Difficult Conversations Around Palliative Care

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At the conclusion of this activity, participants will be able to:

- Define differences between Palliative Care and Hospice Care.
- Provide anticipatory guidance on dying trajectories.
- Establish conversation tools for advance care planning (ACP) discussions.
- Initiate code status discussion and provide education.
- Educate families and better communicate with staff.

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Palliative is a philosophy of care

- Specializes in people with serious, life-long illnesses:
  1. Specialize in symptom management (refractory cancer/end of life pain, shortness of breath, constipation)
  2. Help with difficult treatment decisions (aka goals of care and anticipatory guidance)
  3. Support, support and more support for patients/families
- Rooted in hospice movement, however:
  - Not necessarily for those life expectancy <6months
  - Appropriate at **any age or stage**
  - In addition to potentially curative treatments

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Integrated Palliative Care Framework

NHWG. Adapted from work of the Canadian Palliative Care Association and Frank Ferris, MD.

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"Would I be surprised if this patient died within 12 months?"

- Identifies patients at high 1-year mortality risk
  - Pooled accuracy overall 75%, sensitivity 67% and specificity 80%
  - Pooled accuracy cancer 79%, renal 76%, vs other diseases 72%
  - Predictive value "yes" 93%, "no" 36%
- "Yes, I would be surprised."
  - Surprise question better designed to identify patient who will live >12months
- "No, I would NOT be surprised."
  - Helps identify unmet palliative care needs, advanced care planning

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Medicare Hospice Benefit

- Usually, 100% coverage of all hospice care: medical equipment, nursing, counseling and bereavement
  - Potential (seldom billed) 5% copay for medications and respite care
  - Provides four levels of care pending symptom burden
- Eligibility:
  - Patient must be entitled to Medicare Part A (hospital payments)
  - Two physicians agree life expectancy of <6 months "if patient's disease runs its natural course."
  - DNR status is NOT a requirement for admission
- Keep in mind other insurances may not have same coverage!!!

National Hospice and Palliative Care Organization: Medicare Hospice Benefit

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Hospice Length of Stay?

- Average LOS 89.6 days, median LOS 18 days
- Patients/families receive most benefit from hospice with services lasting at least 80-90 days
  - >50% patients enrolled <30 days
  - 30% only receive care one week
  - **We refer too late!**

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How do you educate families/staff/patients on dying trajectories?

Do you provide anticipatory guidance?

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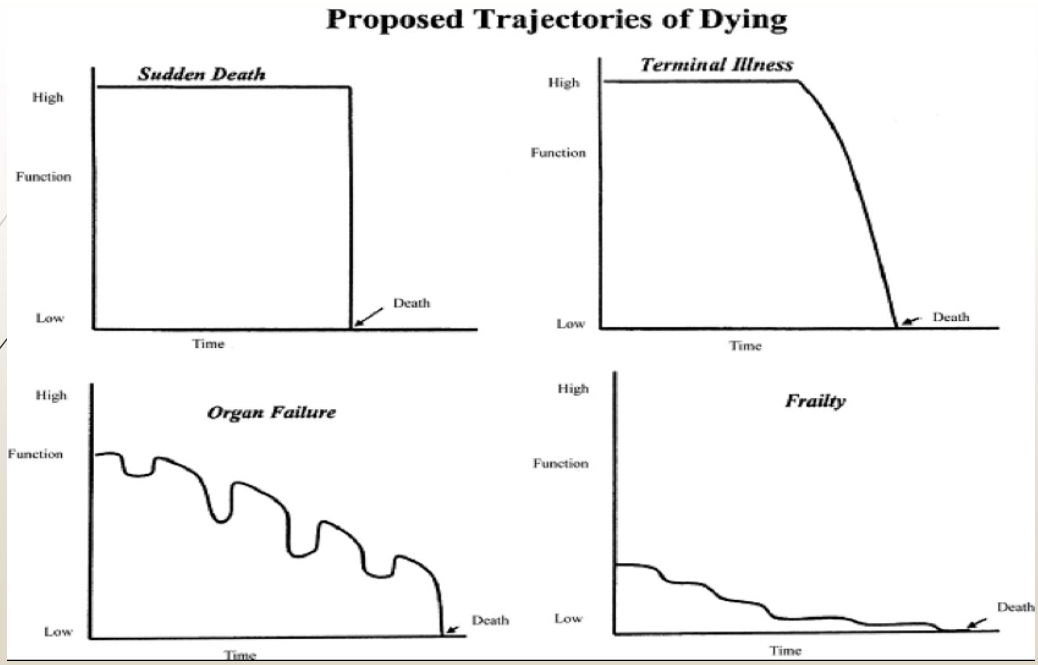

