Foundations of Emergency Medicine
Foundations III: Guided Small Group Experience

Ethics and Clinical Skills

Session 8: "Surrogacy, Goals of Care and End-of-Life Care"

- **Agenda and Learning Objectives**
  - Case Part I – Understanding Advanced Care Planning Documents and Surrogacy (15 min)
    - Discuss surrogacy according to state law
    - Identify advance care planning documents
    - Distinguish key features that differentiate an Advanced Directive, Living Will and POLST/MOLST
  - Case Part II – Goals of Care Discussions (15 min)
    - Name important features of a goals of care discussion
    - Identify useful phrases that can be used when having conversations with seriously ill patients and their families
  - Case Part III – End-of-Life Care (10 min)
    - Discuss medications used to treat common symptoms in the dying patients
    - Define the concept of double effect
  - Case Conclusion and Teaching Points (10 min)
    - Review Session Teaching Points

- **Note to Facilitators**

This session covers commonly encountered clinical questions raised by taking care of patients with terminal illnesses. This includes issues of surrogacy, goals of care discussions and finally clinical end-of-life care. Prior to this session please review these materials. It may also be helpful to review any state specific regulations you have on surrogacy. The session doesn't require any other equipment to implement. It is primarily a large group question led discussion though there are several opportunities to break the group into pairs to discuss questions in a smaller venue prior to reconvening as a larger group.

- **Case Part I –** Understanding Advance Care Planning Documents and Surrogacy (20 min)

MA is a 68-year old male with a history of recently diagnosed stage II colon cancer s/p resection and colostomy, DM, HTN and CAD. He is 2 weeks s/p surgery and has not yet started chemotherapy. He presents to the ED via EMS c/o acute severe R sided chest pain and dyspnea. ECG was non-diagnostic and he was sent to the CT which demonstrated a R middle lobe segmental PE. Upon return to the ED, he is now confused and continues to decline and you are worried he may need intubation. You quickly review his EMR and there is a comprehensive note from his initial oncology visit. As part of their practice routine, an

advanced directive was completed at his first visit last month. You learn that he has 3 adult children, one lives locally and the others live in SC and TN. He lives with Debra, his fiancé. They have lived together for 10 years. She is listed as his emergency contact. This living will is also scanned into the computer.

LIVING WILL

I, _____, being of sound mind, willfully and voluntarily make this declaration to be followed if I become incompetent. This declaration reflects my firm and settled commitment to refuse life-sustaining treatment under the circumstances indicated below.

I direct my attending physician to withhold or withdraw life-sustaining treatment that serves only to prolong the process of my dying, if I should be in a terminal condition or in a state of permanent unconsciousness.

I direct that treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing life-sustaining treatment.

In addition, if I am in the condition described above, I feel especially strong about the following forms of treatment.

I ( ) do (✓) do not want cardiac resuscitation.

I ( ) do (✓) do not want mechanical respiration.

I ( ) do (✓) do not want tube feeding or any other artificial or invasive form of nutrition (food) or hydration (water).

I ( ) do (✓) do not want blood or blood products.

I ( ) do (✓) do not want any form of surgery or invasive diagnostic tests.

I ( ) do (✓) do not want kidney dialysis.

I ( ) do (✓) do not want antibiotics.

I realize that if I do not specifically indicate my preference regarding any of the forms of treatment listed above, I may receive that form of treatment.

- **Discussion Questions with Teaching Points**
  - **Based on the information you have available, what is MA's code status?**
    - We don't know → we only have a living will not an advanced directive or POLST/MOLST
  - **What are the different kinds of advanced care planning documents? How are they different?**
    - The 2 most common types of advanced care planning documents are living wills and POLST or MOLST documents

MOLST/POLST	LIVING WILL
Choices are discussed with a medical clinician	Choices need not be discussed with anyone
Form is completed after a shared decision-making conversation between patient and medical clinician	Can list preferences for any aspect of health care including life support → preferences are only triggered when one lacks decisional capacity & has met the criteria for enactment in the state in which the document was created (often terminal condition or persistent unconscious state as the above living will)
Used by persons whose health status includes late or end–stage life limiting illness	Anyone ≥ 18 years of age regardless of health status can complete it
Requires the signature of a medical provider	Requires the signature of two witnesses
Form is a medical order	Form is a legal document

- **Has MA's living will been triggered? What triggers a living will?**
  - No, it has not
  - Because the language on a living will can vary by state, providers should be aware of what triggers living wills in their state → it is often a very specific set of circumstances
  - Many states use a terminal condition or a persistent unconscious state as their triggers (see below)
  - It is somewhat uncommon for a living will to get triggered in the ED as it is often difficult for us to determine if an unconscious state is persistent or a condition is truly terminal → however knowing the details of any existing living will can provide a framework for further discussions about goals of care

