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# Advance Care Planning in the Elderly

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**KEYWORDS**

• Advance care planning • Advance directives • Surrogate decision maker
• Patient-doctor relationship • Communication

**KEY POINTS**

- Advance care planning (ACP) can help individuals and their loved ones receive medical care that is aligned with their values, and experience more satisfaction and peace of mind.
- ACP involves a process identifying personal values first, and then translating those values into medical care plans.
- ACP can be viewed as a health behavior that involves multiple steps and evolves as a process over time.
- Clinicians can assist older adults with ACP through assessing readiness, promoting identification and documentation of appropriate surrogate decision makers, engaging patients and surrogates in discussions, and helping patients document their medical wishes.
- Outpatient approaches to support ACP can be brief, multidisciplinary, and involve several visits over time.

## INTRODUCTION

Advance care planning (ACP) allows individuals to specify in advance how they want to be treated should serious illness prevent them from being able to make decisions or communicate their choices. Just as tobacco cessation counseling could be considered a primary care provider's "procedure," engaging patients and their potential surrogate decision makers in ACP is a key skill in the care of the older adult. ACP involves multiple conversations that identify a surrogate decision maker, explore the individual's values about medical care, complete advance directive documents, and

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translate values into medical care plans. This article describes the need for ACP in the elderly and highlights several key concepts for clinicians to assist older adults with ACP. Practical approaches for integrating ACP into busy primary care practices are provided, while recognizing common barriers, and recently developed ACP tools for clinicians and the outpatient care team are highlighted.

## WHAT IS ADVANCE CARE PLANNING?

ACP is the process of planning for future medical care with the goal of helping patients receive medical care that is aligned with their preferences, especially in the setting of serious illness or as the end of life approaches. **Table 1** provides common terms and definitions used in ACP. For example, one component of ACP is advance directives, which include medical power of attorney appointments or living wills; these written forms facilitate end-of-life decision making based on a patient's values. Fundamentally ACP involves more than completing an advance directive in isolation because ACP is based on an individual's evolving values regarding future medical care, not only their preference for particular medical procedures, such as cardiopulmonary

**Table 1**
**Advance care planning terms and definitions**

| Advance Care Planning Terms | Description of Terms |
|---|---|
| Advance care planning (ACP) | Process of considering and communicating health care values and goals over time |
| Advance directive | Legal document describing preferences for future care and appointing a surrogate to make health care decisions in the event of incapacity |
| Medical durable power of attorney | Legal documents that appoints an "agent" to make future medical decisions. Becomes effective only when the patient becomes incapacitated |
| Surrogate decision maker or health care proxy | A decision maker that makes medical decisions when the patient becomes incapacitated and the individual did not previously identify a medical durable power of attorney. Most states use a hierarchy system to designate a health care proxy, whereas a few states appoint a proxy that is agreed on by all interested parties |
| Living will | Documents an individual's wishes prospectively regarding initiating, withholding, and withdrawing certain life-sustaining medical interventions. Effective when the patient becomes incapacitated and has certain medical conditions |
| Cardiopulmonary resuscitation (CPR) directive or do-not-resuscitate (DNR) order | Documents preferences to refuse unwanted resuscitation attempts |
| Orders for life-sustaining treatment (ie, Physicians Orders for Life-Sustaining Treatment [POLST] paradigm) | Order set that translates patient preferences for life-sustaining therapies into medical orders<br>Primarily intended for seriously ill people with life-limiting or terminal illnesses and patients in long-term care facilities<br>Portable and transferable between health care settings |

resuscitation (CPR), in specific settings and at one point in time. Thus, the process of ACP involves conversations with family, friends, and clinicians over time, and is much more than a one-time documentation of advance directives. Although the benefits of advance directives in isolation remain controversial,[1,2] recent evidence suggests that ACP conversations and support achieve a range of benefits, including fulfillment of end-of-life wishes and higher patient and family satisfaction.[3–5] Key concepts of the ACP process are summarized in **Table 2** and are discussed later in this article.

