





Underscoring the importance of advance care planning

Abstract: Advance care planning is an essential part of routine medical care. It is a billable, iterative process that can result in the completion of advance directives and medical orders, offering NPs the opportunity to assure goal-concordant care for their patients at the end of life.

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Advance care planning (ACP) is an essential, though often overlooked, part of basic medical care. In 2016, a consensus panel of legal experts, clinicians, researchers, and policy makers described ACP for adults as “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 ACP is to help ensure that people receive medical care consistent with their values, goals, and preferences during serious and chronic illness.”¹ ACP can be a rewarding process, offering NPs the chance to better know their patients and advocate for their goal-concordant care over time. This article will address ACP in adults.

For healthy individuals who do not have an underlying chronic or life-limiting illness, NPs should focus primarily on facilitating the selection of a surrogate decision-maker in the event an individual is incapacitated by an accident or illness and is no longer able to make decisions for themselves. While many healthy individuals, especially young people, may not understand the importance of ACP for them, there have been a number of historic cases that would prove otherwise. For example, in 1990 Terry Schiavo suffered cardiac arrest at the age of 26. Having survived this event, she lived for the next 15 years

in a persistent vegetative state while her parents and husband fought with each other in court over the removal of her feeding tube.² In similar cases, Karen Ann Quinlan and Nancy Beth Cruzan both fell into persistent vegetative states in their early 20s, resulting in lengthy court cases over their right to die.³ Though these well-known historic examples were in part the impetus for the push in ACP today, it is worth noting that even in 2019, the leading cause of death in individuals ages 1 to 44 in the US was unintentional injury.⁴ For those ages 15 to 44, malignant neoplasms and heart disease were also among the leading causes of morbidity and mortality.

To better understand the thoughts of ACP in healthy young adults, a 2015 focus group study found that while some participants believed age to be a protective factor, others believed it to be a motivator.⁵ Of significance to this age group was the desire among participants to make autonomous decisions and though most participants in the study felt ACP was a valuable process, lack of adequate information was a significant barrier. Educating young adults about the process will help empower autonomous decision-making as well as prepare them in the event that they become surrogate decision-makers for others. Including ACP as a part of routine

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medical care, similar to discussion of other health promotion activities, such as wearing a seat belt or following up with routine vaccinations, will help normalize the process for all adults young and old.⁶

For individuals with chronic or life-limiting illnesses, the ACP process is somewhat more involved. In addition to supporting the appointment of a surrogate decision-maker, key components of the ACP process should include educating individuals and their families about their illness trajectory and an open discussion of where they may be on that trajectory; the types of treatment decisions that may need to be made toward the end of their life based on their condition; eliciting individual values and goals about end-of-life care; and supporting the process of decision-making on future treatments based on those values and goals.⁷

For many, patients and providers alike, the ACP process can be a daunting task and some may shy away from discussion of ACP. This is especially true for healthy adults who may not be at the end of life. The Institute for Healthcare Improvement “Conversation Ready” initiative suggests five core principles for the healthcare professional engaging in ACP with their patients.⁸ The first core is to *exemplify* the work of ACP in their own lives. By engaging in this work for themselves and their families, NPs may better understand the benefits and challenges for their patients. The second core principle is to *connect* with patients and families in a way that respects individual and cultural differences in patients, with an awareness of their own biases. The third core principle is to *engage* with patients and families in understanding what is most important to them at the end of life. The fourth core principle is to be a good *steward* by consistently capturing, storing, and retrieving when necessary, end-of-life care wishes. The fifth core principle relies on the completion of the four previous principles and that is to *respect* patient end-of-life wishes and assure goal-concordant care.⁸

ACP does not need to be completed in one visit and can often take multiple visits as patients and their families consider their options. Because healthcare goals may shift over time, especially as one nears the end of an illness trajectory, the process of ACP should be revisited routinely. ACP should also be revisited when changes in condition occur.

■ Advance directives and medical orders

Concrete outcomes that may occur as a result of ACP include advance directives (AD) and medical orders.

The two most common types of ADs include the health care proxy also known as the durable power of attorney for health care (DPAHC) and the living will (LW). The health care proxy or DPAHC is the legal document designating a surrogate decision-maker.⁷ Surrogate decision-makers are authorized to make medical decisions for an individual in the event they become incapacitated and are unable to make their own decisions. An important issue to note of which surrogate decision-makers should be made aware, is that the health care proxy/DPAHC role is only active when the patient is judged to be incapacitated. In the event that the patient regains capacity, the surrogate can no longer make healthcare decisions. It is also important to be aware that in the event that a surrogate decision-maker is not designated through an AD, many states will recognize surrogate decision-makers in acute care settings based on a hierarchy. Laws about the hierarchy of decision-maker and other possible surrogate responsibilities vary by state; therefore, NPs should check with their individual state laws for state-specific regulations.