- **How do we define a persistent state of unconsciousness or a terminal condition?**
  - Terminal Condition: A condition in which a patient would be expected to die **despite** sound medical treatment within a given period of time
  - Persistent state of unconsciousness: Generally brain death

- **What is the difference between an effective (or legally executed) living will and an enacted (or activated) living will?**
  - An effective (or legally executed) living will has been appropriately signed, witnessed and is ready to be triggered
  - An enacted (or activated) living will has been triggered because the patient is in a persistent state of unconsciousness or has a terminal condition for which death would result despite sound medical treatment (or triggered by some other circumstances as laid out by state law)

- **In this case, who is MA's legal surrogate? What are your state's surrogacy laws in the absence of an advanced directive?**
  Note to facilitators: Each state has different surrogacy laws. It will be helpful to review your state's surrogacy ladder prior to facilitating this session.
  - In the absence of any documentation stating otherwise, MA's children are his legal surrogate if he lacks capacity to make decisions (in most states)
  - This is a good reminder to review your state's legal surrogacy hierarchy *before* you need it!

- **What if MA's adult children disagree?**
  - Most state laws do not specify which relative of a certain rank should make decisions → the general recommendation is to gain consensus but does not specify what to do if there is disagreement
  - This is a difficult situation and involving ethics and risk management early can be beneficial
  - Can also try to redirect the children to focus on "*What would MA want?*" and remind them they are not making decisions for themselves but based on what they think he would want → this is known as **substituted judgment** and is discussed in more detail later

❖ **Case Part I Continues**

MA's fiancé arrives and produces the Health Care Proxy Document that identifies her as his legal surrogate. She indicates that all efforts should be made to treat him and prolong his life. He is started on heparin and intubated.

After intubation, one adult child arrives and are upset the patient is intubated. They state he wouldn't want to be intubated and requests he be extubated.

❖ **Discussion Questions with Teaching Points**

- **What would you do? Who gets to make decisions for MA?**
  - In most states, health care agents appointed by the patient in an advanced directive or durable power of attorney for health care trumps anyone else on the surrogacy ladder (besides the patient) so the fiancé gets to make decisions
  - As above, this is a tricky situation so use all your resources and try your best to help everyone reach consensus → focus on the patient and what they would have wanted

❖ **Case Part II** – Goals of Care Discussions (15 min)

Nine months later, MA presents to the ED from oncology clinic. He arrived to clinic for chemotherapy and was sent directly to the ED because of respiratory distress. He recently completed 3rd line chemotherapy and complains of intense fatigue, nausea, vomiting and

dyspnea. He is speaking in 2-word sentences and tells you, "Doc, I am exhausted. I can't do anything anymore."

You are the ED provider and you are struck by how much weight he has lost (34#) since you saw him earlier this year. He is febrile to 38.4C, in moderate respiratory distress but his oxygen saturations improve with a non-rebreather mask. His work-up in the ED reveals that he has pancytopenia, acidosis with AKI {Cr of 4.5, baseline 1.0} and imaging reveals multiple new pulmonary nodules c/w metastatic disease as well as suspicion for an SBO with carcinomatosis.

You review the last oncology note and see that his visit today was to discuss results of the latest PET scan which also showed disease progression. There was a brief mention of hospice by the physician at the last appointment.

His now wife arrives to the bedside and asks how he is doing. MA asks if you can just help him feel better and not be so weak. His wife is quick to reassure him that he is a fighter and he "will be fine". They both look to you to respond.

- **Discussion Questions with Teaching Points**
  - **What is MA's prognosis? What factors do you consider when trying to prognosticate?**
    - He has a terminal condition with continued disease progression
    - He has weight loss and progressive worsening of performance status which are both poor prognostic factors
    - Other clues that prognosis may be poor include frequent unplanned hospitalizations and the presence of co-morbid chronic progressive diseases such as heart failure, diabetes mellitus, COPD or Alzheimer's dementia
    - The National Hospice and Palliative Care Organization has established objective criteria to help identify patients who have a life expectancy of 6 months given the natural history of their illness and thus are hospice appropriate (these are included at the end of the facilitator background information or at http://geriatrics.uthscsa.edu/tools/Hospice_elegibility_card__Ross_and_Sanchez_Reilly_2008.pdf)
  - **Is he hospice appropriate?**
    - Yes, he has a life expectancy of less than 6 months
  - **Would you be surprised if MA died during this hospitalization?**
    - No
    - The surprise question (SQ), "Would you be surprised if this patient died within the next year?" is effective in identifying patients at high risk of death
    - If you anticipate a patient has a high risk of dying during this hospitalization, it is important to share the seriousness of the clinical situation with the family → most

would agree it is unfair for the family to be surprised by an outcome we were almost expecting as health care providers

