

ACC Advance Care Planning Terms to Know

Use this tool as a reference at any point during the clinical encounter to look up commonly used terms in Advance Care Planning (ACP) with a patient, family, and support network. It can also be supplemental material for training residents and fellows. Use of this tool can decrease confusion for patients and clinicians which can improve the patient experience, patient satisfaction, and patient involvement in shared decision making.

GENERALLY RECOGNIZED TERMS:

Advance Care Planning

An ongoing process in which a patient, their family, caregivers, and healthcare providers explore the patient and caregiver's knowledge, fears, hopes, and needs to be able to:

- reflect on the patient's goals, values, and beliefs
- discuss how patient's goals, etc. can inform current and future medical care
- accurately document patient's future healthcare choices.

Decision-Making Capacity

A patient's psychological ability to understand information about the treatment decision, use the information rationally, appreciate the consequences of those decisions, and communicate their personal decision.

Shared Decision Making (SDM)

A model of patient-centered care that enables and encourages patients to play a role in the medical decisions that affect their health in which the healthcare provider and patient work together to make a healthcare decision that best meets the patient's values and preferences and reasonable treatment options. The optimal decision takes

into account evidence-based information about available options, the provider's knowledge and experience, and the patient's values and preferences.

It operates under two premises:

- First, patients or their representatives should participate in the medical decision-making process by expressing personal values and opinions about their conditions and treatment options.
- Second, clinicians will respect patients' goals and preferences and use them to guide recommendations and treatments.*

Treatment Decisions

These include any decisions to provide, withhold, or withdraw informed consent to any kind of medical care including, but not limited to, medical and surgical treatments, life-prolonging interventions, psychiatric treatment, nursing care, hospitalization, treatment in a nursing home, home healthcare, and organ donation.

*Strategy 6I: Shared Decisionmaking homepage. Available at: <https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/6-strategies-for-improving-communication/strategy6i-shared-decisionmaking.html>. Accessed August 22, 2017.

STATE SPECIFIC TERMS:

Advance Directive (Health Care Directive or Advance Health Care Directive)

Clinicians can download state specific information [here](#) and [here](#).

Legal treatment-directing documents completed by a patient who possesses decisional capacity on how treatment decisions should be made on their behalf if they lose their capacity to decide. Each state identifies accepted advance directives, forms and processes for completion.

The following is a list of possible Advance Directives:

- Durable Power of Attorney for Healthcare (DPAHC)
- Living Will
- State-created advance directives
- Five Wishes

These documents become legally valid as soon as they are signed in front of required witnesses, remain in effect until changed, and can be revoked orally.

Combined Directive

Clinicians can download state specific information [here](#) and [here](#).

An advance directive document which designates a surrogate decision maker and may include:

- components of a Living Will or statements about preferences for approach to care in a variety of clinical states,
- a Values History
- an Instructional Directive.

The [“Five Wishes”](#) is a popular example of this kind of document.

Durable Power of Attorney for Healthcare (DPOA/HC) also known as Healthcare Power of Attorney or Medical Power of Attorney

Clinicians can download state specific information [here](#) and [here](#).

An advance directive form through which a patient authorizes a person(s), also known as a surrogate, to make only healthcare/medical decisions on their behalf, if they lose decision-making capacity.

Durable Power of Attorney for Healthcare (DPOA/HC) also known as Healthcare Power of Attorney or Medical Power of Attorney

Clinicians can download state specific information [here](#) and [here](#).

The person(s)/surrogate(s) named by a patient in the Durable Healthcare Power of Attorney document who has the legal authority to make healthcare decisions for the patients when they are incapacitated.

When a patient who loses decision-making capacity has not specified a DPOA/HC, each state has identified a hierarchy that determines how decisions will be made for them.

Healthcare Agent, Proxy, Representative or Surrogate

Clinicians can download state specific information [here](#) and [here](#).

The person(s)/surrogate(s) named by a patient in the Durable Healthcare Power of Attorney document who has the legal authority to make healthcare decisions for the patients when they are incapacitated.

When a patient who loses decision-making capacity has not specified a DPOA/HC, each state has identified a hierarchy that determines how decisions will be made for them.

Instructional Directive

Clinicians can download state specific information [here](#) and [here](#).

A document asking patients to decide in advance which of a set of possible medical interventions they would pre-

fer in the event of specific scenarios (e.g., coma with no chance of recovery, coma with a small chance of recovery, advanced dementia plus terminal illness).

These documents often do not cover the most common late-life scenarios and do not differentiate short-term versus long-term interventions. They are often bulky documents that can overwhelm a patient.

Living Will

Clinicians can download state specific information [here](#) and [here](#).

An advance directive document that addresses a patient's wishes about using, withholding or withdrawing life-sustaining treatment such as resuscitation and life support, but may also cover preferences about hospitalization, pain control, future treatments (e.g., chemotherapy for cancer, tube feedings in the case of dementia, ventilation in the case of respiratory disease, dialysis in the case of renal failure, organ/tissue donation, etc.).

