

Advance Care Planning: When is the Time Right?

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No Relevant Financial Relationships
with Commercial Interests

No Conflicts of Interest

~ Dr. Prather

Roadmap for Today's Talk

- Advance Care Planning versus Advance Directives
- Physician Orders: POLST / MOLST / MOST
 - What is their purpose?
- Why Advance Care Planning Matters
- When is Advance Care Planning Appropriate
- Palliative Care versus Hospice

Advance Directives, Living Wills, HCPOA:

- Definitions:

- Advance Directive: any document or recording addressing one's future health and usually includes a Living Will and HCPOA
- “Substantive Directives” aka *what one should do*
 - ex: Living Will: spells out one's wishes for future care
 - ex: 5 Wishes
- “Process Directives” aka *who should make decisions*
 - ex: HCPOA: names someone to make medical decisions should you be unable to make them yourself
 - Aka: health care proxy, medical power of attorney, durable power of attorney for health care, appointment of a representative

Limitations of ACP “Documents”

- “Standard” Living will forms often fail to cover the grey zone
 - le: no intubation, if I am in a “terminal state” or “no life prolonging measures if in a terminal state”
- Definitions can be challenging (for families and clinicians!)
- Often completed with persons without clinical training or experience
- Often static
 - Once completed with a lawyer, not routinely revisited
 - People change their minds, may not reflect current preferences
- Cannot be located, don’t know what they say
- These are used to develop plans of care, but are not orders
- Barriers to surrogates implementing preferences
 - Knowledge. Accessibility. Ability.
- Do not provide additional guidance around evolving clinical scenarios

Evolution of Advance Care Planning



Movement towards discussion of Goals:

1) Acceptable functional outcomes

- “Life is worth living as long as I can still sing in the choir.”
- “I want to talk and make sense.” “Sail my boat”

2) Milestone events

- “I want to live long enough to see my daughter’s graduation”

Evolution of Advance Care Planning



- Dynamic and evolving (theoretically! ... if implemented as intended!)
- Once elicited, medical treatments can be tailored to an individual's goals
- Barriers often include time, reimbursement, knowledge
 - Knowledge barriers can be prognostic, clinical, organizational, ...

Legal Documents v Medical Orders

Standard of Care

The current standard of care during an emergency is to do everything possible in an attempt to save someone's life, unless there is a medical order to the contrary.

Advance Care Plan Documents

ACP documents allow individuals to share their treatment preferences in the event they can no longer speak for themselves. There are two kinds.

	Legal Documents	Medical Orders
Includes	<ul style="list-style-type: none">• Advance directives• Living Wills• Health Care Power of Attorney	<ul style="list-style-type: none">• Do Not Resuscitate (DNR) Orders• Physician Orders for Life-Sustaining Treatment (POLST) forms – name varies by state- see www.polst.org
Purpose	Identify a surrogate decision maker. Provide general wishes about treatments individual wants.	Orders emergency personnel to provide specific treatments during a medical emergency.
Who Needs	All competent adults	Seriously ill individuals. POLST Forms are only those individuals for whom health care professionals wouldn't be surprised if they died within a year.
Can be used during an emergency	No. These are used to develop care plans, but are not orders EMS can follow.	Yes. These are medical orders signed by health care professionals.

Why Advance Care Planning Matters

- People find it difficult to predict the type of care they would want in a future theoretical state of health
- People might change their mind! Nearly $\frac{1}{2}$ of elderly persons with significant illness have variation in end-of-life preferences vary over time
- Preferences may change to accept previously unacceptable health statuses (or not accept them!)
- Documents tend to have concrete language that is difficult to extrapolate to complex medical conditions
- If clinicians do not know your preferences clearly, we are at risk of inadvertently interpreting preferences within a clinician's values and beliefs

Why Advance Care Planning Matters

- Convey to individual/surrogate:
 - Scope or complexity of illness & usual course
 - Limits of technology
 - Prognosis
- Define “acceptable” and “unacceptable” quality of life from an individual’s view
- Understand what decisions people are able & willing to participate in
- Establish formal documentation to respect wishes
- Recommendations to align with achieving stated goals

Why Does Advance Care Planning Matter?