- **Let's take a few minutes and break into groups of two. Spend some time answering the question "How am I doing?" to both MA and his wife.**
  Note to facilitators: Give the pairs about 5 minutes (as time allows) to practice these discussions. Then bring the small groups together and ask what was said, what went well and what was difficult. Weave the below suggested questions/language into the larger group discussion.
  - The REMAP tool from VitalTalk (adapted below) is a good map to guide goals of care conversations though some of the language should be adjusted for the ED
  - In the ED we are often having these conversations with surrogates and not the patient themselves as they are too ill → in these cases consider substituting "*What do you think the patient would want us to do in this situation*?", "What would be most important to him?" → this is called using **substituted judgment**
  - We are often just beginning to conversation about things like hospice in the ED → think about it as priming for the admitting team who can continue the conversation more easily as an inpatient

Step	**What you say or do**
1. Reframe why the status quo isn't working.	You may need to discuss serious news (eg a scan result, severity of symptoms presenting to the ED) first. "Given this news, it seems like a good time to talk about what to do now."
2. Expect emotion & empathize.	"It's hard to deal with all this." "I can see you are really concerned about [x]." "Tell me more about that—what are you worried about?" "Is it ok for us to talk about what this means?"

3. Map the future.	"Given this situation, what's most important for you?"
4. Align with the patient's values.	As I listen to you, it sounds the most important things are [x,y,z].
5. Plan medical treatments that match patient values.	Here's what I can do now that will help you do those important things. What do you think about it?

- **What are the key components of a goals of care discussion?**
  - When clinically feasible, a call to the patient's oncologist can assist greatly in these conversations to frame the larger medical and social contexts
  - Assess patient and or surrogate understanding of illness and trajectory
  - Provide clarification if understanding is not accurate or incomplete
  - Determine patient values and what is important given understanding and context to illness
  - Identify *achievable* goals based on patient values
  - Offer to make a recommendation on how best to achieve those goals

- **What patients should you have a code status discussion with?**
  - Any patient you are concerned has a significant risk of death on this hospitalization → this means you need to have these tough conversations about prognosis!
  - You can consider code status discussions with patients with terminal conditions even if they are not imminently ill
  - Consider having these discussions more often in the ED → they get easier with practice and sometimes the mental status we have in the ED is the best the patient will have during their hospitalization
  - Though they are difficult and time consuming, these conversations are crucial in respecting patient autonomy and perhaps avoiding unwanted, painful, likely futile and potentially traumatic (for the family and treating team) procedures at the end of life

- **When should you discuss code status? What words have worked for you in the past when having these conversations? How would you approach this conversation with MA and his wife?**
  - Discussing code status outside of the context of goals of care can lead to requests for resuscitation that are not in-line with the patient's values → unless they understand their prognosis, they cannot enter into a conversation about the benefits of resuscitation
  - Can consider using the introduction "*I know this is a difficult conversation to have but we want to make sure we respect your (your family members') wishes and don't do anything to you that you wouldn't want done in an emergency situation"*
  - Remember to use layman's terms when having these conversations! → many patients don't know what intubation or even CPR means
  - After learning what is important to the patient, the provider can summarize what they have heard from the patient or family and offer to make a recommendation about future care
    - For instance, with MA you might say "*I am hearing that you understand that the cancer is continuing to spread and unfortunately we don't have any treatments that can prevent this from continuing. It seems that getting your symptoms under control and getting you home is an important goal for us to set. I am hopeful that we can achieve this. Have you thought about what you would want us to do if things continue to get worse?"*
    - If you believe your conversation with the patient or family is in line with a DNR/DNI code status, you can consider saying *"Based on what you told me about your goals to stay comfortable and minimize pain at the end of life, it seems like you (or your family member) would not want aggressive resuscitation measures like chest compressions or breathing tubes. Does that sound right?"*
    - Depending on the answer, a provider can recommend that *"If things continue to get worse we can focus on the things we can do to aggressively manage symptoms to minimize any pain or distress and allow you to have a natural death"*
    - If the patient or family agrees to this, then the provider can say, *"In this case I will place an order to instruct other care providers that we won't perform chest compressions or put you on machines, we can use medications to ease any symptoms you may be experiencing"*

