

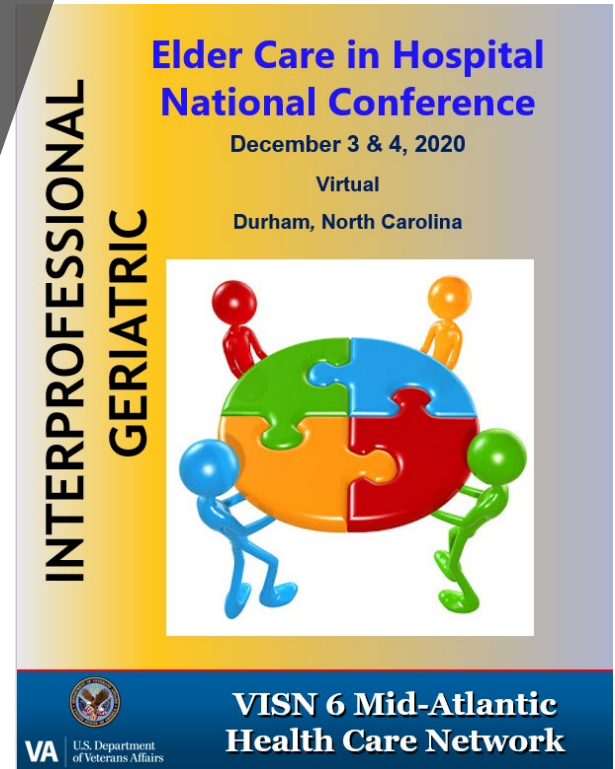
Palliative Care: Goals of Care, Advanced Care Planning & Symptom Management

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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 Statistics [cdc.gov/nchs/fastats/deaths.htm](https://www.cdc.gov/nchs/fastats/deaths.htm)