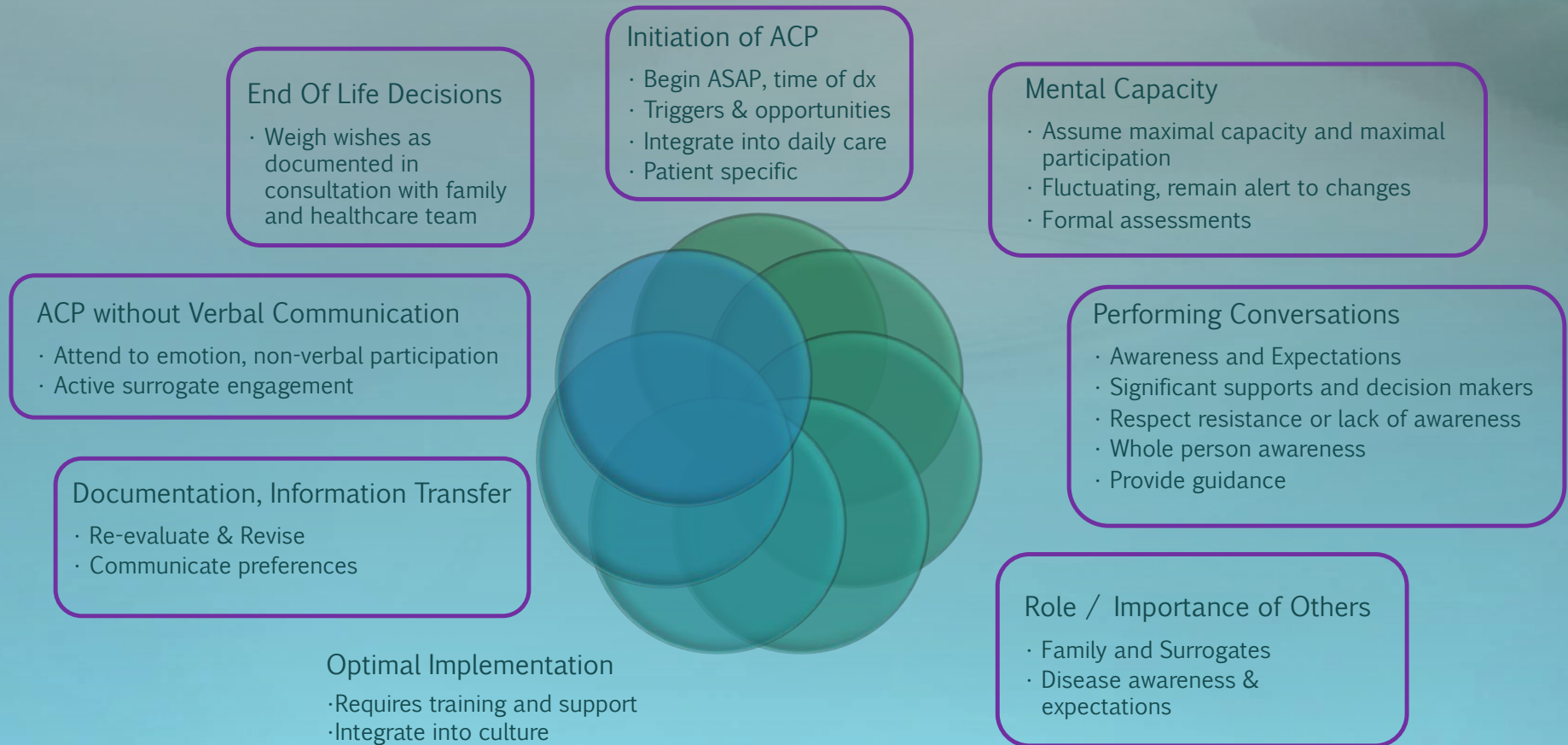
To ensure individual preferences for quality of life and medical care are respected.



When is Advance Care Planning Appropriate in PD?

Guidelines for ACP:

Piers et al. *BMC Palliative Care* (2018)



Advance Care Planning: Core Concepts

Summary of wishes for care in case of serious illness

Health Care Proxy

Decision Making Capacity / Preferences

Questions to Consider

- “When you think about the future, what do you hope for?”
- “When you think about what lies ahead, what worries you the most?”
- “When you think about the future, what are the most important things to you?”
- “What are you hoping for?” “What are your goals?”
- “What are you enjoying these days?”
- “What makes life worth living?”
- “What brings you joy?”
- “What is important for me to know about you as your health care provider?”