## THE NEED FOR ADVANCE CARE PLANNING IN THE ELDERLY

Benefits of ACP include the following:

- Ability to identify, respect, and implement an individual's wishes for medical care, especially in the absence of decision-making capacity, during serious illness, or near the end of life[2]
- Ability to manage personal affairs while able, peace of mind, less burden on loved ones, and peace within the family[6]
- Reduction in stress, anxiety, and depression in surviving family members[4]
- Improved patient satisfaction and quality of life[7,8]
- Decreased use of intensive medical interventions at the end of life[7,8]
- Implementation of preferences to limit unwanted medical treatment (eg, avoid hospitalization or CPR)[9]
- Fewer in-hospital deaths, more hospice use, and lower Medicare costs among older adults, with advance directives specifying comfort-oriented end-of-life care[5,10,11]

A growing evidence base supports the benefits of specific systematic approaches to ACP. For example, Respecting Choices, a trained facilitator-based model whereby individuals engage in multiple ACP conversations, has been successfully implemented into a health care system and has increased the prevalence of advance directives to 90% in the local community.[3,12,13] Respecting Choices has also improved the delivery of goal-concordant end-of-life care through an emphasis on conversations that go far beyond completing advance directives. Another major success related to ACP has been implementation of out-of-hospital orders for medical treatment, such as Physicians Orders for Life-Sustaining Treatment (POLST) forms, which necessitate a doctor-patient discussion about individual preferences for medical care.[9,14,15]

Despite the proven benefits of ACP, many older adults with chronic illnesses die after extended periods of disability, without prior ACP with their family or primary care provider. In 1995, 20% of hospitalized patients had an advance directive, and of those with an advance directive only 12% had been counseled by a physician about writing the directive.[16] Many physicians and surrogate decision makers were unaware of patients' preferences.[17] Although the percentage of older adults completing advance directives has increased over time, there is still a poor correlation between wishes expressed in these documents, documentation in the medical record, and the care individuals receive at the end of life. For example, in recent national studies as many as 70% of elderly decedents had an advance directive,[18] although the presence of an advance directive had little effect on hospitalization rates within 2 years of death.[19] Although the number of deaths in United States hospitals has declined, this trend was not associated with the increased completion of advance directives after adjusting for sociodemographic characteristics. Among hospitalized patients in Canada, concordance between patients' expressed preferences for end-of-life care and documentation in the medical record was only 30.2%.[20] This poor correlation between

**Table 2**
**Advance care planning is a multistep process**

| Key Concept | Description | Examples of Questions to Engage Patients in ACP Discussions |
|---|---|---|
| Assessing readiness and identifying barriers | Exploring patient readiness and identifying and addressing any barriers to the ACP process | "Have you ever completed an advance directive, like a living will? What did it say? Is it up-to-date?"<br>"ACP helps me work with you and your family to understand how to plan your medical care in case you lose the ability to make decisions. Can we talk about this today?"<br>"Are there things that you worry about when you think about planning for future medical care?[26] What keeps you from thinking about these types of things?" |
| Identifying surrogate decision makers | Identifying a trusted person as a surrogate decision maker to help clinicians apply overarching care goals to specific clinical situations in the event that the patient loses decisional capacity. | "Is there someone you trust to be involved in making medical decisions on your behalf, if you are not able to do so?"<br>"What have you talked about?" or "What would you tell this person is important about your medical care?"<br>"Flexibility gives your decision maker leeway to work with your doctors and possibly change your prior medical decisions if something else is better for you at that time. Are there decisions about your health that you would not want your loved one to change?" |
| Asking about patient's values related to quality of life | Exploring the individual's values and priorities in life, and discussing what constitutes an acceptable quality of life | "Have you had any previous experience with making decisions about medical care during a serious illness? Can you tell me about that?"<br>"When (eg, you were hospitalized; loved one died), did this situation change your thoughts about what is important to you in the future or what would be unacceptable, where you wouldn't want to live like that?" |

(*continued on next page*)

