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Goals of Care 101

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Goals of Care 101

Alexandra Evans DO, Adam Pennarola MD, Elham Siddiqui MD
Jefferson Hospice and Palliative Medicine Fellows
Hospice and Palliative Medicine

Alexandra Evans DO
Jefferson Hospice and Palliative Medicine Fellow
What is Palliative Medicine?

Palliative care is a type of medical care that focuses on improving patients’ quality of life by managing pain and other distressing symptoms of a serious illness. It should be provided along with other medical treatments for conditions that might be curable, life limiting or chronic.
What is Palliative Medicine?

Palliative care is for people of any age, and at any stage in illness, whether that illness is curable, chronic, or life threatening.

This can be provided in the hospital or in the outpatient setting.
What is Palliative Medicine?

Palliative care has been shown in studies to improve quality of life, decrease healthcare costs, and sometimes help patients live longer.
What is Hospice?

Hospice is the way we deliver palliative care for patients who are in the final stages of their illness and cure is no longer possible. Hospice care can be provided in patients’ homes, hospice centers, hospitals, long-term care facilities, or wherever a patient resides.
What is Hospice?

To be eligible, the patient must have a prognosis of 6 months or less. This is certified by the hospice medical director every 60-90 days (and so may extended beyond 6 months).
What is Hospice?

Hospice is not about giving up.

It's about giving the patient comfort, control, dignity, and quality of life by helping to ensure that their final months of life are as good and fulfilling as they can be for both the patient and their loved ones.
What is Hospice?

There are many different types of hospice organizations: hospital-affiliated, community based, independent incorporated organizations, for-profit and not-for-profit.

These organizations provide care in a variety of settings including hospitals, nursing homes, dedicated hospice facilities and patients’ homes.
What is Hospice?

Most hospice programs are covered by Medicare and by private health insurance plans.
What is Hospice?

Studies show that patients often begin receiving hospice care when they have only weeks or days to live, instead of months.
Case: Ms Lola

Ms Lola is a 70 year old woman with well controlled blood pressure who lives in an assisted living facility due difficulty keeping up with household chores after her husband died. She lives pretty independently in the facility and has some family in the area that visits her every so often.

What discussions should we have with her?
Advance Care Planning

"Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."
Advance Care Planning

1) Deciding the kind of medical care you want in situations in which you are not able to speak for yourself.
2) Putting those decisions in writing.
3) Communicating with your family and your doctors about your wishes.
Advance Care Planning

**Start the conversation:**

What gives your life meaning?

What does quality of life mean to you?

If you were unable to do the things that you value in life, would that change your decisions about medical interventions?

If you were dying, where would you want to be?
Case: Ms Lola

Three years later, Ms Lola was brought into the emergency department after being found wandering on the street, confused.

Who should we call?
Advance Care Planning

If no designated health care agent/POA?

(i) The spouse, unless an action for divorce is pending, and the adult children of the principal who are not the children of the spouse.

(ii) An adult child.

(iii) A parent.

(iv) An adult brother or sister.

(v) An adult grandchild.

(vi) An adult who has knowledge of the principal's preferences and values, including, but not limited to, religious and moral beliefs, to assess how the principal would make health care decisions.
Capacity vs Competency

Capacity:

Capacity is determined by cognition. It is fluid and may be determined by ANY physician.

Capacity may vary in a single patient, based on the complexity of decision making required.

Capacity refers to the patient’s ability to have insight about an illness and proposed treatment options to make an informed choice.

This decision making must meet the requirements of informed consent.
Informed Consent Requirements

(1) the nature of the procedure

(2) the risks and benefits of the procedure,

(3) reasonable alternatives,

(4) risks and benefits of alternatives, and

(5) assessment of the patient's understanding of elements 1 through 4.
Capacity vs Competency

Competency:

Competency is determined by court hearings.
Case: Ms Lola

Seven years later, the assisted living facility brings her to the emergency room because she is febrile and her breathing is labored. A diagnosis of Lewy Body dementia has been established since you’ve last seen her. Ms Lola’s dementia has been progressive and recently her care team noticed that she is coughing when swallowing food. She improves with oxygen supplementation and is admitted for suspected aspiration pneumonia.
Five Things Physicians and Patients Should Question
Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.

