Palliative Care:
Goals of Care, Advanced Care Planning & Symptom Management

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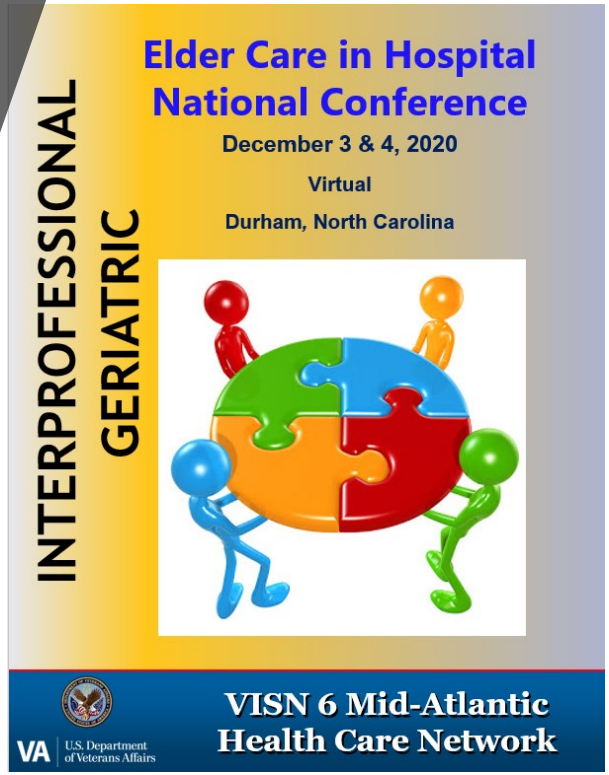


Objectives

Describe:

- Palliative Care vs. Hospice Care
- Resources provided through the Durham VAHCS
- Goals of Care Conversations
- Nursing Care for the dying patient

Current Trends in Acute Care

- 1.7 million deaths of chronic illness
- 70% admitted to the hospital during the last 6 months of life
- 60% of all deaths occur in hospital; 18% in ICU
- 50% of terminally ill die with undertreated pain

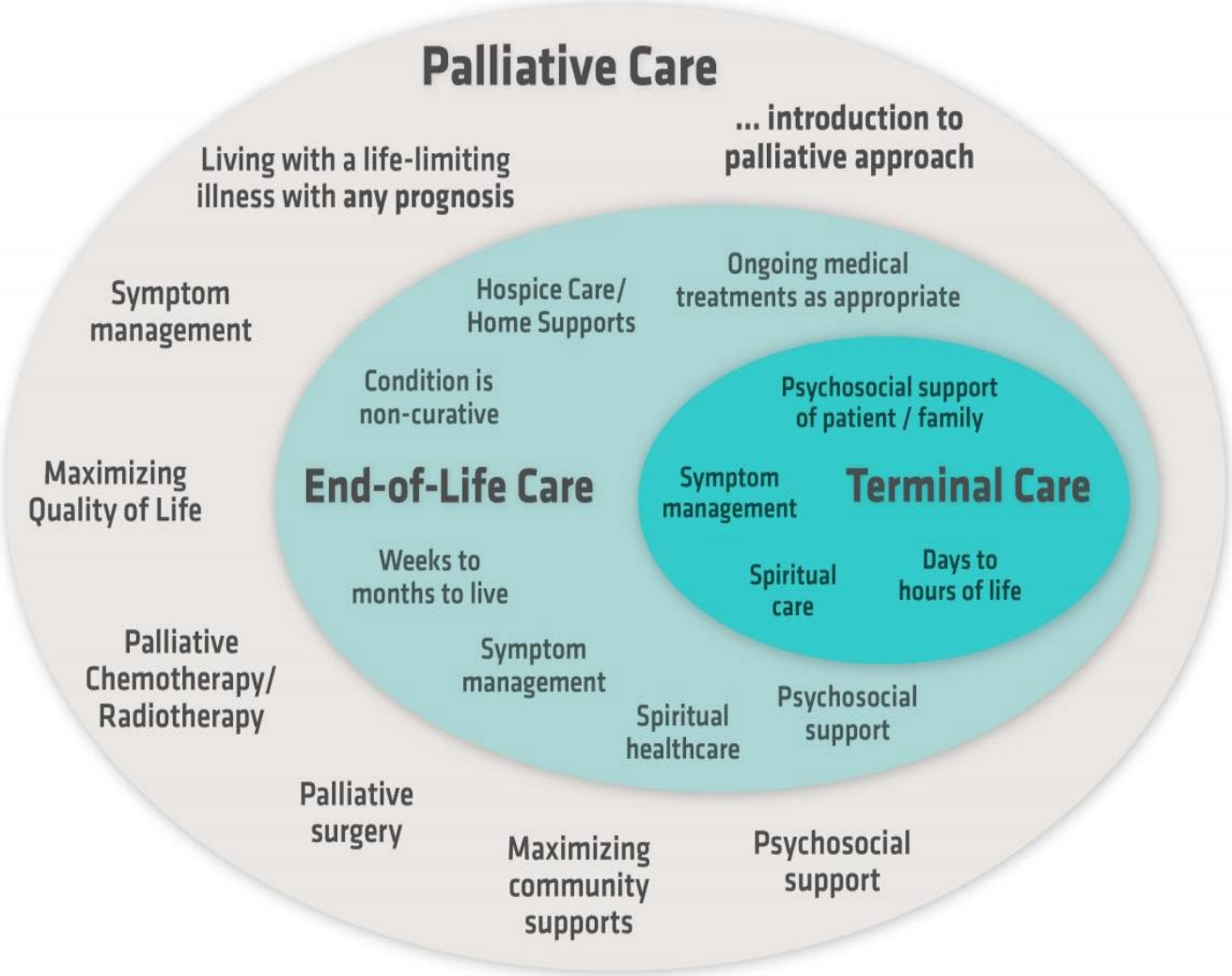
CDC National Center for Health Statisitcs cdc.gov/nchs/fastasts/deaths.htm