- **What do you recommend to manage MA's dyspnea and other symptoms? How do you dose it?**
  - Morphine is the drug of choice to decrease the sense of breathlessness in patients with respiratory distress
  - The typical dose is 2mg IV every 15 minutes until symptoms improve

- **What other common symptoms do we encounter at the end-of-life in the ED and what treatment options do we have?**
  - Pain
    - Opiates are the mainstay agent for treatment of pain at the end of life
    - Often oral regimens cannot continue due to a patient's inability to take oral meds consistently
    - Pain regimens should be converted to a route that is tolerated, in the ED this typically means IV or SQ route → IM route is the least preferable route for administering parenteral medications due to the pain associated with administration
    - Providers should have a good understanding of equianalgesic opiates and the concept of cross-tolerance to assure continued effective relief of pain with opiates (See Foundations III Session 10 "Analgesia Stewardship")
  - Dyspnea
    - Opiates (morphine is the most studied for this use) are the mainstay pharmacologic agent to reduce breathlessness
    - Typical starting dose is 2 mg IV every 15min until some improvement as evidenced by patient report of observation of less distress
    - Benzodiazepines, most commonly lorazepam, may be added if dyspnea continues despite a few doses of opiate medication (0.5-1.0 mg every hour prn)
    - Non-pharmacologic treatments are also effective and include a fan, open window or other means to circulate air
    - Supplemental oxygen is offered via a means best tolerated by the patient → some patients may prefer a trial of NIPPV
    - When patients indicate via verbal or non-verbal communication that they no longer want supplemental 02, discussions with family present should include transitioning to a less offensive means of 02 delivery or discontinuing 02 completely
  - Excessive secretions
    - Very common in end of life
    - Usually more distressing for family hearing the 'death rattle' than the patient themselves
    - Rubinol 0.2-0.4 mg IV q 6 is the treatment of choice → it has the least side effects because unlike other commonly used agents (atropine and scopolamine) it does not cross the blood brain barrier and thus does not cause confusion
  - Anxiety
    - It can be difficult to differentiate anxiety from agitation → lorazepam is administered as described above for dyspnea
  - Delirium/Agitation
    - Commonly caused by urinary retention or constipation so rule these out before treating
    - Haldol 0.5 mg IV q 1 hour as needed

- Consider using both Lorazepam and Haldol when these symptoms occur and seem resistant to monotherapy with an antipsychotic
- Keep in mind that lorazepam can exacerbate delirium particularly in patients with dementia

- **Finally, what is the doctrine of double effect? Why is it important in the care of patients at the end of life?**
  - The Doctrine of Double Effect is the ethical principle that applies to the use of certain medications at the end of life, particularly opiates which can hasten death
  - This doctrine says that if doing something morally **good** (alleviating suffering) has a potentially morally **bad** side-effect (hastening death), it's ethically acceptable to do it providing the bad side-effect wasn't the **intended** result
  - This is true even if you foresaw that the bad effect would probably happen

❖ **Case Concludes and Teaching Points (10 min)**

After a discussion, MA and his wife decide to focus on symptom management. You start aggressive morphine administration to assist with his symptoms and MA is admitted to your inpatient hospice unit with the hope that his symptoms may be brought under control and he can go home once he is on a stable regimen.

❖ **Case Teaching Points Summary**

- **Understanding Advanced Care Planning Documents**
  - Advanced health care directives often include a medical decision maker designation and can include a living will which stipulates what cares a patient would want *only* in the case of a persistent unconscious state or terminal illness
  - Living wills are not synonymous with Do-Not-Resuscitate (DNR) orders
  - Living Wills are generally “enacted” or “activated” when a patient is incapable of decision-making, has a terminal condition [not a critical illness] or is in a persistent vegetative state [PVS]
  - DNR orders generally apply only to patients with terminal conditions found pulseless or apneic
  - POLTS or MOLST documents are portable medical orders that apply when a patient lacks capacity to discuss their care preferences and often include more detailed information such as artificial nutrition, IV medications and DNR/DNI status

- **Surrogacy**
  - Surrogacy statutes vary significantly by state and you should become familiar with your state’s statutes
  - State statutes should only be used in the absence of patient decision making capacity *and* a lack of other advanced directive documentation (ie advanced directive with a designated health care decision maker)

- EM physicians should be aware of the hierarchy for determining who the default decision maker is if the patient lacks capacity and there are no advanced directives
- "Common Law Marriage" is not recognized in all states and definitions vary by state → it is important to confirm that a spouse is legally married if they are directing care on their incapacitated spouse's behalf
- Surrogate decisions makers, whether explicitly appointed by a document or by default, are required to use substituted judgement when making decisions on behalf of the patient for whom they are representing
    - A good way to frame this for the surrogate is *"Think about what MA would want us to do"*