Physician or Medical Orders for Life-Sustaining Treatment (POLST or MOLST) or Physician or Medical Orders for Scope of Treatment (POST or MOST)

POLST information can be found [here](#).

Physician signed standing medical orders for emergency care that are transportable (valid across healthcare settings and facilities and also by EMS) which delineate the specific care that should be given or withheld for end-of-life treatment.

These orders are designed for patients with higher likelihoods of dying. They are particularly useful as a patient transitions through healthcare institutions (hospital, nursing care, home care) and are reviewed and updated as needed based upon changes in the patients' conditions.

While individual states and regions implement their own POLST programs with variance in name (e.g., MOLST, MOST, and POST) and content of their forms, a National POLST Paradigm program exists to “promote the essential elements of a POLST Paradigm Program”

Values History

Clinicians can download state specific information [here](#) and [here](#).

A questionnaire that asks patients to state their religious background, views on dependency, attitude toward physicians, and the aspects of life that are most important to the patient in order to provide information on how they would want to die.

ACC Advance Care Planning Conducting the Conversation

Use this tool to help facilitate multiple, in-depth conversations with a patient about Advance Care Planning (ACP). ACP is an ongoing discussion with a patient, family and caregivers about the patient's values, beliefs and goals for their medical care. These conversations may be difficult, but they improve the quality and length of life for a patient and can address anxiety, stress and depression among family and friends. This table is a general framework to help a clinician conduct a conversation with a patient about ACP.

CREATE THE SETTING:

ACP should be discussed early in the treatment process before there is an acute healthcare issue. Certain cardiac conditions, such as Stage III or IV heart failure, have an unpredictable clinical course, so it is important to normalize the conversation as a part of clinical care. Having these discussions during a planned visit gives patients time to gather and review documents and think through concerns and questions.

Many patients feel better after ACP discussions, but they may feel awkward bringing up ACP. When clinicians inform patients that the purpose of ACP is to give patients control of their care, this can reduce resistance to having conversation and minimize uncomfortable feelings.

ACP can occur when the patient is first seen, annually during routine check-ups, after a hospital discharge and when there is a change in the patient's condition.

Throughout the discussion, clinicians should use language that is at the patient's educational level; avoiding euphemisms and medical jargon.

Some cultures focus on family-oriented and spiritual or religious decision-making, so it is important to ask how decisions are made for the patient and who plays a role in those decisions.

When a patient seems reluctant to having an ACP conversation, ask the patient who they would like to have speak on their behalf.

Steps:	Useful Questions and Statements:
1. Set the Stage	
2. Ask for other participants who should be present	<p><i>"Is there anyone else you would like to include in our discussion of your long term medical plans?"</i></p> <p><i>"Who else would you like to be a part of our conversation?"</i></p> <p><i>"Are there any family members, friends or religious leaders who you would like to be a part of our conversation?"</i></p>
3. Seek Permission	<p><i>We try to talk about goals of care with all new patients and annually thereafter. Can we do that now?"</i></p> <p><i>"What would you like to know about your condition and your prognosis? (Note that about 1/5 patients may not want to know their prognosis.)"</i></p>
4. Go over patient's communication preferences	<p><i>"How do you like to get information?"</i></p> <p><i>"Do you like to hear details or hear about the big picture?"</i></p> <p><i>"Is it OK if I speak directly?"</i></p> <p><i>"Would you like more details about your diagnosis and prognosis?"</i></p>
5. Normalize the content by including it in conversations about preventive health	<p><i>"Previously, we've talked about . . . (state topics such as medication changes, lifestyle modifications). Looking forward, have you thought about who you would like to make decisions for you if there is a time you cannot speak for yourself?"</i></p>

ASKING APPROPRIATE QUESTIONS:

Ask questions throughout the conversation that clarify, empathize and show active listening. Make sure to name and respond to emotions as they are expressed. Gently correct misinformation as it comes up.

Using such phrases as:

- "Tell me more."*
- "I can see that this has been really hard on you."*
- "It must be difficult to feel ..."*
- "That sounds really hard..."*
- "I can only imagine how it would be..."*
- "What I've heard you say is _____. Is this correct?"*

Each of these phrases can help the patient feel understood, advance the conversation and provide a way for the patient to clarify their thoughts and emotions.

Discussing the patient's values and preferences covers a wide variety of subjects including his/her hopes, thoughts about meaning and acceptable quality of life.

Identifying what is most important to patients now and in the future helps to frame ACP within their goals for care. Goals for care are ideally arrived at jointly by the patient and the clinician, based on patient preferences and what is medically reasonable. Emphasizing the patient's goals and values is crucial to their care management.