Facts: Veterans Deaths

- More than 50,000 Veterans die each month (600,000/year).
- Veteran deaths account for almost 28% of all deaths in the U.S.
- Only 4% die in a VA facility

http:National Hospice & Palliative Care.Org. (2010), retrieved 1/21/14.

The phases and layers of care



Palliative Care Services: Benefits for Patients and Hospitals

- Increases patient/family satisfaction
- Increases support for staff
- Decreases Length of Stay (LOS)
- Cost Savings
- Decreases readmission rates

The National Consensus Project for Quality Palliative Care Clinical Practice Guid for Quality Palliative Care 3rd edition 2013

Differences in Hospice & Palliative Care

	Palliative Care: Newer specialty	Hospice Care: Well Established
Goal:	• Prevent/ relieve suffering & improve QOL for chronic illnesses/ life threatening illnesses	• Provide comfort & manage symptoms during the End of Life • Death is inevitable outcome
Patient Population:	• Follows those with complicated or advanced medical disease • No life expectancy requirement • Can be receiving concurrent therapies	• Accepts those near the "end of life" • Medical prognosis of 6 months or less if the disease runs its normal course

http://www.nextstepincare.org: Retrieved 1/16/16

Differences in Hospice & Palliative Care

	Palliative Care:	Hospice Care:
Who Provides the Care:	• Doctors & Nurses with specialized training • Multidisciplinary	• Doctors & Nurses with specialized training • Multidisciplinary
Payer for Services:	• No special insurance benefit-health insurance usually covers services	• Medicare • Some state Medicaid plans & private health insurance plans

- **All Hospice patients receive palliative care.**
- **Not all Palliative Care patients are eligible for Hospice.**
- **Palliative Care provides education about Hospice so that patients & families have a better understanding of Hospice services when they are eligible.**

http://www.nextstepincare.org: Retrieved 1/16/16

Hospice & Palliative Care at the DVAHCS

- 10 Bed Inpatient hospice unit (Total: +140 admissions FY19)
- Consultation service: Inpatient and Outpatient
- Inpatient consults in hospital, ICU's, CLC, ED
- Outpatient clinic three ½ day/week
- Telehealth Clinic at Greenville HCC