In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.
Don’t delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.

Numerous studies—including randomized trials—provide evidence that palliative care improves pain and symptom control, improves family satisfaction with care and reduces costs. Palliative care does not accelerate death, and may prolong life in selected populations.
Don’t leave an implantable cardioverter-defibrillator (ICD) activated when it is inconsistent with the patient/family goals of care.

In about a quarter of patients with ICDs, the defibrillator fires within weeks preceding death. For patients with advanced irreversible diseases, defibrillator shocks rarely prevent death, may be painful to patients and are distressing to caregivers/family members. Currently there are no formal practice protocols to address deactivation; fewer than 10% of hospices have official policies. Advance care planning discussions should include the option of deactivating the ICD when it no longer supports the patient’s goals.
Don’t recommend more than a single fraction of palliative radiation for an uncomplicated painful bone metastasis.

As stated in the American Society for Radiation Oncology (ASTRO) 2011 guideline, single-fraction radiation to a previously un-irradiated peripheral bone or vertebral metastasis provides comparable pain relief and morbidity compared to multiple-fraction regimens while optimizing patient and caregiver convenience. Although it results in a higher incidence of later need for retreatment (20% vs. 8% for multi-fraction regimens), the decreased patient burden usually outweighs any considerations of long-term effectiveness for those with a limited life expectancy.
Don’t use topical lorazepam (Ativan), diphenhydramine (Benadryl), haloperidol (Haldol) (“ABH”) gel for nausea.

Topical drugs can be safe and effective, such as topical non-steroidal anti-inflammatory drugs for local arthritis symptoms. However, while topical gels are commonly prescribed in hospice practice, anti-nausea gels have not been proven effective in any large, well-designed or placebo-controlled trials. The active ingredients in ABH are not absorbed to systemic levels that could be effective. Only diphenhydramine (Benadryl) is absorbed via the skin, and then only after several hours and erratically at subtherapeutic levels. It is therefore not appropriate for “as needed” use. The use of agents given via inappropriate routes may delay or prevent the use of more effective interventions.
COVID-19 Response Resources for Clinicians
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is my grandfather going to make it?</td>
<td>I imagine you are scared. Here’s what I can say: because he is 90, and is already dealing with other illnesses, <strong>it is quite possible that he will not make it out of the hospital. Honestly, it is too soon to say for certain.</strong></td>
</tr>
<tr>
<td>Are you saying that no one can visit me?</td>
<td>I know it is hard to not have visitors. The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. <strong>They will be in more danger if they come into the hospital.</strong> I wish things were different. You can use your phone, although I realize that is not quite the same.</td>
</tr>
<tr>
<td>How can you not let me in for a visit?</td>
<td>The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. We can help you be in contact electronically. <strong>I wish I could let you visit, because I know it’s important. Sadly, it is not possible now.</strong></td>
</tr>
<tr>
<td>Notifying</td>
<td>When you are telling someone over the phone</td>
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<td>-----------</td>
<td>-------------------------------------------</td>
</tr>
<tr>
<td><strong>What they say</strong></td>
<td><strong>What you say</strong></td>
</tr>
<tr>
<td>Yes I’m his daughter. I am 5 hours away.</td>
<td>I have something serious to talk about with you. Are you in a place where you can talk?</td>
</tr>
<tr>
<td>What is going on? Has something happened?</td>
<td>I am calling about your father. He died a short time ago. The cause was COVID19.</td>
</tr>
<tr>
<td>[Crying]</td>
<td>I am so sorry for your loss. [Silence][If you feel you must say something: Take your time. I am here.]</td>
</tr>
<tr>
<td>I knew this was coming, but I didn’t realize it would happen this fast.</td>
<td>I can only imagine how shocking this must be. It is sad. [Silence] [Wait for them to restart]</td>
</tr>
</tbody>
</table>
Saying goodbye virtually...

