

Palliative Care and Advanced Care Planning

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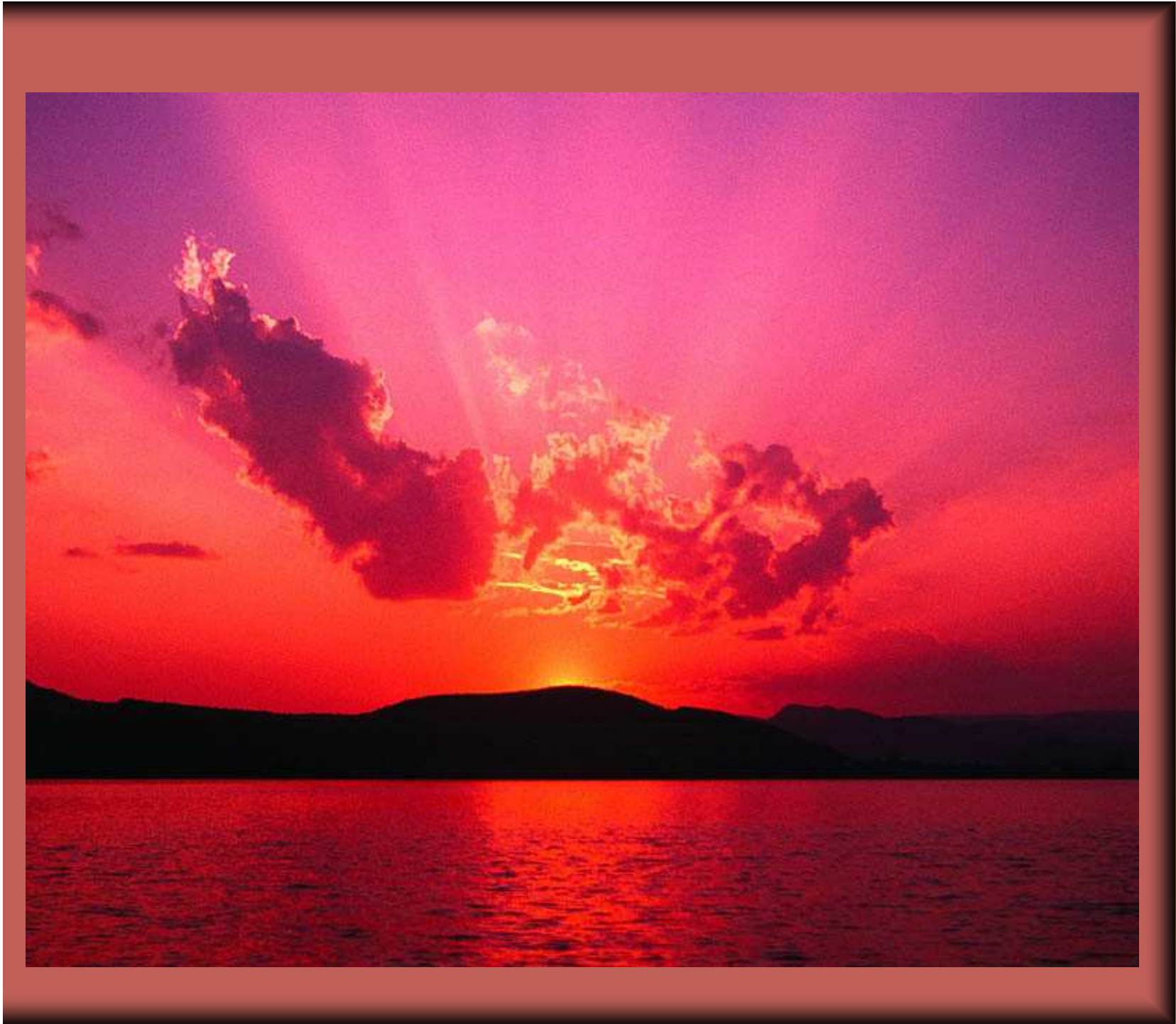
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Learning Objectives

- Define Palliative Care.
- Define Advance Care Planning.
- Describe the skills needed to engage in effective conversations with your family and your physician.
- Identify key points in a serious chronic illness in which to discuss palliative care goals.
- Learn how to clarify treatment goals.
- Identify appropriate times to discuss comfort care and hospice during ACP Planning Conversations.





Palliative Care Definitions

- Comprehensive care of patients who are living with a chronic illness.
 - Alleviate symptoms (physical, emotional, spiritual, social)
 - START at time of diagnosis
 - BLEND palliative and curative tx
 - Focus on patient goals and QOL.
 - Requires a team approach.
 - Involve family and friends.