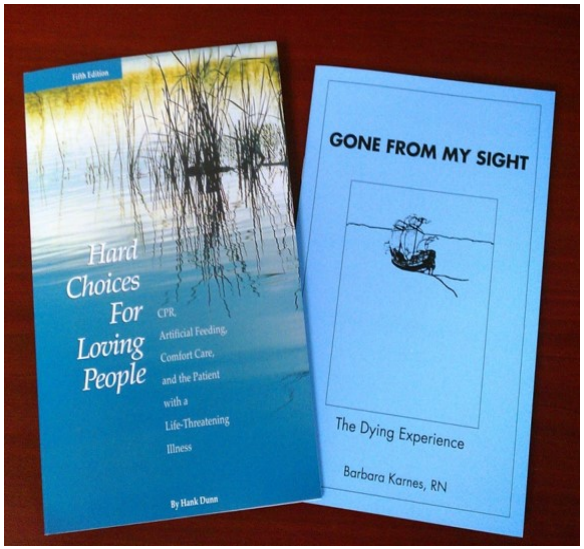
- Referrals: oncology, pulmonary, renal, liver, radiation oncology services and primary care
- VA funds one position of Duke affiliated Palliative Medicine fellowship

Resources for Families & Patients

- **Hard Choices For Loving People**
  (Author: Chaplain Hank Dunn)
  -provides guidance with medical care treatment decisions in laymen's terms

- **Gone From Sight: The Dying Experience**
  (Author: Barbara Karnes RN)

- The hospice unit can answer questions, please use us as a resource x 172840 for the nurses' station, x 177836 for Michaelene Moore, NP M-F 7-4



Durham Palliative Care Medicine Service/Hospice purchase and provide theses books to families and staff. If you are caring for a dying patient & feel the family may benefit call Michaelene Moore extension: 177836.

Goals of Care Conversations

- **Provider(s), Patient and Family Verbal Discussions**
- **Goals of Care Discussions Focus On:**
  - -Cure and aggressive treatment
  - -Stabilization of functioning
  - -Preparing for a comfortable and dignified death
- Goals may change as the patient's condition changes
- Readdressing goals may be an ongoing and fluid process

Goals of Care Conversations

Benefits of Discussing:

- Associated with better QOL
- Reduces anxiety & increases care satisfaction
- Reduced use of Life Sustaining Treatment near death
- Earlier Hospice referrals
- Care is consistent with Patient Preferences
- Cost savings for hospital and patient
- Improved bereavement outcomes for family members after death

Bernacki,R.E, & Block, S. (2014).Communication about serious illness care goals. JAMA Int. Med. 174(12); Izumi,S. & Van Son, C.(2016). "I didn't know he was dying." Missed opportunities for making EOL care decisions for older family members Journal Hospice Pall Med, 18(1).

Goals of Care Conversations: When & Who

Triggers

- Life-limiting illness
- Multiple Comorbidities
- Patients 80 or older-big trigger
- Change or deterioration in status
- Multiple hospital admissions
- **You say "No" to the following question:** Would I be surprised if this patient died in a year?
- CAN score

Mullick, A , Martin ,J & Sallnow, L. (2013) Advance Care Planning. BMJ, 347; Boyd, K et.al. (2010) Advance care planning for cancer patients in primary care. BJGP, 303(3). Bernacki , RE,& Block ,S . (2014). Communication about serious illness care goals. JAMA Int. Med, 174(12)..

Who is Responsible to Initiate Conversation?

As Providers "We All Are"

- **Medicine Internists/Surgeons**
- **Specialists (Oncology, Nephrology, Cardiologists)**
- **Primary Care Physicians**
- **Nurse Practitioners & Physician Assistant's**
- **Nurses, Social Workers, Chaplains**
- **Consult Palliative Care: If patient situation is complex, with family dysfunction, or other compounding factors exist**

Bernacki, R.E. & Block, S.A.(2014). Communication about serious illness care goals. JAMA Internal Medicine, 174(12)

Barriers to Goals of Care Conversations

Patient Factors	**Anxiety** **Desire to protect family members** **Denial**
Clinician Factors	**Lack of communication skills & confidence** **Source of discomfort** **Lack of time for quality discussions** **Difficulty with prognostication**
System Factors	**Lack of Education on LSTDI** **Non compliance with LST policy**

Mullick, A., Martin, J. & Sallnow, L. (2013). Advance care planning. British Medical Journal, 347, 28-32;Boyd, K., et.al. (2010). Advance care planning for cancer patients in primary care: a feasibility study. British Journal of General Practice, 303(3), 1-22.