Lead the way forward

Offer the four things that matter to most people:

Forgiveness
Thanks
Love
Goodbye

“Here are five things you might want to say. Only use the ones that ring true for you.”

“Please forgive me”

“I forgive you”

“Thank you”

“I love you”

“Goodbye”

“Do any of those sound good?”
Saying goodbye virtually...

Validate what they want to say

“I think that is a beautiful thing to say”

“I think he/she can hear you even if they can’t say anything back”

“Go ahead, just say one thing at a time. Take your time.”

Expect emotion

“I can see that he/she meant a lot to you.”

“Can you stay on the line a minute? I just want to check on how you’re doing”
Approaching GOC in the Outpatient World

Elham Siddiqui MD
Jefferson Hospice and Palliative Medicine Fellow
Many studies show that most patients would rather die at home than in a hospital or nursing home and 9/10 of these patients would put in writing that they prefer limited or comfort driven care at the end of their lives.

- Yet a QUARTER of Medicare beneficiaries still die in acute care hospitals!!

Why does this happen?

How can we fix it?
● The Primary care physician is often the best positioned person to initiate goals of care discussions
  ○ A result of the rapport and relationship that has already been established with the patient and family due to ongoing continuity of care

● Despite being the best-positioned, it often does not happen...why?
What barriers do outpatient physicians face?

- We may not feel it’s the right time
  - Not sure? Ask yourself...
    - “Would I be surprised if this patient died in the next year?”
      - If you answered YES...it’s the right time
- We may not feel comfortable bringing this up
- We may not feel confident enough
- We may be limited by time
Why don’t patients bring this up?

- They may feel like it is too early to discuss the end-of-life
- Lack of knowledge of disease processes
- Fear of dying
- Cultural beliefs
- Religious beliefs
- Waiting for their doctor to bring it up
How do we improve this?

● Firstly – stop calling it an “End-of-Life” discussion
  ○ Start calling it “Advance Care Planning”
    ■ This helps avoid the ”finality” of death that often frightens patients and families
      ● Conveys importance of learning about their values and wishes
      ● Places value on creating a plan to enforce when they aren’t able to.
      ● Helps family know their wishes
Timing is Key - when to approach?

- Well, first, we need to make sure we have ample time to listen
  - Generally, more time is available during annual wellness visits and transitions of care visits
  - Many would argue that a Transition of Care visit is an ideal time to either initiate or revisit these discussions
    - Patients have just returned from an acute hospital stay where they can re-evaluate their experiences and assess what their future desires for medical care are
  - Consider Telemedicine as alternative space for discussion

- Upon new diagnosis of chronic medical condition or exacerbation of chronic illness
Some scenarios to consider

A 33 year old male with PMH of obesity who presents to your office for an annual wellness visit. He has a strong family history of coronary artery disease and shares that his father recently had a massive heart attack. He has been your patient for the last three years and you have provided care for not only him, but also his wife who is currently 7 months pregnant.

- How would you approach this conversation?
Conversation starters...

“I’m so sorry about your father’s heart attack, how have you been doing with this?”

“Tell me more about how this has affected you?”

“I can only imagine the impact this has had on you as you’re preparing for your child, how are you doing?”

“This sounds like it is very stressful for you, tell me what’s going through your mind?”
Early Conversations

- Along with preventative counseling that often happens at these visits, offering information surrounding ACP could be appropriate!
- Consider a younger patient with few to no health problems
- This may be a gentle nudge to help patient consider what is important to them as their health changes over the years
- Consider providing handouts that give information on ACP documents
Your 73 year old female patient is following up with you today after being discharged from the hospital after being treated for another acute exacerbation of her congestive heart failure. This is her second time in the hospital for these symptoms over the last 3 months. You can see she appears short of breath, weaker, frailer and is using a walker to help her into the room. She expresses worry about to go back to the hospital again.