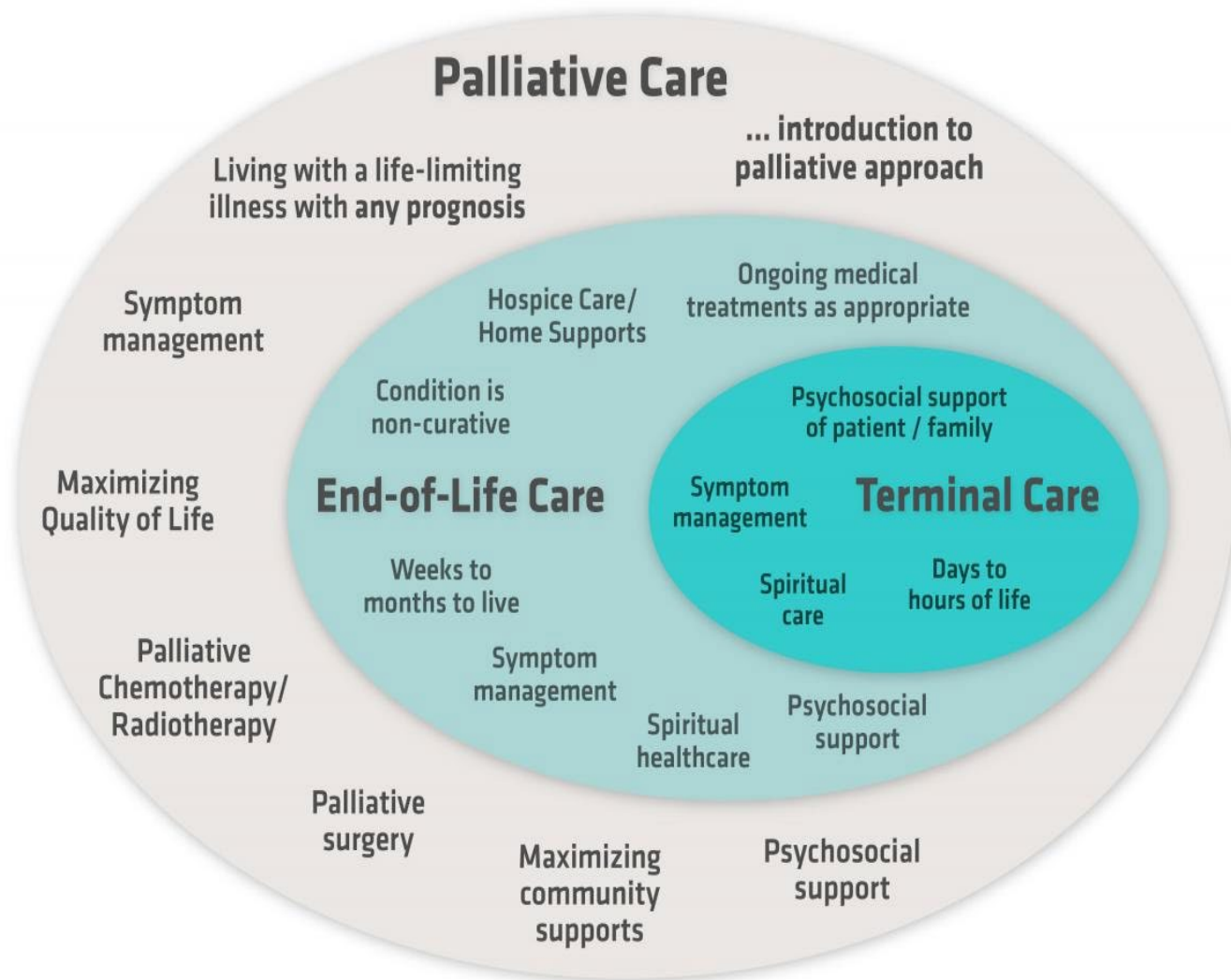
Facts: Veterans Deaths

- 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.](http://NationalHospice.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:	<ul style="list-style-type: none">• Prevent/ relieve suffering & improve QOL for chronic illnesses/ life threatening illnesses	<ul style="list-style-type: none">• Provide comfort & manage symptoms during the End of Life• Death is inevitable outcome
Patient Population:	<ul style="list-style-type: none">• Follows those with complicated or advanced medical disease• No life expectancy requirement• Can be receiving concurrent therapies	<ul style="list-style-type: none">• Accepts those near the “end of life”• Medical prognosis of 6 months or less if the disease runs its normal course

Differences in Hospice & Palliative Care



	Palliative Care:	Hospice Care:
Who Provides the Care:	<ul style="list-style-type: none">• Doctors & Nurses with specialized training• Multidisciplinary	<ul style="list-style-type: none">• Doctors & Nurses with specialized training• Multidisciplinary
Payer for Services:	<ul style="list-style-type: none">• No special insurance benefit-health insurance usually covers services	<ul style="list-style-type: none">• 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.**

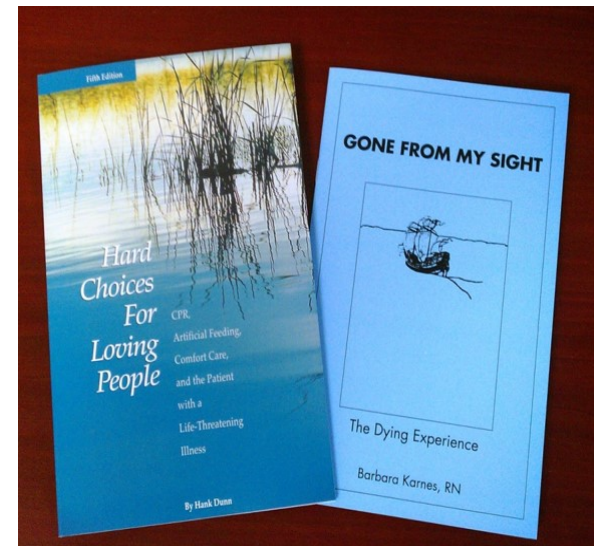
Hospice & Palliative Care at the DVAHCS

- 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 these 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

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

Sections of Advanced Directive:

- **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)

STOP DO NOT Resuscitate

Effective Date: _____
Expiration Date, if any: _____

Check box if no expiration

DO NOT RESUSCITATE ORDER

Patient's full name: _____

In the event of cardiac and/or respiratory arrest, the intent of this order is to withhold all cardiopulmonary resuscitation of the patient (CHLAD) until the physician is present. This order does not affect other medical interventions and treatments.

I have documented the patient's wishes and the consent required by the NC General Statute 90-21.11(a) on the patient's records.