**Table 2**
**(*continued*)**

| Key Concept | Description | Examples of Questions to Engage Patients in ACP Discussions |
|---|---|---|
| Documenting ACP preferences | Documenting expressed care preferences in an advance directive document (eg, medical power of attorney, living will); ensuring written plans are communicated, stored, and retrievable | "Since you've chosen (loved one) to help make decisions on your behalf if you're very sick and unable to talk with me, I recommend that you complete the medical power of attorney form to make it official."<br>"Can you bring in your advance directives? It helps me, the clinic, and the hospital, know what is important to you if you are very sick." |
| Translating preferences into medical care plans | Translating values and preferences into current medical care documents (ie, POLST form, CPR directive); documenting discussions, preferences, and care plans in the medical record | "You told me that if you were not able to interact with your family and friends, your life would not be worth living. Did I get that right? Many patients who feel as you do, opt not to have life support treatments if they become so sick they cannot recognize family. Based on what you told about what is important to you, I'd like to go through the POLST form if that's OK so that (emergency medical services, other doctors) know what you want."<br>"At this point, (medical intervention) is no longer providing you with benefit. Given what you have told me, I recommend that we focus on treatments that maximize your quality of life (such as…) and stop (medical intervention)." |

*Adapted from* Refs.[25,26,28,43,50]

advance directive completion, medical record documentation of preferences, and care provided at the end of life support the need for novel, practical, and systematic approaches for integrating ACP into health care systems.

### *Clinician and Health Care System Barriers to Advance Care Planning*

Despite the benefits of ACP, clinicians face significant barriers to engaging patients in ACP. Personalized, comprehensive ACP involves conversations between clinicians and patient or surrogate decision makers that can be time consuming. In one study, primary care providers described barriers such as variation in how providers approach

ACP, lack of useful information about patient values to guide decision making, and ineffective communication between providers across settings.[21] Although patients infrequently initiate these discussions, clinicians missed opportunities to engage in ACP discussions when patients expressed concerns regarding their future care.[22] Health care systems often lack the personnel or work flow processes to systematically approach ACP. The Affordable Care Act instituted a requirement for ACP during Medicare Annual Wellness visits, but there are no evidence-based guidelines to direct this process or consensus on appropriate patient-centered outcomes. Furthermore, the lack of specific reimbursement for ACP counseling, especially if completed by ancillary staff, is a significant limitation in clinical practice.

Nonetheless, older adults with chronic illnesses described the importance of preparing for medical decision making and were more satisfied with their primary care physicians when ACP was discussed.[7,23] Primary care settings remain a critical opportunity to engage older patients and surrogate decision makers in ACP discussions.[24] Older adults experience significant life, social, and health-related changes that may lead to increased awareness of the need and readiness for ACP. **Box 1** highlights opportunities to initiate or revisit ACP in older adult patients.

## KEY CONCEPTS IN ADVANCE CARE PLANNING

Key steps in ACP are (1) assessing patient readiness and identifying barriers, (2) identifying surrogate decision makers, (3) asking about individuals' values related to quality of life and serious illness, (4) documenting ACP preferences, and (5) translating individuals' preferences into medical care plans. **Table 2** summarizes brief approaches to each key concept.

ACP is a stepwise process that does not need to occur in a single clinic visit; it is a process that can unfold over time. For instance, clinicians and outpatient staff can engage older adults in ACP through introducing key concepts over time. Each concept can be discussed individually and in 5 minutes, based on time constraints and patient needs, and can be used by trained staff members as part of team-based or health care system–based approaches (see later discussion).

### *Assessing Patient Readiness and Identifying Barriers*

Engaging an individual in ACP can begin with assessing patient readiness. Studies show that patients are in varying stages of readiness to engage in ACP,[6,25,26] and often barriers may need to be addressed before patients can engage. **Table 2** suggests

**Box 1**
**Indications for advance care planning (ACP) in the elderly patient**

- Medicare Annual Wellness examination (ie, routine preventive visits)
- Diagnosis of mild cognitive impairment or early dementia
- Need for increased caregiver involvement
- Identification of new functional impairment
- Transition to an assisted living facility or nursing home
- Post-hospitalization, post–subacute rehabilitation, or other care transition
- Change (decline or improvement) in health status
- Changes in family or social situation, including death of loved ones

brief opening questions that explore the patient's readiness through understanding their past experiences with ACP. The process can be introduced alongside other common future planning considerations (ie, financial planning, place of residence). Questions should be tailored to the individual's clinical context, such as new medical diagnoses, increased care needs, or changes in social support. Responses of patients or available family members can help clinicians identify how ready patients are to engage in the ACP process (**Table 3**), and lead clinicians to appropriate next ACP steps or, if the patient is not ready, asking permission to revisit in the future.

