ~85% of palliative care deaths!
- Hyperactive/agitated or hypoactive or mixed
- Medical management [= PSU] - M.S. +
  - Neuroleptics
    - haloperidol, chlorpromazine
  - Barbiturates - phenobarb
  - Benzodiazepines
    - Lorazepam [Ativan], midazolam [Versed]
- Family needs support, education

Terminal Delirium

Neuroleptics:

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

- Thorazine [chlorpromazine] – 25-50mg q30min prn until controlled, then 100mg q6h; [max = 2000mg/day] – caution re subQ necrosis, so IV preferred (unless close to death)

…T. Delirium & Drug Toxicity

- R/O Opioid-Induced Neurotoxicity (OIN)
  - Relatively dehydrated = increase concentration
  - Abnormal sensitization of pain receptors
  - May need to rotate opioids and will need to know MEDD -- Morphine Equivalent Daily Dose

Opioid-Induced Neurotoxicity

- History/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 stimulus is painful)
  - Hyperalgesia (exaggerated pain response)
  - Myoclonus + ‘jitters’ & 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 & agonal breaths
  - Cheyne-Stokes respirations
    - Not necessarily associated w/ active dying
  - accessory muscle use
  - last reflex breaths

. . . Changes in respiration

- Fears
  - suffocation
- Management
  - family support
  - **oxygen may prolong dying process**
  - Irritates nasal-pharyngeal
  - breathlessness

Loss of ability to swallow

- Loss of gag reflex
- Buildup of saliva, secretions
  - Scopolamine/glycopyrrolate to dry secretions
  - postural drainage
    - **Positioning – "position of safety" *** !!**
    - **Trendelenberg !!!!!**
  - Suctioning (<u>avoid</u> 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
- 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

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

As expected death approaches . . Medications

- Limit to essential medications
  - ***Stop everything not for comfort !!!***
  - ***Deactivate AICD !!! [donut magnet backup – does not effect 'pacer']***
- Choose less invasive route of administration
  - buccal mucosal or oral first, then consider rectal
  - **Subcutaneous !!!** intravenous rarely
  - intramuscular almost never

As expected death approaches . . .

- Discuss
  - status of patient, realistic care goals
  - role of physician, interdisciplinary team
- What patient experiences ≠ what onlookers see
- Provide information packet early
  - e.g. Caring for the Dying
  - Gone from my Sight [the ‘Blue Book’]

. . . As expected death approaches

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

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

- [Don’t call 911 or coroner]
- Who to call – PMD & consultants
  - Family +, Hospice if involved
- No specific “rules”
- RN “determines” death, calls MD to “pronounce” death [for PC pts only]
- 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
- 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

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

2. Patient Choice & Role of the physician/nurse . . .

- Help the patient and family
  - elucidate their own values
  - decide about life-sustaining treatments
  - dispel misconceptions
- Understand & reemphasize goals of care
  - e.g. goal = not to prolong dying
- Facilitate decisions, reassess regularly
  - ***Adjust drugs prn when family perceives inadequate control !!***

. . . 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

Common concerns . . .

- Legally required to "do everything?"
- Is withdrawal / withholding = euthanasia?
- Are you killing the patient when you remove a ventilator or treat pain?
- Does *turning* patient trigger death?

. . . 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 !!
  - Important to titrate 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
- Opioids
- Diagnostic tests
- Artificial nutrition, hydration
- Antibiotics
- Other treatments
- Future hospital, ICU admissions
- Pacer/AICD

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?

EOLC Myths

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

Preferences - Stopping Artificial feeding, hydration

- Difficult to discuss
- Food, water are symbols of caring
- Myths of starvation & dehydration
- Address misperceptions
- ANH [Artificial Nutrition & Hydration]
  - ANH is Not Food ! It 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

1. Accelerating opioids for pain or dyspnea
2. Stopping life-sustaining therapy
3. Voluntarily stopping eating and drinking
4. Palliative sedation
5. 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

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’ [W.Berry]
- Educational handouts

  [www.comfortcarechoices.com]

  [Getpalliativecare.org]

  Hank Dunn’s *Hard Choices for Loving People*

  END-of-LIFE - NIA/NIH

3. Ventilator withdrawal

- Rare, challenging
- Ask for assistance
- Assess appropriateness of request
- Role in achieving overall goals of care
- FOLLOW Protocol

Option 1: Immediate extubation

- Remove the endotracheal tube after appropriate suctioning & <u>sedation</u>
- Give humidified air or oxygen to prevent the airway from drying
- Ethically sound practice
- Usually for someone in PVS/brain dead

Option 2: Terminal weaning

- Rate, PEEP, O2 levels are decreased first
- Over 30–60 minutes or longer
- A Briggs T piece may be used in place of the ventilator
- Patients may then be extubated
- Usually for someone w/ consciousness – but, ensure ‘sedated’ & comfortable !

Prepare the family . . .

- Describe the procedure
- Reassure that comfort is a primary concern
- Medication is available
- Patient may need to sleep to be comfortable
- Involuntary movements
- Provide love and support
- Describe uncertainty !!!

Ensure patient comfort

- Anticipate and prevent discomfort
- Have anxiolytics, opioids immediately available
- Titrate rapidly to comfort
- Be present to assess, reevaluate
- Follow the protocol / order set

Prior to withdrawal

- Prior to procedure
  - discussion and agreement to discontinue
    - with patient (if conscious)
    - with family, nurses, respiratory therapists
    - Give family option of being present
  - document on the patient's chart

. . . Withdrawal protocol–

- After the patient dies
  - talk with family and staff
  - provide acute grief support
- Offer bereavement support to family members
  - follow up to ensure they are okay

Final Thoughts: Dalai Lama – Advice on Dying

- "It is crucial to be mindful of death—to contemplate that you will not remain long in this life. Analysis of death is not for the sake of becoming fearful but to appreciate this precious lifetime during which you can perform many important practices."

Dalai Lama – Advice on Dying

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

[Death is not an adverse event when one is dying!!]

Giving Up & Letting Go

- Giving up implies a struggle – Letting go implies a partnership
- Giving up dreads the future – Letting go looks forward to the future
- Giving up lives out of fear – Letting go lives out of grace and trust

Giving Up & Letting Go cont'd

- Giving up is unwillingly yielding control to forces beyond myself – Letting go is choosing to yield to forces beyond myself
- Giving up believes that God is to be feared – Letting go trusts in God to care for me.

Hank Dunn: *Hard Choices for Loving People*

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

What you can do…

- Help patients & families & doctors 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 how they died will last forever !!!!]

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!

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

- Maxine

THANK YOU !