Signature of Treating Physician, Assistant Physician, or Practitioner: _____
Printed Name of Treating Physician: _____
Address: _____
City, State, Zip: _____
Telephone Number (Office): _____
Telephone Number (Emergency): _____

Do Not Copy Do Not Alter

HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Medical Orders for Scope of Treatment (MOST)
This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. **When the need occurs, first follow these orders, then contact physician.**

Patient's Last Name: _____ Effective Date of Form: _____
Form must be reviewed at least annually.

Patient's First Name, Middle Initial: _____ Patient's Date of Birth: _____

Section A
Check One Box Only
CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.
 Attempt Resuscitation (CPR) Do Not Attempt Resuscitation (DNR/no CPR)
When not in cardiopulmonary arrest, follow orders in B, C, and D.

Section B
Check One Box Only
MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.
 Full Scope of Treatment: Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. **Transfer to hospital if indicated.**
 Limited Additional Interventions: Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation; also provide comfort measures. **Transfer to hospital if indicated. Avoid intensive care.**
 Comfort Measures: Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in current location.**
Other Instructions: _____

Section C
Check One Box Only
ANTIBIOTICS
 Antibiotics if life can be prolonged.
 Determine use or limitation of antibiotics when infection occurs.
 No Antibiotics (use other measures to relieve symptoms).
Other Instructions: _____

Section D
Check One Box Only in Each Column
MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: Other oral fluids and nutrition if physician orders.
 IV fluids long-term if indicated Feeding tube long-term if indicated
 IV fluids for a defined trial period Feeding tube for a defined trial period
 No IV fluids (provide other measures to ensure comfort) No feeding tube
Other Instructions: _____

Section E
Check The Appropriate Box
DISCUSSED WITH AND AGREED TO BY:
 Patient Majority of patient's reasonably available parents and adult children
 Parent or guardian if patient is a minor Majority of patient's reasonably available adult siblings
 Health care agent Legal guardian of the person
 Attorney-in-fact with power to make health care decisions Spouse
 Any individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient

MD/DO, PA, or NP Name (Print): _____ MD/DO, PA, or NP Signature (Required): _____ Phone #: _____

Signature of Person, Parent of Minor, Guardian, Health Care Agent, Spouse, or Other Personal Representative (Signature is required and must either be on this form or on file)
I agree that adequate information has been provided and significant thought has been given to life-prolonging measures. Treatment preferences have been expressed to the physician (MD/DO), physician assistant, or nurse practitioner. This document reflects those treatment preferences and indicates informed consent.
If signed by a patient representative, preferences expressed must reflect patient's wishes as best understood by that representative. Contact information for personal representative should be provided on the back of this form.
You are not required to sign this form to receive treatment.

Patient or Representative Name (Print): _____ Patient or Representative Signature _____ Relationship (write "self" if patient) _____

SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

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

- bed bound
- loss of interest and ability to drink/eat
- cognitive changes: either hypoactive or hyperactive delirium or increasing sleepiness

MID STAGE

- further decline in mental status— obtunded
- "death rattle" -- pooled oral secretions that are not cleared due to loss of swallowing reflex
- fever is common

LATE STAGE

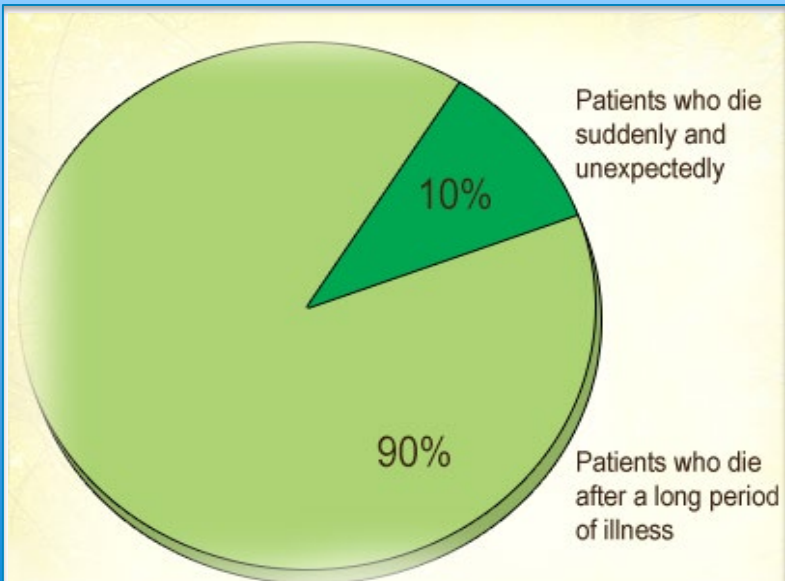
- coma
- cool extremities
- altered respiratory pattern--either fast or slow,
- fever is common; death.