With the absence of any further documentation, surrogates must rely on substituted judgment, that is to say, they must make decisions based on what they believe the patient would have wanted or is in the patient’s best interest.⁹ Because of this, an important part of the ACP process is not only encouraging individuals to choose their health care proxy/DPAHC carefully, but also encouraging and supporting individuals to discuss their wishes with their designated surrogate decision-makers to assure understanding of their end-of-life wishes. This will avoid any possible confusion or undue stress if and when they must take on the role of surrogate decision-maker.

The LW is the written document used to specify treatment choices at the end of life such as the use of artificial hydration and nutrition; the use of antibiotics or opiates; or the use of medical treatments such as intubation or dialysis. The LW can also be used to specify the circumstances for which a specific treatment may or may not be wanted.¹⁰ In addition to appointing a surrogate decision-maker and having an open and honest conversation describing end-of-life treatment wishes, the LW can help assure goal-concordant care. While not a medical order, an LW can also provide healthcare professionals clear and convincing evidence for treatment wishes.

NPs and patients should be aware of a few caveats regarding the use of LWs. Because the LW is not a

medical order, healthcare providers may not be obligated to follow them, especially in emergent situations.¹¹ There is also some argument against the ability to accurately predict what one's healthcare wishes may be at some unforeseen future as treatment preferences may change over time.⁹ It is also important for patients to know that because the health care proxy/DPAHC and LW are not medical orders, emergency medical technicians cannot honor either in the event that emergency personnel are called.¹² Patients and their families should be encouraged to carry a copy of important documents such as the LW and health care proxy with them; provide a copy each to their surrogate decision-maker and NP; and to store the original copy safely as with any other legal documents.

For patients with serious life-limiting illness with a prognosis of 1-2 years, ACP should include discussions about medical orders such as in-hospital do-not-resuscitate (DNR) or out-of-hospital DNR orders depending upon patient location as well as POLST: Portable Medical Orders.¹³ Depending upon the state in which practice occurs, POLST can also be called Physician Orders for Life-Sustaining Treatment (POLST), Provider Orders for Scope of Treatment (POST), Medical Orders for Life-Sustaining Treatment (MOLST), among others. POLST forms provide actionable medical orders similar to the DNR order and are not a substitute for the completion of ADs such as the health care proxy or LW. POLST forms include sections for individuals to indicate whether they would want resuscitation to be attempted in the event of cardiopulmonary arrest as well as whether they would wish to receive certain treatments, including full treatment or supportive care. POLST orders are also valid across care settings such as hospitals, skilled nursing facilities, and the home, as opposed to DNR orders, which are specific to location. This means that a hospital DNR order is not valid in the home setting, and an out-of-hospital DNR order is not valid in the hospital while the POLST form is valid across care settings. This can be an area of confusion for patients and families who believe that a DNR order signed in the hospital is valid in the community as well. Though each state is responsible for regulations about ACP and the individual state's POLST form, POLST is a national movement and as such is recognized as a valuable way to communicate emergency and end-of-life wishes. Of note, one troublesome issue is that many states do not explicitly recognize POLST forms from other states.¹³

The National POLST organization suggests that completion of the POLST form would be appropriate for individuals with serious illnesses such as severe heart disease, advanced lung disease, metastatic cancer, or advanced neurodegenerative disease; those with increased risk for a medical emergency based on their condition; those experiencing multiple unplanned hospitalizations in the last 12 months; and those whose death within 1 to 2 years would not surprise the NP.¹⁴

NPs who are discussing resuscitation with their patients, whether in the form of DNR orders or POLST, should ensure well-informed decisions. For example, most patients and families overestimate the chances of survival following CPR.¹⁵ However, statistically, only about 10% to 20% of those who experience cardiac arrest out of the hospital and receive CPR survive to hospital discharge. Those who experience in-hospital cardiac arrest and receive CPR have a greater chance of surviving to discharge; however, survival is still quite low at 25%.¹⁶ Those with underlying health conditions and of older age are even less likely to survive CPR.¹⁷ Whether cardiac arrest is witnessed or unwitnessed, both the time from collapse to the start of CPR and the skill level of the person providing CPR have an impact on success. Complications of CPR can include broken chest bones, collapsed lungs, and potential neurologic problems secondary to anoxia.¹⁷