- How would you approach this conversation?
Conversation starters...

“I can only imagine how you must feel, tell me more about about what worries you.”

“It sounds like you’re worried about having to go back to the hospital again, what about that worries you?”

“I’m sorry you are feeling worried, some people in your situation share your worries and want to talk about their future and what’s important to them, and some people don’t. Where do you think you fall?”
Consider during a time when patient’s health is declining
- Patients may still not be ready to have this conversation
- Give them resources and allow them time to think
- Ask them if they’d like to involve their family or friends
You are called by one of the family medicine residents from your local hospital to inform you that your long-time 69 yo patient is admitted with severe complications from their most recent round of chemotherapy for metastatic colon cancer. The oncologist has notified the patient and family that they are really concerned about their ability to tolerate any future cancer-directed treatments. The team is asking for your help guiding this patient and family on choosing the next appropriate step for them.

- How would you approach this conversation?
Conversation starters...

“I’m so sorry you’re going through this, can you tell me what is going through your mind?”

“Tell me about what is most important to you right now.”

“I know your cancer doctors are worried about your ability to tolerate any further cancer treatment, how does this make you feel?”

“What do you hope for in light of what the doctor’s concerns are?”
Late

- Most frequent type of discussion but the least ideal!
- Life span here is often measured in days to weeks
  - Patient may already have been experienced aggressive care that may or may not be in line with their goals
  - May have missed windows of opportunity that would allow them care that is in line with their goals
- Very important to include family here
NURSE statements

<table>
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<td><strong>Exploring</strong></td>
<td>“Could you say more about what you mean when you say that…”</td>
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*If you’re stuck, these can be helpful…*
How do we increase our own comfort?

● Many wonderful resources available to improve your communication techniques
  ○ www.vitaltalk.org
  ○ Mastering Communication with Seriously Ill Patients by Anthony Back, Robert Arnold, and James Tulksy

● Practice, practice, practice!
● Keep having discussions, with more experience comes more confidence.
● Familiarize yourself with patient resources
ACP Planning Resources

- There are many, some of our favorites
  - www.prepareforyourcare.org
  - www.fivewishes.org

- Check with your institution for preferred one
Briefly on Billing...

- Advance care planning is billable!
  - CPT code **99497** for the first 16 to 30 minutes
  - CPT Code **99498** for each additional 16 to 30 minutes
Take home points...

● Advocate to include PCPs in these discussions
  ○ They can offer valuable insight into the patient’s quality of life, family dynamics, goals, values and wishes
● It is important to build rapport and relationships with patients in the outpatient setting before approaching these conversations
● These discussions are billable
● Many resources to build your own comfort on this topic
● Many resources for patients in the outpatient world
Inpatient Goals of Care Discussions

Adam Pennarola MD
Jefferson Hospice and Palliative Medicine Fellow
Overview

- Fundamentals of Inpatient Goals of Care Discussions
  - Code Status Discussion
  - Identification of Surrogate Decision Maker
  - Fundamental GOC communication skills
- Advanced Inpatient Goals of Care Discussions
Fundamentals
Fundamentals: Code Status Discussions

- **Background**
  - CPR Event survival rate: 44% obtain ROSC
  - CPR Survival to hospital discharge: 17%
- **Cancer Patients Specifically**, survival to discharge
  - Localized disease: 9.1%
  - Metastatic disease: 7.8%
Fundamentals: Code Status Discussions

- Factors associated with increased mortality following in hospital cardiac arrest
  - Organ failure
    - ESRD, hepatic/renal dysfunction
  - Acute stroke
  - Malignancy
  - Critical illness
    - Shock, sepsis
    - Mechanical Ventilation
**Fundamentals: Code Status Discussions; Steps**