*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.mypcnw.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

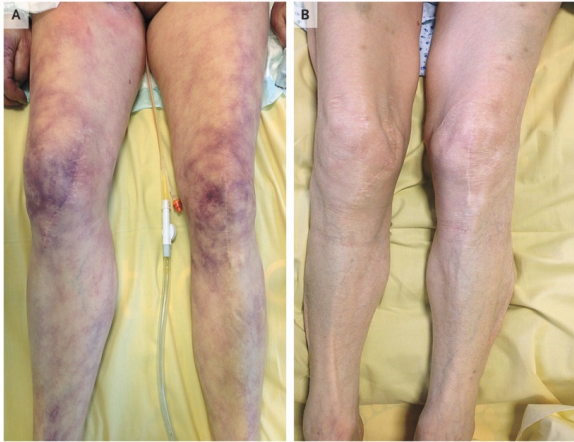
MOST COMMON SYMPTOMS AND PREVALENCE

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 Respiratory is 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



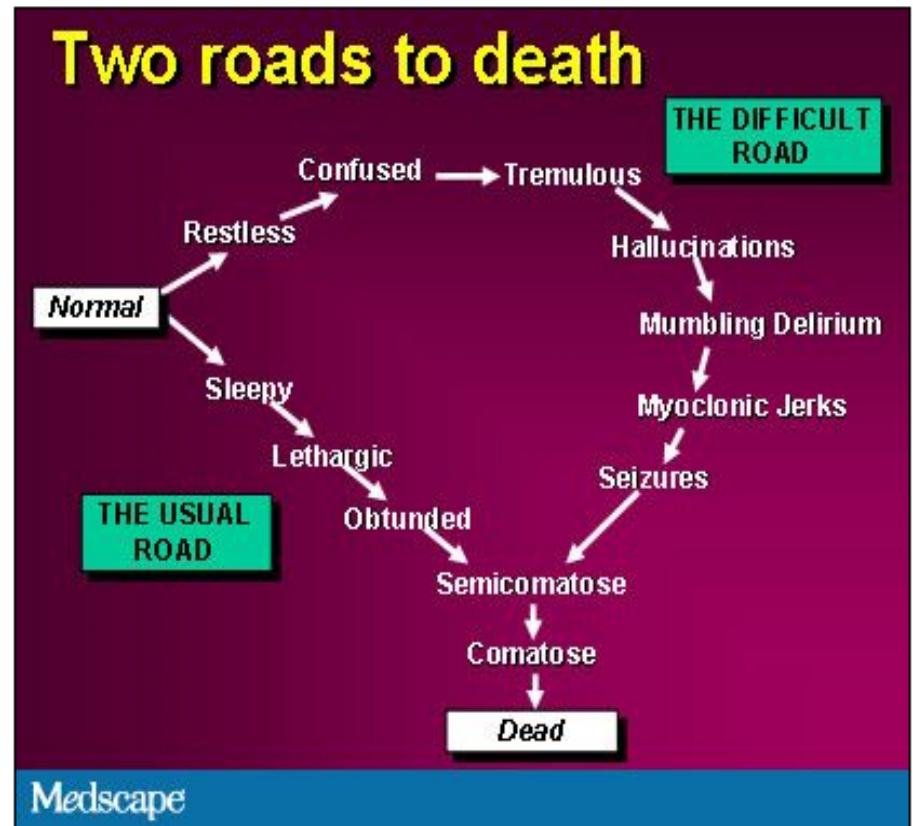
pallor

- 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)

- Comfort
- Airway
- Restlessness and delirium
- Emotional and spiritual support
- Self-care



VETERANS HEALTH ADMINISTRATION

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

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