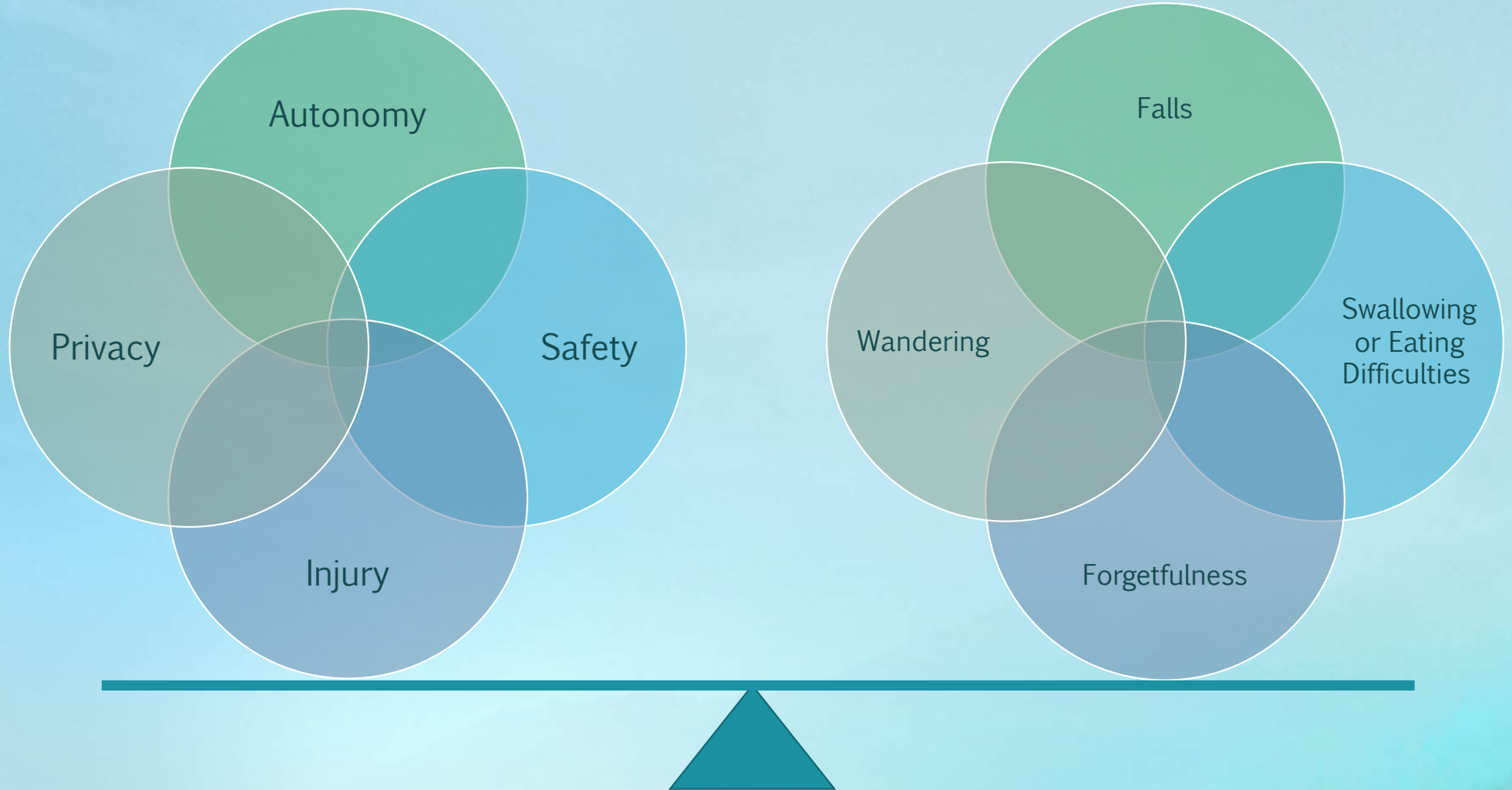
Questions to Consider

- “How do you like to make decisions about your healthcare?”
- “Are there people who support you in making decisions about your health?”
- “Are there any beliefs you have that influence your health care decisions?”
- “Who would you want to make health care decisions for you if you were unable to do so?”
 - “Do they know that?”
 - “Have you spoken about your preferences for care?”

Triggers for ACP Discussions

- A new or worsening symptom
- Sensation that “the medications don’t seem to be helping”
- Feeling that
 - “This isn’t getting better”
 - “I hoped it would help, but it didn’t”
 - “It’s not working anymore”
- New “issue” around every turn
- A hospitalization, especially a rehospitalization
- An emotional response

Areas of Interest in PD





Real Life Application

Case 1: Early/Mild Stage Disease

Mr. Kay comes into the office accompanied by his daughter. He is 69 y/o, with diabetes, COPD, cardiovascular disease and osteoarthritis. He is here for his annual visit. On exam, the physician notices that he has a soft voice, some rigidity, and cogwheeling. On questioning, he had a fall around the holidays. He hasn't noticed the tremor or softening of his voice, but now that it is mentioned, his daughter does observe that yes, these things do seem new and different over the past year.