Palliative Care Descriptions

Goals of Palliative Care





- ❑ Determined by patient goals, values and choices.
- ❑ Primary Goal is to relieve symptoms and suffering whenever possible.
 - ❑ Achieve the best possible QOL for patient and family.
 - ❑ Assist patient and family to live well with their illness during curative and palliative phases.

❑ Maintain hope and reassess goals of care



Advance Care Planning Definition

Advance Care Planning

-  A process which assists individuals, their family, friends and advocate to:
 -  reflect upon, discuss, understand and plan current and future care choices based upon the values of the patient.
-  An organized approach to initiating thoughtful and respectful conversations:
 -  Regarding the person's current state of health, goals, values/preferences for treatments at various points in the illness, esp. at the end of life.



When to Discuss Palliative Care

- At the time of sharing a diagnosis of a chronic illness
 - Relief of symptoms
 - Impact on a person's lifestyle
 - Impact on person's self-image and concept's of self and life-roles
 - Meaning that the person places on this illness or chronic disease diagnosis and treatments



When to Discuss Palliative Care

■ Major changes in Course of Disease

- Lack of benefit of standard treatments
- Change in personal experience of illness – change in person's goals
- Disease changes that affect family dynamics

■ Physicians: “Would you be surprised if this patient died within the next year?”

■ Patients: “Tell me, what is it like to live with your illness, now?”





ACP: The Process

- Shift from crisis mode to engaging in reflective conversation with the person and family.
- Develop partnership
- Identify patient values and choices
- Build trust
- Commit to the conversation



ACP: The Process

- Clinicians: honor a person's choices, values and decisions
- Individuals: articulate values and improve knowledge of HC status
- Holistic Focus: patient concerns, experience of current illness, short and long-term goals, personal values, prognosis








ACP: The Process

- Discuss choices, values and treatment approaches with:
 - Family members
 - DPOA-HC
 - Your physician
 - Friends
 - Clergy or Spiritual Advisor
- Gives moral direction and emotional comfort to family



ACP: The Process

BENEFITS OF ACP

-  Enhances the patient-physician relationship
-  Increase in patient belief that the physician cares about them
-  Increase in patient belief that the physician understands and values their preferences
-  Enhances the quality of the conversations
-  Enhances the commitment to having conversations with family and friends



Basic ACP Facilitation Skills

- Affirms your relationship with the patient
- Schedule appropriate time(s) for these discussions
- These discussions are an element of good primary care
- Initial goal: explore issues, understand their preferences, and answer questions
- Affirm the importance of palliative care all along the spectrum of their illness





ACP Planning with Healthy Adults

- Acknowledge that this type of planning may be difficult – and offer appropriate reflective emotional support
- Allow time for patient to discuss their illness experience and their current and long-term goals
- Let patient know that they have time to reflect upon and discuss goals/choices with you and those they love over time
- First visit is not necessarily the time for any final decisions!



ACP Planning

- The conversation is more important than any particular document
- It is vital that the person you choose as DPOA-HC is included in the conversation!
- This person must be comfortable speaking with physicians, with being in a hospital or NH... AND –
- Be able to articulate your choices as written in your Adv Directive and your conversations; when you have lost your capacity to make treatment decisions.
- 5 Wishes Advance Directive Document



ACP Planning with Healthy Adults

- Have the patient reflect upon their personal values, beliefs, or cultural values in light of their treatment or care goals.
- Have them consider who they would choose as their DPOA-HC in light of the above.
- Affirm the need for good quality time to engage in appropriate conversations on these issues.
- Assure them that you or others on the team will assist them when needed during this process.



Spectrum of Palliative Care

- ACUTE CARE: Focus on aggressive treatments for cure.
- PALLIATIVE CARE: Focus on relief of symptoms for comfort and improvement of QOL.
 - Active comfort and urgent palliation
 - May relieve symptoms within minutes, hours, days or weeks



Spectrum of Palliative Care

- Active: active investigations and treatments that modify the disease and relieve symptoms - -
 - Chemotx, hormonal tx, antibiotics, steroids, oxygen, radiation tx, surgery, etc.
- Comfort: Tx goal is comfort and relief of suffering - -
 - Opioids, benzos, NSAIDS, antidepressants
 - Relaxation tx, meditation, prayer, counseling, art, music, aroma tx, etc.




Spectrum of Palliative Care

Urgent: Symptom emergencies

 Pain crisis ($\geq 5/10$)

 Sudden complications:

 Severe dyspnea, anxiety, restlessness, intractable nausea, seizures, severe mental status changes

 Treat with appropriate medications or other treatments





ACP Skills for Adults with a Chronic Disease

- Opportunity for patient and physician to discuss patient values and goals of care
- Address information and/or understanding gaps
- Slow trajectory of chronic illness – many exacerbations and times of relative health
- Opportunity for multiple conversations over time - -
- continuity of professional relationship



Chronic Disease Skills

■ Initial conversations:

- Explore attitudes and concerns
- Discuss values and beliefs, answer questions, clarifications

■ “At this point, how can I help you live well?”