- **Goals of Care Conversation**
    - Prior to discussing goals with seriously ill patients and their families, it important that the EM physician has an understanding of the potential benefits of treatments that may be offered in the context of the patient's illness trajectory → a call to the patient's primary physician or oncologist may be very helpful to gain context
    - REMAP is a helpful framework to navigate Goals of Care discussions
    - Have code status conversations in the greater goals of care discussions
    - Consider using the phrasing "*I know this is a difficult conversation to have but we want to make sure we respect your (your family members') wishes and don't do things to them they wouldn't want done in an emergency situation"* to frame code status conversations
    - Consider having this conversation with any patient you think has a real chance of dying in the hospital → it's not fair for the family to be surprised by something you expect
    - Don't be afraid to have these conversations → they get easier with practice and are important in order to respect patient wishes, autonomy and avoid potentially unwanted, unnecessary, painful and likely futile procedures at the end of life

❖ Facilitator Background Information

There are many different kinds of advanced care planning documents that can help guide emergency physicians when making decisions about care especially for patients with serious or terminal illnesses. Some of these include advanced directives, POLST/MOLST or living wills. This background information will cover some of these document as well as explain the concept of surrogacy in the absence of these documents. The facilitator background information ends with a discussion of commonly encountered symptoms at the end-of-life and medications that may be beneficial for the management of these symptoms.

Advance Care Planning Documents and Tools

Advanced Directives

The *Patient Self Determination Act of 1991* mandates that every person be asked about advance directives when seen in both the inpatient and outpatient setting. These "Advanced Directive" forms are typically completed in advance of an illness and may contain several parts. The key portions that will influence patient care are:

- **Health care agent** ('power of attorney for health care,' 'health care proxy') - a document in which the patient appoints someone to make decisions about his/her medical care if he/she cannot make those decisions
- **Living will** ('health care directive') - a written document in which a patient's wishes regarding the administration of medical treatment are described if the patient becomes unable to communicate in the setting of a serious or terminal medical condition

Written advance directives are legal in every state; laws and forms, however, vary state to state. "Five Wishes" is a proprietary document that is approved for use as Living Will in many states.

Medical Orders for Life Sustaining Treatment (MOLST/POLST) and Living Wills

MOLST or **POLST** is a portable document of *physician/provider medical orders*, often limiting (but not necessarily so) certain unwanted treatments in patients near the end-of-life. They allow physician from one health system to write orders that may be carried out in another health system. These orders pertain to a particular patient's explicit wishes in the event they are critically ill and unable to speak for themselves. They differ from living wills in several ways which are outlined in the table below.

MOLST/POLST	LIVING WILL
Choices are discussed with a medical clinician	Choices need not be discussed with anyone
Form is completed after a shared decision-making conversation between patient and medical clinician	Can list preferences for any aspect of health care including life support; preferences are only triggered when one lacks decisional capacity & is either in a **terminal condition** or **permanently unconscious**
Used by persons whose health status includes late or end–stage life limiting illness	Anyone $\geq$ 18 years of age regardless of health status can complete living will
Requires signature by medical provider	Requires signature of two witnesses*
Form is a medical order	Form is a legal document

* Typically a living will shall be signed by the declarant in the presence of at least two competent adults who, at the time of the execution of the living will, to the best of their knowledge: (1) Are not related to the declarant by blood or marriage; (2) Would not be entitled to any portion of the estate of the declarant upon the declarant´s decease under any testamentary will of the declarant, or codicil thereto, and would not be entitled to any such portion by operation of law under the rules of descent and distribution of this state at the time of the execution of the living will; (3) Are neither the attending physician nor an employee of the attending physician nor an employee of the hospital or skilled nursing facility in which the declarant is a patient; (4) Are not directly financially responsible for the declarant´s medical care; and (5) Do not have a claim against any portion of the estate of the declarant.

Medical Surrogacy

Determining the legal surrogate in the absence of advanced directives

There is broad ethical consensus that other persons may make life-and-death decisions on behalf of patients who lack decisional capacity. Many states have enacted legislation designed to delineate decision-making authority for patients who lack proper documentation naming a surrogate decision-maker and lack capacity themselves. If such documentation exists it is not required to rely on state law to determine the surrogate. However, in the absence of such documentation, knowledge of state laws around determining surrogacy are key to identifying the legally authorized default decision-maker. To make matters even more complex, only 41 states have statutes that allow for the appointment of default surrogate.[1] In a NEJM review article, DeMartino and colleagues provide an extensive summary of the current US Statutes regarding surrogacy. In the majority of these states, a hierarchy is established with regard to the order in which a default surrogate is appointed. Therefore, knowing your state's laws regarding this as well as your employer's institutional policies is critical to identifying the appropriate decision maker when a patient lacks capacity. Remember, surrogacy (or power of attorney for health care) only comes into effect when the patient themselves lacks capacity.