Early/Mild Stage disease

- Individuals often retain capacity and can participate in decision making
- Living wills, financial power of attorney and other legal documents should be completed at this time
- Brain donation/autopsy if desired by pt should be secured now
- Advance care planning discussions should begin
- Can an individual truly imagine a realistic future? Can they forecast their needs/desires a decade forward?
- www.dementiadirrective.org

Stage 1 -- Mild dementia

People may often lose ability to remember recent events in their lives.

Routine tasks become difficult (such as cooking.) Some tasks can become more dangerous (such as driving.)

If you were to be at this stage of dementia what level of medical care would you want for yourself?

Stage 2 -- Moderate dementia

People lose the ability to have conversations, and communication becomes very limited.

People lose the ability to understand what is going on around them.

People require daily full-time assistance with dressing and sometimes toileting.

If you were at this stage of dementia what level of medical care would you want?

Stage 3 -- Severe dementia

People are no longer able to recognize loved ones and family members. People may be awake through the night, disruptive, and yelling.

Some may be calm or serene most or all of the time, but many become angry and agitated at times, and sometimes even violent toward people they love.

People need round-the-clock help with all daily activities, including bathing and wiping off their genitals, generally needing to wear an adult diaper at all times.

- ☐ **To live for as long as I could.** I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.
- ☐ **To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine.** Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.
- ☐ **To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill,** and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.
- ☐ **To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness.** I would not want any care that would keep me alive longer.

<https://dementia-directive.org/>

Case 2: Mild-Moderate Stage Disease

72 yo M with cognitive impairment and Parkinson's Spectrum Disorder (atypical DLB v early cognitive loss in PD v MSA) presents to memory clinic for evaluation of memory loss and advance care planning on referral of his neurologist. He lives with his wife in the community. At time of first assessment, he and she report he has limited cognitive deficits, management is primarily on motor symptoms and dysphagia. Referred for a swallow evaluation, results pending. Several falls, no injuries. Discussed dopamine replacement therapy with his neurologist but wants to save it for when "I get worse and really need it." On initial assessment, HCPOA and living will reportedly documented as having been completed by a lawyer. HCPOA is a niece, neurologist. No children.

Advance Care Planning: Lay the Groundwork

- Initiate discussions at time of diagnosis or first contact
- Incorporate key players (build your team!)
 - Surrogates, family, other health care providers
- Establish role and purpose of discussions (“it’s my job”)
 - “My most important job is to get to know what is important to you, so that we can make medical decisions that reflect your wishes and I can make recommendations that are right *for you*.”
- Identify common ground
 - Prior documentation as framework for future discussions
 - Beginning discussions are key clinical issues or perceived concern areas
- Identify potential areas that could impact quality of life

Case 2: Mild-Moderate Stage Disease

Follow-Up Visit:

- Experiencing progressive dysphagia
- Reluctant to try dopamine replacement
- Additional fall

Integrating Opportunities for ACP

- Recognize opportunities to discuss disease progression or clinically important events as springboards for discussion
 - Feeding difficulty
 - New or worsening frequency of falls
 - Injury or a *near miss*
 - Changing behavioral or neuropsychiatric symptoms
 - Emergency room visit or hospitalization
 - New clinical diagnosis or time when care is being referred
 - Change in living situation or needs

Case 2: Mild-Moderate Stage Disease

Outcome of Visit:

- Family and patient with increased awareness of dysphagia implications on health and QOL as well as being a sign of disease progression and risk factor for complications (ex pneumonia)
- Family and patient with increased understanding of spectrum of motor and cognitive symptoms in Parkinson's Spectrum Disorders as well as risks and benefits of dopamine replacement
- Patient's Decision: Trial of dopamine; modified diet; feeding tube if needed with limits; invitation to talk to his HCPOA

ACP Pearls for the Clinical Team (In A Nutshell)

- Identify priorities and values:
 - “What brings you joy?” “What makes life good?” “What could you not live without?”
- “Can you imagine a time?” statements
- Identify a surrogate and engage in discussions if possible
- Educate re limits of prior advance directives and how they may be implemented going forward
- Introduce additional documentations more appropriate for advancing disease states: MOLST, POLST, MOST

Late Stage Disease Considerations

- Medical: Feeding/nutrition and mobility challenges are prominent
- Location: Do needs outstrip what can be provided in the setting? Can the care setting meet the needs?
- Hospitalization: Recurrent acute care needs; Variable rehabilitation
- Caregivers: Are resources appropriate? How can needs otherwise be met? What is the risk or level of caregiver burnout?
- Knowledge: What are you hoping for?
- Hospice: When is hospice appropriate? Can hospice be implemented in a way that meets an individual's needs? What are the barriers to the hospice benefit?