■ Provide the patient with examples of how her particular disease is likely to progress...

- Treatment decisions she is likely to face in the future
- What situation would be worse than death?



Chronic Disease Skills

- Provide the patient with typical outcomes
- Offer treatment options and reasonable approaches
- Discuss personal and/or spiritual impact of her decisions
- Discuss financial impact of decisions
- Offer opportunity to discuss her experiences and possible choices with others with same diagnosis
- Make as many follow-up appts as needed to complete the discussion..



Discussions with Adults with a new Serious Medical Illness

- Determine if the person is well enough and capable of having a conversation
- Provide an opportunity to discuss concerns and fears
- Offer support and be open, use supportive listening
- Goal of ACP: to understand how you want your care to proceed and respect your choices



Clarification of Treatment Goals

■ Prepare for the conversation

- Review the case facts, identify concerns of the person, family, other physicians, etc
- Know the family dynamics




■ Prepare the Interview Atmosphere

- Arrange for uninterrupted time
- Silence phones, pagers, radio, t.v., mp3s ...
- Include appropriate family members
- Sit close to patient and use appropriate touch during the discussions



Clarification of Treatment Goals

Arrange Emotional Atmosphere

-  SIT DOWN
-  Make appropriate introductions
-  Be sure facial tissues are in the room

Assess the person's knowledge and emotional response to current illness and treatments

Assess how much the person wants to know



Clarification of Treatment Goals

■ Sharing Information:

- Use plain language
- Adapt to the person's style
- Fire “warning shots” - - “I’m afraid the situation is worse than we thought...”

■ Stop frequently to assess the person's understanding of shared information

■ Provide information about prognosis



Clarification of Treatment Goals

- Elicit and respond to person's feelings
- Use therapeutic silence and touch appropriately
- Provide reassurance, support and hope
- Make a follow-up plan



Clarification of Treatment Goals

- Help patients and families understand the diagnosis and prognosis
- Identify key concerns of patient and family or surrogate concerning the disease progress, current sx, and need for rethinking tx goals
- Work on an interdisciplinary plan
- Provide ongoing guidance and support





Comfort Care And Hospice Discussion Points

- Relief of symptoms and patient comfort are goals throughout the illness
- Clue for the doctor to switch focus from curative to comfort and palliative focus:
 - “Would I be surprised if this patient died within the next year?”



Comfort Care and Hospice Discussion Points

- When the patient is exhibiting physical signs of end-stage illness, significant physical decline, or is not responsive to the usual curative tx's
- Need to discuss palliative or comfort care, and hospice care as the best path of comprehensive and compassionate care for the patient and family at this point of their illness journey



Hospice Discussion Points

- Demystify hospice - - not a place to die; it is a comprehensive program of coordinated and compassionate care for the patient and family for patients with a life-limiting illness.
- Hospice recognizes the patient as a complex human person with many dimensions: spiritual, physical, emotional, and social.



Hospice Discussion Points

- Demystify and correct misconceptions regarding diagnosis, prognosis and beneficial treatments
 - REMEMBER, CPR is a Treatment!!
 - Use reframing to help the family or patient recognize other perspectives
- Help the family and patient identify sources of personal and spiritual strength



SUMMARY POINTS

- ACP is a **PROCESS**
- ACP is an on-going conversation with the patient, family members, DPOA, physician, and other trusted advisers
- It is very important to choose a person who will be your advocate to:
 - Be a person you trust
 - Be a person who can comfortably share your goals and choices for treatments with your doctor and other family members
 - Be comfortable in the hospital or nursing home settings



SUMMARY POINTS

- ACP is an organized communication approach to assure that your values and choices are honored throughout your illness.
- The DPOA-HC function is valid only when you have lost all capacity to make decisions about your care.
- These conversations need to be on-going, and should occur when your illness changes significantly or you have new insights regarding your illness experience.
- Review your adv directive at least every couple of years if healthy, annually if you have a serious illness.
- Inform your doctor, DPOA-HC of any new updates!



SUMMARY POINTS

- Palliative care is the comprehensive care of patients living with a chronic illness and their families
- Hospice is a comprehensive program of compassionate services to assist the patient with a life-limiting illness and their families
- Both focus on relief of symptoms and improving the QOL of the patient
- Both recognize the importance of an interdisciplinary team
- Both recognize that the human person is the focus, in all our complexity, not a physical disease to be “conquered”.