In Georgia, for instance, the hierarchy for legal surrogate is as follows**:**

- The legally authorized surrogate for Adult Patients who require medical or surgical procedures the order of rank is as follows:
    1. Patient
    2. Health Care Agent Appointed in Advance Directive or Durable Power of Attorney for Healthcare
    3. Spouse (legally married)
    4. Adult Child **
    5. Parent **
    6. Adult Sibling**
    7. Grandparent **
    8. Adult Niece, Nephew, Aunt Uncle who is a first degree relative**
    9. Adult friend (required to sign Adult Friend form)

When more than one person in this relationship rank exists, the law does **not specify **which** relative would be the designated decision-maker. It is generally recommended to gain consensus.

A surrogate decision-maker is tasked to use substituted judgment when making decisions on the patient's behalf. The surrogate is asked to make the medical choice that the patient might make given the surrogate's understanding of the patient's values and goals and not necessarily one that the surrogate might make for himself or herself. Additionally, the surrogate should consider the best interest of the patient, as well, as they weigh the medical options offered.

Goals of Care Discussions

Goals of care discussions are a difficult but extremely important part of our care of ill ED patients. We have many obstacles challenging us as ED physicians including time, limited knowledge of the patient's prognosis and treatment options, concerns over appropriate surrogacy and the often critical nature of the patient's illness. That being said, it is imperative to have these discussions in order to ensure we are respecting patient's wishes and not exposing them to painful, likely futile and potentially even traumatic interventions they would not want at the end-of-life.

Goals of care discussions can be structured using the REMAP tool shown in the session above. It begins by gathering information from the patient (or surrogate) about their condition. In this process, the physician must clarify and correct any significant misconceptions about prognosis. The physician then goes on to gather the patient's goals (for us often comfort vs limited interventions vs full interventions). Once we have established goals we can suggests interventions that follow those goals.

True code discussions (ie establishing DNR/DNI) should be made in the context of larger GOC conversations. If not, requests are often made for resuscitation that are not in line with the patient's true goals of care. Care should be made to avoid medical terminology (even CPR or intubation) as many patients don't truly understand what those terms mean. If their goals seem to be comfort, it is ok to suggest that being DNR/DNI falls within those goals and suggest that an order is placed. Many families

or surrogates look to the physician for advice in these discussions and if you believe an intervention is likely going to be futile (or not lead to a quality life after resuscitation consistent with the patient's goals or values) it is ok to share that information to allow the family to make a more informed decision.

End-of-Life Clinical Care

There are several common symptoms encountered at the end of life and as ED physicians, we should feel comfortable managing them. The most commonly encountered symptoms are pain, dyspnea, secretions, anxiety and delirium/agitation. Many patients at the end-of-life are on narcotic pain medications for pain management and will need to be transitioned to IV or subq in the setting of illness or dying. It is important to become familiar with opiate conversion and tolerance so you can dose these medications appropriately (see Session 10: Anesthesia Stewardship). There are many tables available online to assist you with this. Dyspnea is generally treated with morphine at 2 mg q15 min and other non-pharmacologic measures (fans, open windows). You may also consider starting a morphine drip so you can titrate more easily. Oxygen may or may not help. Secretions are very common at the end of life and are generally more distressing to the family than the patient. The best treatment for this is Rubinol 0.2-0.4 mg IV q6 as it does not cross the blood-brain-barrier and so does not cause delirium. Finally, psychiatric symptoms including anxiety, delirium and agitation are very common. These are best treated with Haldol 0.5 mg IV and/or Ativan 1 mg IV to start and titrated as necessary. Knowing common symptoms at the end-of-life and how to treat them can help us as ED physicians to relieve suffering and aid the dying process for both our patients and those families that bear witness.