Things that may be difficult to consider

- “We know that people with advanced neurologic disease, like Parkinson’s, at some point have trouble eating. Most people get little benefit from artificial nutrition and in many cases, it can make them worse.”
- “We know that people with neurologic disease at some point stop eating. It is the disease itself that leads to death and refusing food or stopping eating, is the body’s way of shutting down.”
- “Hoping that your loved one will get better/stronger with artificial nutrition is understandable. If we start artificial nutrition through a feeding tube, what are you hoping will happen?”

End-of-Life Care Transition Patterns of Medicare Beneficiaries by Shi-Yi Wang et al JAGS

- 1/3 of the Medicare beneficiaries (218,731) who died in 2011 had four or more transitions within their last 6 months of life
- More than 80% decedents (n = 556,437) had at least one transition within the last 6 months of life
- The most-frequent transition pattern (19.3% of all decedents; n = 127,435) was home to hospital, back to home or skilled nursing facility, to hospital again, and then to settings other than hospital, ending with four or more transitions.

Why Does Advance Care Planning Matter?

To ensure individual preferences for quality of life and medical care are respected.



A Venn diagram illustrating the relationship between Palliative Care and Hospice Care. It consists of two concentric ellipses. The outer ellipse is light blue and contains the text 'Palliative Care' and 'Symptom management of a life-limiting illness.' The inner ellipse is light red and contains the text 'Hospice Care' and 'Symptom management and comfort care at the end of life.' The inner ellipse is entirely contained within the outer ellipse, indicating that hospice care is a subset of palliative care.

Palliative Care

Symptom management of a life-limiting illness.

Hospice Care

Symptom management and comfort care at the end of life.

Palliative Care

- Palliative care is specialized medical care for people with serious illness. It is focused on providing patients with **relief from the symptoms**, pain, and stress of a serious illness, whatever the diagnosis. The goal is to **improve the quality of life** for both the patient and the family.
- Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is **appropriate at any age and at any stage** in a serious illness and can be provided along with curative treatment.
- <http://capc.org> Center to Advance Palliative Care

What is Palliative **CARE**?

Care **D**ecisions, including open discussions about treatment options when diagnosed with a serious or chronic illness and the importance of Advance Care Planning

Addressing **O**verwhelming **S**ymptoms, for example, pain, shortness of breath, fatigue, nausea, loss of appetite and difficulty sleeping

Recognizing **P**sychosocial **D**istress that may include anxiety, depression, fears and spiritual tension

Emphasizing **Y**OU with a focus on the entire person including family

<https://healthcare.ascension.org/Specialty-Care/Palliative-Care-Medicine>

Hospice

- Medicare hospice benefit (and most other insurances)
- Hospice is a program of **care and support** for people who are terminally ill. The **focus is on comfort, not on curing** an illness. Care is generally provided in the home. The doctor and the hospice medical director certify **prognosis is expected to be 6 months** or less if illness runs its normal course.
- A **specially trained team of professionals and caregivers** provide care for the “whole person,” including his or her physical, emotional, social, and spiritual needs.
- Services may include physical care, counseling, medications, equipment, and supplies for the terminal illness and related condition(s).

Electronic Resources

- <https://TheConversationProject.Org>
 - Conversation guides online, resources in many languages, free
- <https://PrepareForYourCare.Org>
 - Step-by-step program with video stories to guide thinking, online directive to print out, English & Spanish, free
- <https://mydirectives.com>
 - Online, update and share anytime, mobile app allows creation of video messages that connect to the directive, free
- ❖ <https://dementia-directive.org/>

Thank You For Time and Open Minds

- This talk is dedicated to the family of my lifelong friend and college roommate, with whom all tough things are just a bit easier
- Christina Pernia Prather, MD
 - cprather@mfa.gwu.edu
 - Twitter: @DocPrather