1) Normalize the Conversation
2) Frame the “code event” as unexpected, emergency plan when appropriate
3) Start a conversation
   a) Some people would...
4) Discuss Intubation First
   a) Intubation is part of cardiac resuscitation.
5) Ask if you may make a recommendation
   a) You should make a recommendation!
Remember, there are 3 viable code statuses: full code, DNR, DNR/DNI.
Fundamentals: Surrogate Decision Makers

- Identifying who would make decisions in the patient’s stead if they are incapacitated
- Surrogacy Hierarchy in PA
  - POA
  - Spouse or adult child from previous marriage
  - Other adult children
  - Parent
  - Adult grandchild
  - An adult who knows the patient well
Fundamentals: Communication Techniques

- “Tell me more about ...”
- Ask-Tell-Ask
- “I wish...”
- “I worry...”
Fundamentals: Communication Techniques

- "Tell me more"
  - Useful tool to explore something further; if something doesn’t make sense or you are unsure of the patient’s meaning
Fundamentals: Communication Techniques

- **Ask-Tell-Ask**
  - Asking what the patient understands, telling important information in a concise way, asking for feedback
  - Important to think ahead about what the form of your “tell” will be ahead of time
Fundamentals: Communication Techniques

- “I wish... I worry ...”
  - Allows you to respond to patients in a way that preserves your alignment with them but can acknowledge that reality may not be consistent with their beliefs/hopes
Advanced
Advanced: Goals of Care Techniques

- There are several published frameworks which guide providers through goals of care conversations with patients and families.
- Additionally, communication techniques may aid providers in discussing difficult or distressing information with patients.
Advanced: Goals of Care Techniques, REMAP

- **R**: Reframe
  - Guiding the patient to understand that the reason for the conversation is that we are in a different place now.
  - Start by asking patients what they understand
    - Patients may already be in the “reframe” mindset
  - The reframe may also take the Ask-Tell-Ask form
Advanced: Goals of Care Techniques, REMAP

- **E**: Expect emotion
  - Most often, patient’s first responses to these first steps of GOC are emotional rather than cognitive
  - Many of us have our own intuitive ways to respond to patient’s emotions
  - NURSE is a helpful framework if you get stuck
<table>
<thead>
<tr>
<th></th>
<th>Example</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naming</td>
<td>“It sounds like you are frustrated”</td>
<td>In general, turn down the intensity a notch when you name the emotion</td>
</tr>
<tr>
<td>Understanding</td>
<td>“This helps me understand what you are thinking”</td>
<td>Think of this as another kind of acknowledgment but stop short of suggesting you understand everything (you don’t)</td>
</tr>
<tr>
<td>Respecting</td>
<td>“I can see you have really been trying to follow our instructions”</td>
<td>Remember that praise also fits in here eg “I think you have done a great job with this”</td>
</tr>
<tr>
<td>Supporting</td>
<td>“I will do my best to make sure you have what you need”</td>
<td>Making this kind of commitment is a powerful statement</td>
</tr>
<tr>
<td>Exploring</td>
<td>“Could you say more about what you mean when you say that…”</td>
<td>Asking a focused question prevents this from seeming too obvious</td>
</tr>
</tbody>
</table>
Advanced: Goals of Care Techniques, REMAP

- M: Map out patient’s values
  - After reframing, take time to reflect on the patient’s values
  - Open ended questions which try to elucidate patient’s hopes, fears, wishes that will guide decisions about their treatment
  - Values may be conflicting; attempt to explore these and help patients prioritize their own values
<table>
<thead>
<tr>
<th>Strategy</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asking about advance directives</td>
<td>“Have you ever completed a living will?”</td>
</tr>
<tr>
<td>Asking about values directly</td>
<td>“What’s most important to you now, with what you know about your illness?” “What else?”</td>
</tr>
<tr>
<td>Reflecting on emotion</td>
<td>“You feel sad thinking about the possibility that you won’t see your children grow up. It sounds like time with your children is one of the most important things for you now.”</td>
</tr>
<tr>
<td>Exploring worries</td>
<td>“As you think about the future, what concerns you?”</td>
</tr>
<tr>
<td></td>
<td>“What do you want to avoid?”</td>
</tr>
<tr>
<td>Exploring life outside the hospital or clinic</td>
<td>“What kind of things do you like to do when you’re feeling stronger?”</td>
</tr>
<tr>
<td>Personal experience with medical interventions</td>
<td>“What has chemotherapy been like for you?”</td>
</tr>
<tr>
<td>Family/friend experience with medical interventions</td>
<td>“Has anyone close to you been in the intensive care unit or on a breathing tube? What was that like?”</td>
</tr>
<tr>
<td>Exploring recent quality of life</td>
<td>“How has your life been for the past year since you’ve had more health problems?”</td>
</tr>
</tbody>
</table>
Advanced: Goals of Care Techniques, *REMAP*