- **Key Resources for Further Study:**
  - **Author:** Dr. Joanne Kuntz
  - **Secondary Author:** Dr. Natasha Wheaton
  - **References**

1. DeMartino ES, et al. Who Decides When a Patient Can't? Statutes on Alternate Decision Makers N Engl J Med. 2017 April 13; 376(15): 1478–1482.
2. Mirarchi F, MD et al. TRIAD III: Nationwide assessment of living wills and do not resuscitate orders. J Emerg Med 2012 42 (5) 511–520
3. Haydar SA, Almeder L, Michalakes L, Han PKJ, Strout TD. Using the Surprise Question To Identify Those with Unmet Palliative Care Needs in Emergency and Inpatient Settings: What Do Clinicians Think? J Palliat Med 2017 Jul;20(7):729-735.
4. Fast Facts attached
5. American Bar Association https://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives.html
6. http://geriatrics.uthscsa.edu/tools/Hospice_elegibility_card__Ross_and_Sanchez_Reilly_2008.pdf

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following **A)** Improperly putting on clothes without assistance or cueing . **B)** Unable to bathe properly (not able to choose proper water temp) **C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) **D)** Urinary incontinence **E)** Fecal incontinence
7	**A)**Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. **B)** Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview **C)** Ambulatory ability is lost (cannot walk without personal assistance.) **D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) **E)** Loss of ability to smile. **F)** Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant.
Psychopharmacology Bulletin, 1988 24:653-659.

Palliative Performance Scale (PPS)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Level of Conscious
100	Full	Normal activity, no evidence of disease	Full	Normal	Full
90	Full	Normal activity, some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort, some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal work, some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby or some housework, significant disease	Occasional assist necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work, extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work, extensive disease	Mainly assistance	Normal or reduced	Full, drowsy, or confusion
30	Totally bed bound	Unable to do any work, extensive disease	Total care	Reduced	Full, drowsy, or confusion
20	Totally bed bound	Unable to do any work, extensive disease	Total care	Minimal sips	Full, drowsy, or confusion
10	Totally bed bound	Unable to do any work, extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	—	—	—	—

Hospice Card

A hospice is a program designed to care for the dying and their special needs. Among these services all hospice programs should include:
(a) **Control of pain and other symptoms** through medication, environmental adjustment and education.
(b) **Psychosocial support** for both the patient and family, including all phases from diagnosis through bereavement.
(c) **Medical services** commensurate with the needs of the patient.
(d) **Interdisciplinary "team"** approach to patient care, patient/ and family support, and education.
(e) Integration into existing facilities where possible.
(f) Specially trained personnel with expertise in care of the dying and their families.

Hospice Eligibility Criteria

GENERAL (NON-SPECIFIC) TERMINAL ILLNESS

1. Terminal condition cannot be attributed to a single specific illness. And
2. Rapid decline over past 3-6months Evidenced by:
Progression of disease evidenced by sx, signs & test results
Decline in PPS to ≤ 50%
Involuntary weight loss >10% and/or Albumin <2.5 (helpful)

ADULT FAILURE TO THRIVE

Patient meets ALL of the following:

- Palliative performance Scale ≤ 40%
- BMI <22
- Pt refusing enteral or parenteral nutrition support or has not responded to such nutritional support, despite adequate caloric intake

CANCER

Patient meets ALL of the following:
1.Clinical findings of malignany with widespread, aggressive or progressive disease as evidenced by increasing sx, worsening lab values and/or evidence of metastatic disease
2.Palliative performance Scale (PPS) ≤ 70%
3.Refuses further life-prolonging therapy OR continues to decline in spite of definitive therapy
Supporting documentation includes:
Hypercalcemia > 12
Cachexia or weight loss of 5% in past 3 months
Recurrent disease after surgery/radiation/chemotherapy
Signs and sx of advanced disease (e.g. nausea, requirement for transfusions, malignant ascites or pleural effusion, etc.)

DEMENTIA

The patient has both 1 and 2:
1. Stage 7C or beyond according to the FAST Scale
AND
2. One or more of the following conditions in the 12 months:
Aspiration pneumonia
Pyelonephritis
Septicemia
Multiple pressure ulcers (stage 3-4)
Recurrent Fever
Other significant condition that suggests a limited prognosis
Inability to maintain sufficient fluid and calorie intake in the past 6months (10% weight loss or albumin < 2.5 gm/dl)

7.

HEART DISEASE

The patient has 1 and either 2 or 3.

1. CHF with NYHA Class IV* sx and both :
Significant sx at rest
Inability to carry out even minimal physical activity without dyspnea or angina

2. Patient is optimally treated
(ie diuretics, vasodilators, ACEI, or hydralazine and nitrates)

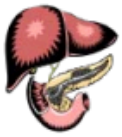
3. The patient has angina pectoris at rest, resistant to standard nitrate therapy, and is either not a candidate for/or has declined invasive procedures.