"Dying in America"
Institute of Medicine
Communication and Advanced Care Planning

Recommendations

- **Professional Societies & Organizations:**
  develop **measurable, actionable, evidenced-based standards** for clinician-patient communication & advanced care planning
- **Payers & health care delivery systems:**
  Adopt standards & integrate them into **assessments, care plans and the health care quality reports**
- **Payers:**
  Standards to **reimbursement incentives**
- **Professional Organizations:**
  Adopt standards into **credentialing, reimbursement & licensing**

Institute of Medicine of the National Academies. (2014) Dying in America Improving quality & honoring individual preferences near end of life. Retrieved from: http/www. ***iom****.nationalacademies.org/Reports/2014/****Dying-In-America****-Improving on 11/8/16.*

Advanced Directives

Legal instruments intended to secure a patients wishes regarding health care

<u>Sections of Advanced Directive</u>:

- **Instruction Directive:**

  -known as living wills. Instructions on what the person would or would not want

  (Trigger phrase: “If I am in a coma.. or “ If I am terminally ill…)

- **Appointment Directive:**

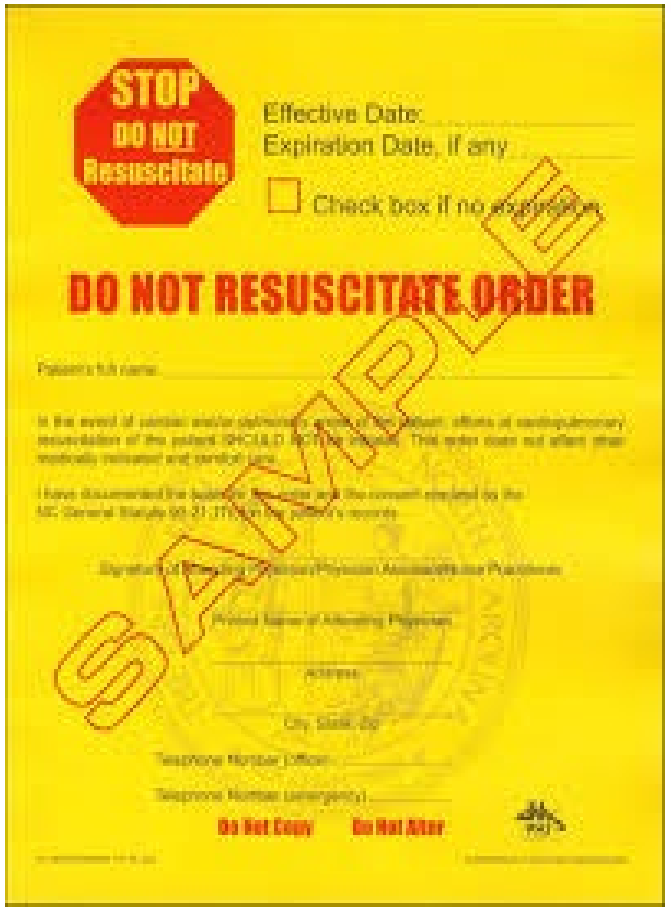
  -known as health care proxy or durable power of attorney

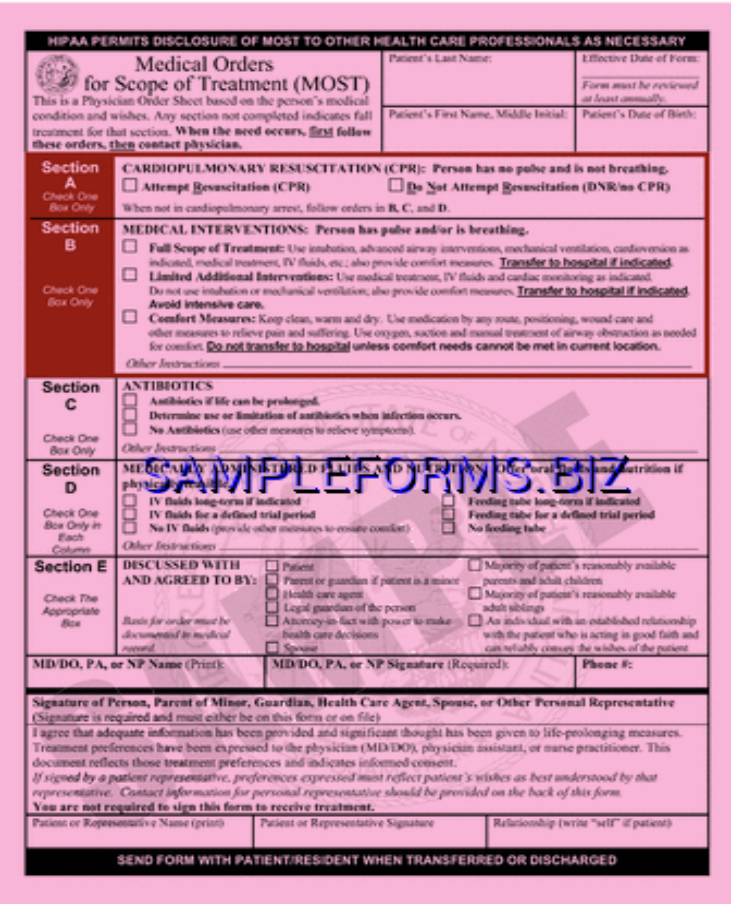
  -capacitated person can legally appoint another decision maker if capacity is lost