■ Capacity vs. competency

Key to successful ACP is the understanding of whether an individual has the capacity or the legal right based on competency to make decisions about ADs. Though often used interchangeably, capacity and competency are two distinctly different terms.¹⁸ Competence, or more specifically, incompetence, can only be determined in a court of law. It is the legal determination that an individual no longer has the ability to make their own decisions. All adults are considered competent to make decisions such as those pertaining to property, finances, and even healthcare until determined to be incompetent by a court of law.¹⁸

Capacity, on the other hand, is the medical determination that an individual has the ability to make healthcare decisions.¹⁹ Understanding whether an individual has the capacity to make healthcare decisions or has lost that capacity and must hence rely on a surrogate decision-maker is a key responsibility of the NP during the ACP process. The four components of capacity include 1) an individual's ability to understand

ACP resources for NPs

CDC: Advance Care Planning – Selected Resources for the Public	www.cdc.gov/aging/pdf/acp-resources-public.pdf
Centers for Medicare and Medicaid Services: Medical Learning Network: Advance Care Planning	www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf
Compassion and Choices: Plan Your Care Resource Center	https://compassionandchoices.org/end-of-life-planning/
Institute for Healthcare Improvement: “Conversation Ready”: A Framework for Improving End-of-Life Care (2nd ed.)	www.ihl.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx
National Institute on Aging: Advance Care Planning: Health Care Directives	www.nia.nih.gov/health/advance-care-planning-health-care-directives
National POLST	https://polst.org/
Respecting Choices: Advance Care Planning Billing Resource Guide	https://respectingchoices.org/wp-content/uploads/2018/09/RC_5009_ACP_Billing_Resource_Guide_09.19.18.pdf


a situation or decision, 2) the appreciation of its significance, 3) the ability to reason, and 4) the ability to communicate preferences. Capacity can be situation-specific. For example, a patient with mild to moderate dementia may be able to understand the significance of appointing a surrogate decision-maker yet unable to make a more complicated medical decision such as the decision to forgo medical treatment for a serious condition. Those who are more likely to lack capacity and for whom further investigation may be necessary can include individuals over 85 years of age and those with chronic neurologic or psychiatric conditions.^{18,19} Patients can also temporarily lose capacity during an acute event such as a serious accident or delirium.

■ Billing for ACP

In 2016, the Centers for Medicare and Medicaid Services (CMS) recognized the value of and began reimbursing for Common Procedural Terminology (CPT) codes for ACP.²⁰ All NPs who have the state authority to bill Medicare Part B services can report CPT codes for ACP in any setting including the home, office, hospital, and skilled nursing facility. ACP is considered to be a voluntary, time-based service. When billing for ACP, NPs should use the CPT code 99497 for the first 16 to 30 minutes of a face-to-face encounter with the patient and/or surrogate decision-maker. This code may not be used if the ACP encounter is less than 15 minutes. If the patient is not able to be present at the encounter such as a patient incapacitated by dementia, the reason for nonparticipation should be

documented. CPT code 99498 can be used for each additional 30 minutes spent in the face-to-face ACP encounter. ACP can be billed as the primary service using these codes; these codes can be used along with Evaluation and Management (E/M) codes with modifier 25; and they can also be used as part of a Medicare Annual Wellness Visit (AWV) with modifier 33 so the patient does not have to pay a copay. There are no limitations to the number of times or length of time spent when using ACP CPT codes; however, if used more than once a year, there should be clear documentation for the rationale. Examples of more frequent ACP coding might include a change in condition, a change in patient goals, distress related to end-of-life decision-making, and uncertainty about prognosis.²⁰

Many resources are available to NPs and their patients looking for more information on ACP (see *ACP resources for NPs*).

In conclusion, ACP is a process that should be addressed across care settings and for all adults regardless of age or health condition. A 2017 study published in *Health Affairs* found that only one in three adults complete ADs; the opportunity for NPs to improve those numbers is very real.²¹ NPs who work with adult populations for whom ADs are key can perhaps better understand the process and documents involved by completing their own ADs. That being said, NPs who engage in the rewarding process of ACP and the completion of ADs, whether for themselves or their patients and their families, take the important step toward assuring goal concordant-care at the end of life. 

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