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Anticipatory Guidance: Stages of Active Dying

- Patients and families need to feel they will not be abandoned
- Use active listening
- **Offer** to provide anticipatory guidance about expected changes in cognition and physical exam
- Inquire if family are interested in prognosis
  - If so, estimate in windows of time (ex. hours to days vs. days to short weeks)

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Anticipatory Guidance: Stages of Active Dying

- Early stage: **(long days to short weeks)**
  - Bedbound
  - No longer taking PO
  - Cognitive changes: hyper or hypoactive delirium
- Mid Stage: **(short to long days)**
  - Worsening mental status
  - Sleeping more
- Late stage: **(hours to short days)**
  - Pooling oral secretions, loss of swallow reflex (death rattle)
  - Unresponsive
  - Cold extremities, mottling, blue hue
  - Alternating respiratory patterns
  - **Limited urine output ~ <24hours**

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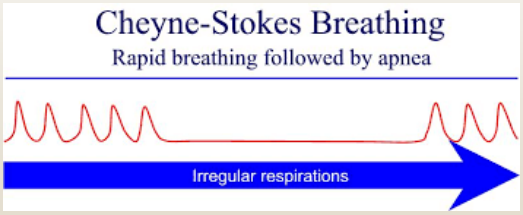
Normal Breathing changes during dying process

- Frequently seen changes, not associated with discomfort
  - Cheyne stokes respiration
  - Apneic pauses



https://www.firstaidforfree.com/what-is-cheyne-stokes-respiration/

- These are <u>normal</u> and patients not expected to be in pain or distress

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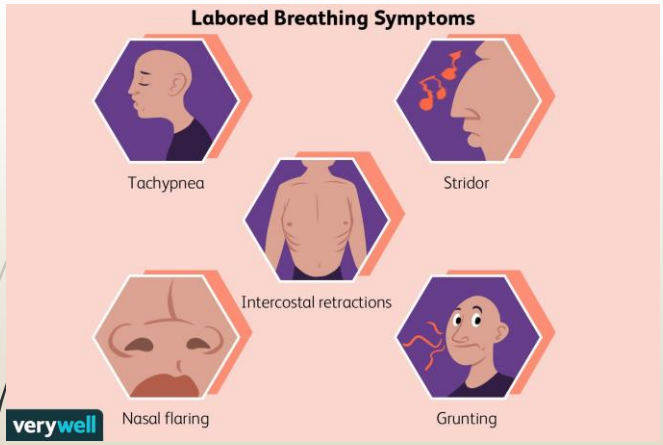

https://www.verywellhealth.com/labored-breathing-5087061

Distressed or Uncomfortable Breathing changes during dying process

- When do you consider a patient in distress who is unable to report?
  - Tachypnea (rapid breathing)
  - Restlessness
  - Accessory muscle use, paradoxical breathing
  - Grunting at end of expiration
  - Nasal flaring, <u>furrowed brow</u>, stressed/angry/fearful facial expression
  - Sweating

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Anticipatory Guidance: "The Rally"

- Surge of energy, interactive and lucid for hours or days after a period of unresponsiveness
- Confusing to families, may question decision to focus on comfort
- Encourage families to use this time meaningfully to interact with the patient, while remaining realistic about prognosis and comfort goals

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Palliative Oxygen Therapy

- Lancet 2010, double blinded randomized study
- NC with oxygen vs ambient air
- No symptomatic benefit for relief of refractory dyspnea (subjective feeling of shortness of breath)
  - Best data is use of opioids for refractory dyspnea
- May prolong dying process
  - Need to have discussions with family
  - Little reason to go beyond 4-6L
- Those with symptomatic hypoxemia do benefit from oxygen

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Time Limited Artificial Hydration

- Cancer patients at end of life (EOL) 1000mL vs 100mL daily x 7 days
  - Prolong dying process by 6 days in 1000mL group
  - No difference in delirium or fatigue
- IV and SQ studies with 1000mL vs placebo
  - No difference in delirium
  - May reduce nausea

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Will Morphine Kill Mom Faster?!?!?