Boltz, M.,et.al, (2016). Evidenced –based geriatric nursing protocols for best practice,5th Ed. Springer Pub.: New York NY.

North Carolina: Legal Forms

State DNR & MOST (Medical Orders for Scope of Treatment





VA Life-Sustaining Treatment Decisions Initiative

National quality improvement initiative to promote personalized, proactive, patient-driven care for Veterans with serious illness

Desired outcomes:

The values, goals, and life-sustaining treatment decisions of Veterans with serious illness are proactively elicited, documented, and honored

https://myees.lrn.va.gov/Watch/Video%20Center.aspx?vid=5249271653001

Why LSTDI?

- **Conversations about goals and LST decisions often initiated too late** – after the patient has lost decision-making capacity or during a medical crisis
- **Difficult to locate CPRS documentation** of the patient's goals of care and LST decisions
- **VA orders pertaining to LST were limited to CPR** – no orders available regarding other LSTs (mechanical ventilation, feeding tubes, others)

LST Orders

- To address all LST decisions - not just CPR
- At the top of the list on the CPRS Orders tab in 'Default' view
- Can be written for patients in any care setting
- Durable – **DO NOT AUTO-DISCONTINUE** when patient changes location of care
- Can be written by physicians, residents, APRNs and PAs, without need for follow-up attending orders*

*Supervision documented through co-signature or addendum to LST progress note

Practice Makes Perfect(sort of)

- Empathetic responses
- What Do I Say?
- Silence IS OKAY

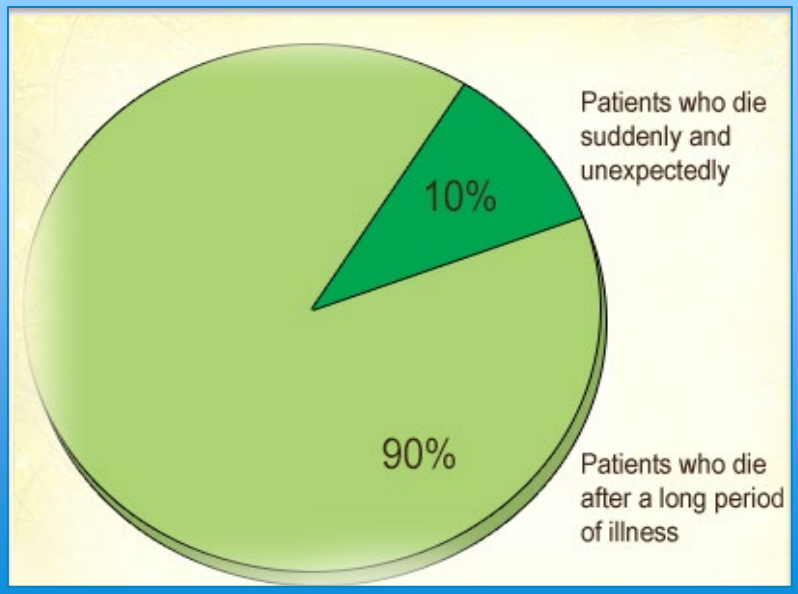
Typical Stages of Dying

EARLY STAGE	MID STAGE	LATE STAGE
• bed bound • loss of interest and ability to drink/eat • cognitive changes: either hypoactive or hyperactive delirium or increasing sleepiness	• further decline in mental status—obtunded • "death rattle" -- pooled oral secretions that are not cleared due to loss of swallowing reflex • fever is common	• coma • cool extremities • altered respiratory pattern--either fast or slow, • fever is common; death.