Steps:	Useful Questions and Statements:
6. Understand the Patient's Perspective of Illness	<p><i>"Tell me what you believe is going on with your illness."</i></p> <p><i>"What have the doctors told you?"</i></p> <p><i>"How do you see things now?"</i></p>
7. Discuss patient's hopes and what brings meaning or purpose to his/her	<p><i>"What are you hoping we can do for you?"</i></p> <p><i>"What are your hopes for treatment?"</i></p> <p><i>"What are you hoping for?"</i></p> <p><i>"Are there things you are unable to do now that you hope to be able to do?"</i></p> <p><i>"Given your current health state what do you hope for?"</i></p> <p><i>"Looking back, what has been most important to you?"</i></p>
8. Explore patient's thoughts on an acceptable quality of life	<p><i>"Are there conditions in which you would not want to have doctors try to keep you living?"</i></p> <p><i>"What is most important to you?"</i></p> <p><i>"If you were unable to care for yourself and needed others to care for you, how would that be for you?"</i></p>
9. Address Patient's Fears and Worries	<p><i>"What are your concerns and worries?"</i></p> <p><i>"Is there anything you are worried about?"</i></p> <p><i>"What are you most worried about?"</i></p> <p><i>"What are the most difficult things for you?"</i></p> <p><i>"When you think about the future, what are you most concerned or frightened about?"</i></p>
10. Talk through patient's strengths and the role spirituality/faith/religion in his/her life	<p><i>"Do you have cultural or spiritual beliefs that are important to you?"</i></p> <p><i>"What role does spirituality or religion play in your life?"</i></p> <p><i>"Who/what supports you the most?"</i></p>
11. Ask Questions Specifically About Durable Power of Attorney/Health Care	<p><i>"If you couldn't speak for yourself, who would you like to make medical decisions for you? Have you talked with that person about what you would want and not want? What did you say?"</i></p> <p><i>"How would you like decisions to be made about your medical care?"</i></p>

TELL AND PARTNER:

It is important to provide education about the patient's diagnosis, prognosis and details of specific medical interventions, as some patients think they have more time than they actually do.

Steps:	Useful Questions and Statements:
12. Identify and Normalize Uncertainty	<i>"Like many things, we don't know what will happen."</i>
13. If the patient wants to know, present average life expectancy with the possibility for exceptions Discuss possibilities in terms of time, functionality, quality of life and symptoms Describe what the patient can expect with built in uncertainty	<i>"Some individuals live longer, and we hope you will. But some individuals live shorter, so we need to make sure you are prepared for that possibility."</i>
14. Identify your own goals as a clinician, link those to the patient's priorities and identify plans	<i>"<Heart failure> is a disease that can last for years, but it does shorten your life. My goal is to work with you to do our best to help you____." "Are there any special events you are looking forward to?"</i>
15. Make recommendations such as: "Hope for the best, plan for the worst"	<i>"I hope you can do that, but in case things don't go as we both hope, what things should be done now to prepare?" "We hope you can do _____. But if you are not able to, let's make a plan for what we'd do if things don't go as we hoped."</i>

ASK FOR PATIENT FEEDBACK:

Patients need help understanding all the information and options clinicians provide. Encouraging patients to ask questions gives them an opportunity to clear up any confusion or misunderstanding. They may also have some emotions that they need to express about the ACP conversation.

Steps:	Useful Questions and Statements:
16. Allow Patients to Ask Questions	<i>"What I'm hearing you say is ___. Is that right?" "What are your questions?"</i>

WRAPPING UP:

Providing a synopsis of the conversation, with specific highlights about the patient's needs, can help the patient feel heard. Going over the patient's care plan can help the patient feel more at ease with his/her illness and management.

Provide printed and online resources for patient-oriented information.

Steps:	Useful Questions and Statements:
17. Summarize Goals and Next Steps	<i>"So this is what we've discussed today..."</i> <i>"It sounds as if your goals are to___. We need to find a way to best meet those goals based on what is reasonable for us to offer you from a medical <and surgical> standpoint."</i>

DOCUMENT AND COMMUNICATE WITH THE CLINICAL TEAM:

Steps:	
18. Document the conversation and plan in the chart/EMR using a template	
19. Communicate the discussion with your team and the patient's other providers	

Further references can be found in the PINNACLE ACP Toolkit References document.

Goodlin, S. (2012). Ethics and End-of-Life Approaches to the Patient with End-Stage Cardiovascular Disease [PowerPoint slides]. Retrieved from http://www.cardiologyinoregon.org/2012_Symposium/Speaker_Presentations/Goodlin-Ethics.pdf.

LeMond, L. and Goodlin, S. J. "Management of Heart Failure in Patients Nearing the End of Life—There is So Much More To Do." *Cardiac Failure Review*, 2015; 1(1), 31-4.

Whellan, D.J., Goodlin, S.J., Dickinson, M.G., et al. "End-of-Life Care in Patients With Heart Failure." *J Cardiac Fail*, 2014; 20: 121–134.

Further information can be found in the PINNACLE ACP Toolkit References document found on CVQuality.ACC.org