- Initially respond with emotion NOT medical explanations
  - Is the family scared? Do they have unspoken guilt/worry?
  - Have they had a bad experience with hospice in the past?
- **Name the emotion**…."I see your worried/scared about morphine being used in your loved one's care…."
- Educate that appropriate dosed opioids for air hunger will not hasten death
- They are dying due to the underlying process not the opioid

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A word on opioids at End of Life

- Patients/families fear opioids at end of life!
  - Communication is key
- Right patient right dose right situation
  - Doses do not work the same on all patients
- Opioids first line for air hunger
  - No opioid better than another, morphine most common
- Tolerance occurs but does not mean opioids should be "saved"
- Efficacy is related to dose not route of administration
  - IV should be used for rapid dose escalation, malabsorption, nausea/vomiting, obstruction
- Urticaria, nausea and pruritis may not be true allergy but known side effects

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Advance Care Planning Discussions

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- Advance Care Planning (ACP)
  - Process of communication between patient, family/health care proxy and staff
  - Purpose to identify surrogate, discuss treatment preferences and develop individualized goals of care
- Advance Directive (AD)
  - Legal documents with varying capabilities pending jurisdictions (POLST, living will, HCPOA, etc)

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Personally Ask about HCPOA and Code Status

- **Surrogate**: determine the surrogate decision maker
- **Preferences**: assess patient preferences for care: Full vs DNR
- **Assume:** Full Code/treatment: if no preference of care can be determined
- **More:** discussions in the future

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Have you heard of Code Status before?

- Ask everyone this question
- Even if unlikely to happen during this stay
- We always try to prevent your heart and lungs from stopping however if despite our usual medical treatment (IVF, antibiotics, hospitalizations, etc) your heart or lungs still stop and you die what interventions would you want?
  - Give patient/resident a few second to think
- Some say they would NOT want things like CPR, shocking, intubation/breathing tube and life support = DNR/DNI
- Other say they would want these interventions done = Full Code

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What will be provided if someone is Do Not Resuscitate (DNR) Do Not Intubate (DNI)?

Emergency provider as appropriate will provide:	Emergency provider will NOT:
• Clear airway • Administer oxygen • Position for comfort • Splint • Control bleeding • Provide pain medication • Provide emotional support • Contact hospice or home health agency if either has been involved in patient's care, or patients attending physician	• Perform chest compressions • Insert advanced airways • Administer cardiac resuscitation drugs • Provide ventilator assistance • Defibrillate

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What does a DNR mean for other treatments?

- Decision to accept or decline CPR does NOT impact other treatment options such as:
  - Antibiotics
  - Intravenous fluids
  - Medications to try and prevent heart and lungs from stopping
  - Hospitalizations
  - Other medical treatments as appropriate
- DNR **does not** = no treatment or no hospitalizations!
- DNR means we do not do CPR or intubation once heart or lungs stop

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Does choosing DNR mean I'm giving up?

- **NO!**
- Everyone should weigh the risk and benefits of any medical intervention that might be done to them
- We ask consent for all invasive procedures
- There is no intervention more extreme and invasive than CPR, intubation/breathing tube and life support
- One is simply making a choice or placing limits on what interventions they want preformed to their body

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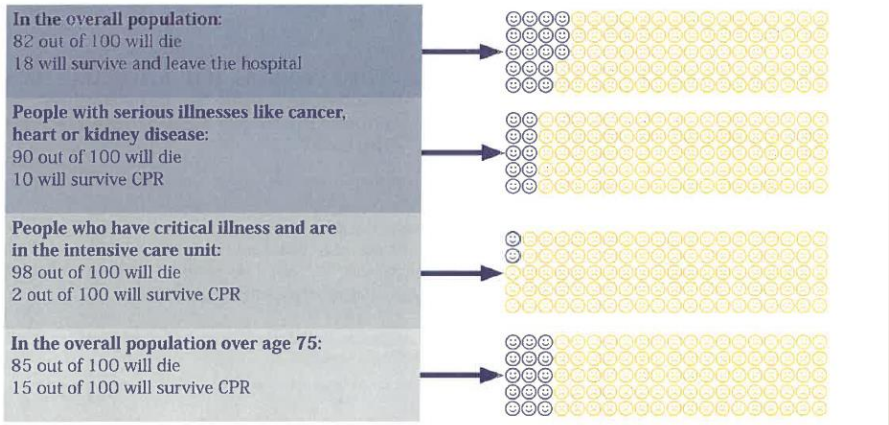
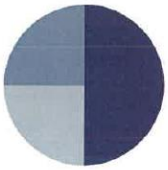


What is the chance of survivors going home from hospital?