*Not always sequential, not everyone will have all of these symptoms
*May have a “rally” period

Weissman,D. (2014) Fast Fact #3: Syndrome of Imminent Death. Retrieved from: http://www.mypcnow.org on 1/6/2017
Image from http://www.carefacts.com/images/Hospice.jpg

Predicting Time of Death



MOST hospice deaths have a period of decline with some variety of predictable signs and symptoms

- All deaths are individual and unique to the person dying
- We can not predict exactly
- Time **ranges** can be very helpful for families
- Nurses can and should let families know when in "**hours to days**" phase

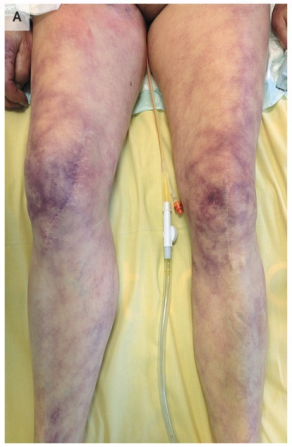
Symptoms & Signs in Last 48 Hours

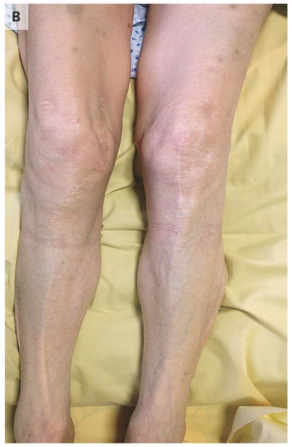
MOST COMMON SYMPTOMS AND PREVALENCE	
Noisy, moist breathing (terminal secretions)	56%
Urinary incontinence	32%
Urinary retention	21%
Pain	42%
Restlessness, agitation	42%
Dyspnea	42%
Nausea, vomiting	14%
Sweating	14%
Jerking, twitching (myoclonus)	12%
Confusion	8%

* Terminal Respiratoryis a strong indicator of impending death->76% will die in 48 hours

Hallenbeck, J., Katz, S. & Stratos, G.(2003). Stanford Faculty Development Center. Retrieved from: http://www.growthhouse.org/stanford on 1/6/2015.