Supporting documentation includes:
EF ≤ 20%, Treatment resistant symptomatic dysrythmias h/o cardiac related syncope, CVA 2/2 cardiac embolism H/o cardiac resuscitation, concomitant HIV disease

HIV/AIDS

The patient has either 1A or 1B and 2 and 3.
1A. CD4+ < 25 cells/mcL **OR** 1B. Viral load > 100,000
AND
2. At least one (1) : CNS lymphoma, untreated or refractory wasting (loss of > 33% lean body mass), (MAC) bacteremia,
Progressive multifocal leukoencephalopathy
Systemic lymphoma , visceral KS, Renal failure no HD, Cryptosporidium infection, Refractory toxoplasmosis
AND
3. PPS* of < 50%

LIVER DISEASE



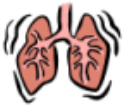
The patient has both 1 and 2.

1. End stage liver disease as demonstrated by A or B, & C:
A. PT> 5 sec **OR** B. INR > 1.5
AND
C. Serum albumin <2.5 gm / dl
AND

2. One or more of the following conditions:
Refractory Ascites, h/o spontaneous bacterial peritonitis, Hepatorenal syndrome , refractory hepatic encephalopathy, h/o recurrent variceal bleeding

Supporting Documents includes:
Progressive malnutrition, Muscle wasting with dec. strength. Ongoing alcoholism (> 80 gm ethanol/day), Hepatocellular CA HBsAg positive, Hep. C refractory to treatment

PULMONARY DISEASE



Severe chronic lung disease as documented by 1, 2, and 3.

1. The patient has all of the following:
Disabling dyspnea at rest
Little of no response to bronchodilators
Decreased functional capacity (e.g. bed to chair existence, fatigue and cough)
AND
2. Progression of disease as evidenced by a recent h/o increasing office, home, or ED visits and/or hospitalizations for pulmonary infection and/or respiratory failure.
AND
3. Documentation within the past 3 months ≥1:
Hypoxemia at rest on room air (p02 < 55 mmHg by ABG) or oxygen saturation < 88%
Hypercapnia evidenced by pC02 > 50 mmHg

Supporting documentation includes: Cor pulmonal and right heart failure Unintentional progressive weight loss

NEUROLOGIC DISEASE (chronic degenerative conditions such as ALS, Parkinson's, Muscular Dystrophy, Myasthenia Gravis or Multiple Sclerosis)

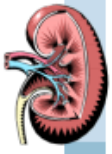
The patient must meet at least one of the following criteria (1 or 2A or 2B):

1. Critically impaired breathing capacity, with all:
Dyspnea at rest, Vital capacity < 30%, Need O_2 at rest, patient refuses artificial ventilation
OR
2. Rapid disease progression with either A or B below:
Progression from :
independent ambulation to wheelchair or bed-bound status
normal to barely intelligible or unintelligible speech
normal to pureed diet
independence in most ADLs to needing major assistance in all ADLs
AND

A. Critical nutritional impairment demonstrated by all of the following in the preceding 12 months:
Oral intake of nutrients and fluids insufficient to sustain life
Continuing weight loss
Dehydration or hypovolemia
Absence of artificial feeding methods
OR

B. Life-threatening complications in the past 12 months as demonstrated by ≥1:
Recurrent aspiration pneumonia, Pyelonephritis, Sepsis, Recurrent fever, Stage 3 or 4 pressure ulcer(s

RENAL FAILURE



The patient has 1, 2, and 3.

1. The pat is not seeking dialysis or renal transplant
AND
2. Creatinine clearance* is < 10 cc/min (<15 for diabetics)
AND
3. Serum creatinine > 8.0 mg/dl (> 6.0 mg/dl for diabetics)

Supporting documentation for chronic renal failure includes: Uremia, Oliguria (urine output < 400 cc in 24 hours), Intractable hyperkalemia (> 7.0), Uremic pericarditis, Hepatorenal syndrome, Intractable fluid overload.

Supporting documentation for acute renal failure includes:
Mechanical ventilation, Malignancy (other organ system) Chronic lung disease, Advanced cardiac disease, Advanced liver disease

STROKE OR COMA

The patient has both 1 and 2.

1. Poor functional status PPS* ≤ 40% **AND**
2. Poor nutritional status with inability to maintain sufficient fluid and calorie intake with ≥1 of the following:
≥ 10% weight loss in past 6 months
≥7.5% weight loss in past 3 months
Serum albumin <2.5 gm/dl
Current history of pulmonary aspiration without effective response to speech therapy interventions to improve dysphagia and decrease aspiration events

Supporting documentation includes:
Coma (any etiology) with 3 of the following on the third (3rd) day of coma:
Abnormal brain stem response
Absent verbal responses
Absent withdrawal response to pain
Serum creatinine > 1.5 gm/dl