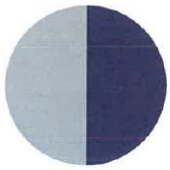


About ¼ will go home independently.

Another ¼ will go home but require help at home.

About ½ will need to live in an institution – like a nursing home or rehab centre

What is the chance that survivors will have thinking or communication difficulties?



About ½ will have problems such as memory loss, problems with attention and problems getting things done.

How well does CPR work?

You may have seen CPR on TV, in real life it is much less successful.

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Can I revoke or change my DNR/DNI status?

- Yes, a DNR/DNI can be changed at any time

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Does my religion allow DNR/DNI?

- This can be very difficult to respond to, Try:
  - It sounds like your religion/spirituality is important to you, tell me more about that
  - Choosing DNR/DNI is not causing death, preventing improvement or miracles from occurring. It is allowing a natural death when it is someone's dying time
  - Offer to contact spiritual leader to further discuss with them

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Transitioning to DNR/DNI. Now what?

- Recommend community DNR paperwork and bracelet
  - This alerts others of your wishes if something should happen in public
  - If in event 911/EMS called they know your wishes
- Educate family, friends, POA on your decision
  - Things are smoother when everyone is on same page

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Can't decide right now.

- That's ok!
- Place Full Code and discuss with provider at next visit
  - We should be comfortable providing a recommendation
- I recommend you talk with family/friends/POA and describe to them your goals for quality of life, interaction with environment and function levels that are important to you
  - This will help guide future decisions

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NURSE

- **Name the emotion**
  - **"I wonder if your feeling…" It sounds like your feeling…"**
- Understanding
  - "If I understand what you are saying….."
- Respecting
  - "I can see you are a fierce advocate for…" "You are dealing with a lot…"
- Supporting
  - "I/we will help navigate through this difficult time…"
- Exploring
  - "Tell me more…" "What else is important for me to know about your loved one…"
- Communicate with staff concerns from family and education provided
  - This will create a unified front for family and increase confidence

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Moderating a Family Meeting/Breaking bad News

- **Set** up the situation/**Start** with Introductions
- **Perception** of medical situation from family/patient
  - What have you heard about your….
- **Invitation/Information:** The Warning Shot!
  - Ask if they want to know…
  - Is it ok to share information with …. in the room?
  - "We are going to talk about hard things related to your (illness), is that ok?"
- **Knowledge** (patient's illness/treatments and prognosis)
  - "Show your work." and share your knowledge of situation
- **Empathetic** statements
  - "I can't imagine how hard this is to hear."
- **Strategy/Summary**
  - "We talked about a lot of things today, let's plan to meet tomorrow and you can write down all your questions."

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ELSEVIER

JAMDA

journal homepage: www.jamda.com

Review Article

Interventions Guiding Advance Care Planning Conversations: A Systematic Review

Check for updates

Jurrianne C. Fahner MD [a,*], Alexandra J.M. Beunders MD [a], Agnes van der Heide MD, PhD [b], Judith A.C. Rietjens MSc, PhD [b], Maaike M. Vanderschuren MD [a], Johannes J.M. van Delden MD, PhD [a], Marijke C. Kars RN, PhD [a]

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Fahner, Jurrianne C., et al. "Interventions guiding advance care planning conversations: a systematic review." Journal of the American Medical Directors Association 20.3 (2019): 227-248.

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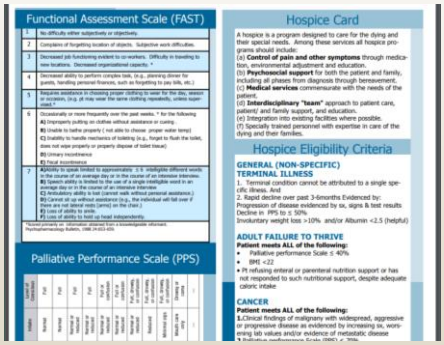
www.mypcnow.org/fast-facts

Smartphone application: Palliative Care Fast Facts

Hospice Eligibility Criteria Hospice Card



https://emed.unm.edu/common/documents/hospice-eligibility-criteria.pdf

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Thank you?
Questions?

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