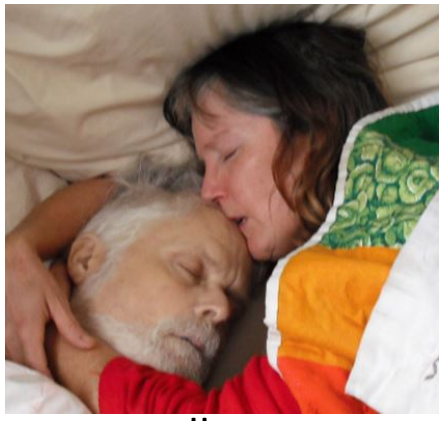
Signs of ACTIVE Dying Process





mottling

obtunded



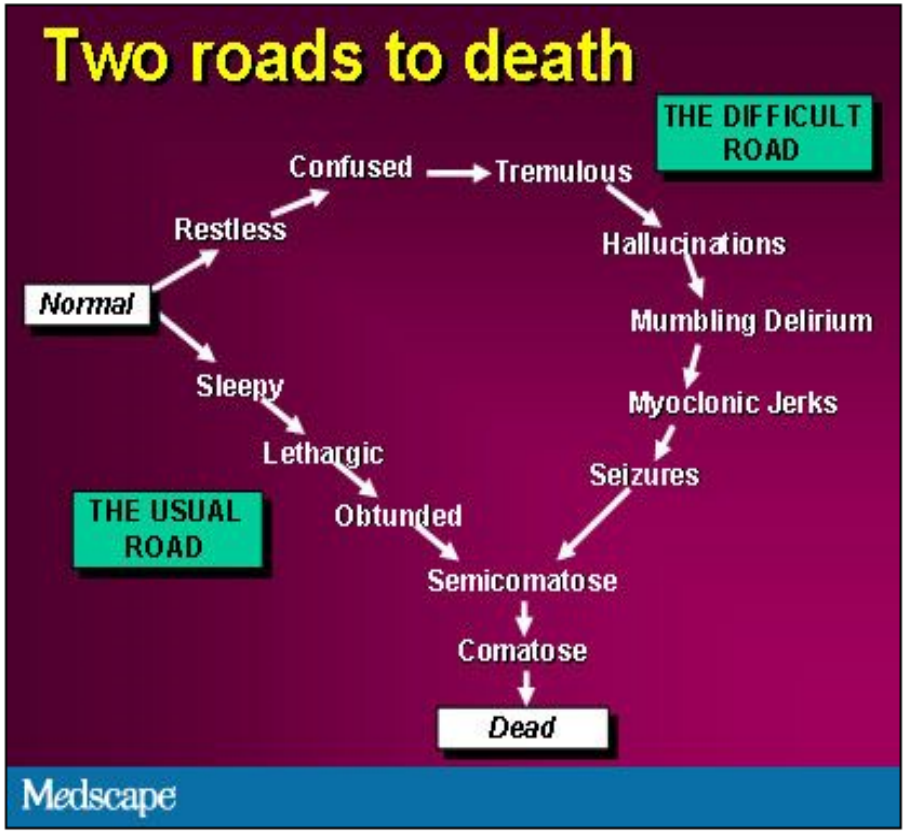
pallor

- No intake of water or food
- Non-responsive
- Skin color changes pallor, ashen, mottling
- Respiratory mandibular movement
- Sunken cheeks, relaxation of facial muscles
- Terminal Secretions: “Death Rattle”
- Cheyne Stokes respirations: periods of apnea Lack of pulse

Hallenbeck, J., Katz, S. & Stratos, G.(2003). Stanford Faculty Development Center. Retrieved from: http://www.growthhouse.org/stanford on 1/6/2015
Images from :http://blogs.reuters.com/photographers-blog/files/2013/02/mdf1491867.jpg; http://www.orderofthegooddeath.com/jeremys-death

The Dying Process Difficult vs Typical Path

- Be aware that “terminal delirium” is possible
- Assess for reversible causes, but know that it is likely irreversible
- Will require extra management: time, medications, education and support



C.A.R.E.S. acronym (Freeman, City of Hope)

- **C**omfort
- **A**irway
- **R**estlessness and delirium
- **E**motional and spiritual support
- **S**elf-care

Image from: http://www.my-personaltrainer.it/salute/img/palliativo-cure-palliative.jpg
Freeman,B. CARES: An acronym organized tool for the care of the dying. J Hosp Palliat Nurs. 2013; 15 (3) 147-153

Pearls for Pain at the End of Life

Precepts

- Pain progressively worsens during EOL for both cancer & non-cancer diagnoses.
- Pain is the most feared symptom at EOL
- Existential distress impacts on degree of suffering from pain. Pay attention to psychological, social and spiritual distress.
- Maximize use of adjuvant agents, non-opioid analgesics & non-pharmacologic therapies (heat , cold, positioning)for best results.
- Pain is always unpleasant and therefore an emotional experience.
- Address "Existential Distress" impacts pain experience (psychological, social & spiritual suffering)
- Fear that opioids will hasten death is an inappropriate barrier to their use

Prevalence

- In general 50% experience pain at EOL
- Non-cancer diagnosis: more than 40% experience severe pain within days of death
- Advanced stage cancer: 64% of patients with ratings moderate to severe
- 43% of patients with cancer receive inappropriate care for pain

Take Away Point

It is a Professional & Ethical responsibility to provide adequate pain relief for patients during EOL trajectory

Chi,N. & Demeris, G.(2017) Family caregivers' pain management in EOL care: A systematic review. *Journal of Hospice & Palliative Medicine*, 34 (5): 470-485. Stitzlien Davies,P. (2016) Pharmacologic pain management at the end of life. *The Nurse* Practitioner, 41 (5):26-37. Weinstein, S., Portenoy, R., & S.E. Harrington. (2012).*UNIPAC 3: Assessing and Treating Pain.* C.Porter Storey (Ed.). Boulder, Co: AAHPM., Paice,J.(2015) Pain at the end of life. In B. Ferrell, N. Coyle & J. Paice (Eds.), Oxford textbook of palliative nursing (135-153). New York: Oxford University Press.

Family Education and Support

- CALM & CLEAR COMMUNICATION
- Address concerns related to FEEDING and HYDRATION
- Educate about EOL breathing patterns-very distressful to family but NOT causing suffering to veteran
- Use INTERDISCIPLINARY TEAM: chaplain service, psychology, social work
- Family may need or want to give veteran permission to let go
- TOUCH and HEARING-last senses to go, make use of them
- Your presence and humanity are important!
- Normalize the experience: Grief is expected!

Case Study

Palliative Care:

Symptom Management/Advanced Care Planning

Meet Mr. B