- **A: Align with values**
  - Once values are mapped, reflect back to the patient your interpretation of their values and how they match to the current situation
  - This is a hypothesis or interpretation of the information the patient has provided in the mapping phase
Advanced: Goals of Care Techniques, REMAP

- P: Propose a plan
  - Once you are aligned, based on the information from the mapping and aligning phases, propose a plan of action
  - Incorporate values and feasibility/reality of the medical situation
  - Ask for feedback and questions following this
<table>
<thead>
<tr>
<th>REMAP</th>
<th>Physician Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reframe</td>
<td>“You’ve worked very hard with all the treatments over the years, and I hear that now you’re feeling more tired and it’s harder for you to do the things you enjoy. I’m seeing that you’re in a different place now. Further treatments may be too hard on you.”</td>
</tr>
<tr>
<td>Emotion</td>
<td>“What worries you most about this?” “It’s understandable that you would feel sad when thinking about these things.” “This is hard to talk about.” “Is it OK to talk about what this all means for the future?”</td>
</tr>
<tr>
<td>Map</td>
<td>“Tell me about some of the things you enjoy doing.” “What’s most important to you given that time is limited?”</td>
</tr>
<tr>
<td>Align</td>
<td>“From what I’m hearing from you, the most important thing for you is to have time at home, sitting on the porch with your family. You feel like at this point you’ve spent too much time in the hospital, and you wouldn’t want to come back if it could only extend your life a few days or weeks.”</td>
</tr>
<tr>
<td>Propose a Plan</td>
<td>“Given what you’ve told me, I’d propose that we do everything to help you spend time at home with your family. I don’t think more cancer treatment is likely to help with that. I think getting hospice involved would help you do what you want to do with the time you have. What do you think?”</td>
</tr>
<tr>
<td></td>
<td>Setting up</td>
</tr>
<tr>
<td>---</td>
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</tbody>
</table>
| S | - Arrange for privacy.  
- Involve significant others, sit down, make connection and establish rapport with the patient, manage time constraints and interruptions. | - Determine what the patient knows about the medical condition.  
- Listen to the patient's level of comprehension, accept denial but do not confront at this stage | - Ask patient if s/he wishes to know the details of the medical condition, accept patient's right not to know.  
- Offer to answer questions later if s/he wishes | - Use language intelligible to patient  
- Consider educational level, socio-economic background, current emotional state, give information in small chunks  
- Check if patient understand what you have said, respond to patient's reactions as they occur, give any positive aspect first | - Prepare to give an empathetic response  
- Identify emotion expressed by the patient  
- Identify cause/source of emotion, give the patient time to express their feelings | - Close the interview.  
- Ask whether they want to clarify something else.  
- Offer agenda for the next meeting |
Advanced: Family Meeting Framework

- Set the stage
- Pre-meeting
- Introductions
- Explain what is happening (reframe, ATA)
- Empathize (expect emotion, NURSE)
- Bring in the patient’s voice (if absent)
- Plan next steps together (recommendation)
- Reflect/debrief post meeting
Please complete post-survey!

Link in chat
Sources

1. Aahpm.org
6. Vitaltalk.org