**Table 2** provides examples of open-ended questions to help identify barriers. There are many reasons why patients and families may be reluctant to address difficult or frightening health care issues, including ACP.[27] Understanding the personal barriers that patients experience related to ACP is important, as some barriers may be general (eg, fear of dying) while others may be specific aspects of ACP, such as communication or identifying a surrogate decision maker.

**Table 4** shows barriers identified by older adults[6] and suggestions on how to approach them. The diverse barriers reflect the need for clinicians to explore each individual's perspective on ACP, as willingness to engage in ACP may be influenced by personal experiences and family, cultural, religious, or spiritual values. As barriers are identified, the clinician and other team members should work with the patient to offer targeted support.

### *Identifying Surrogate Decision Makers*

Even with limited time, clinicians can emphasize the importance of choosing a trusted person as a surrogate decision maker. **Table 2** provides language to assist clinicians with promoting the choice of a surrogate and discussing the concept of flexibility in decision making. The surrogate needs to be asked to assume the responsibility and to agree to his or her role, and there needs to be communication and documentation of the surrogate as a medical power of attorney in the medical record.[26,28] In some cases, it may be appropriate for clinicians to facilitate a family meeting or conference call to assist patients in identifying and communicating their wishes with a surrogate and others they wish to be involved.

There are challenges with involving surrogate decision makers. For example, surrogates may incorrectly understand patients' values and preferences.[29] Clinicians can encourage patients and surrogates to have ongoing discussions over time as patients'

**Table 3**
**Characteristics of advance care planning stages of change**

| Stage of Change | Description |
|---|---|
| Precontemplation | Individual lacks awareness of or has no desire to engage in ACP |
| Contemplation of future care wishes and values | Individual understands the relevance of ACP their own lives and begins to form intentions to engage in ACP |
| Preparation | Values clarification and planning stage for actions related to ACP |
| Action | Engaging in the ACP process through doing an action, such as:<br>• Discussions with family or friends<br>• Discussion with clinicians<br>• Advance directive documentation (ie, medical power of attorney, living will) |
| Maintenance | Reflecting on choices and evolving values, revising advance directive documents accordingly |

*Adapted from* Refs.[6,25,28,31]

**Table 4**
**Potential barriers to advance care planning and general suggestions for clinicians**

| Barriers Identified by Patients[6,27] | Suggestions for Overcoming Barriers |
|---|---|
| Too difficult to think about dying | Empathic and reflective listening |
| Lack of knowledge | Ask permission to discuss ACP specifically, including arranging specific clinic visit time |
| Inability to plan for the future because of challenging current life/social issues | Refer to a social worker to assist with unmet social/financial needs |
| Planning not necessary because of the assumption that family/doctors know what to do, or there are no medical choices to be made | Refer to chaplain, behavioral health, or bereavement or other community-based support resources |
| Future in God's hands | Invite family to clinic visit |
| Suffering is necessary | Address depression, grief, or losses |
| Physician will make decisions | Recommend an ACP decision tool |
| Lack of available surrogate decision maker | Provide health education in easy-to-read format |
| Putting things down in writing might result in treatment being withdrawn too soon | Consider health navigators[51] or trained facilitators[3] (ie, Respecting Choices program) |
| Loved ones unable or unwilling to discuss ACP | |
| Educational materials are too difficult to understand | |

values may change. Despite these problems, the authors believe that surrogates are generally beneficial, particularly when they are able to provide illustrations of patients' life stories to inform medical decision making.[30]

### *Asking About Values Related to Quality of Life*

Clinicians should initiate conversations that help patients articulate their values related to medical options and quality of life, especially in the setting of serious illness. **Table 2** provides questions to help individuals describe what quality of life means to them, consider their attitudes or preferences toward life-sustaining treatments, and reflect on trade-offs between quality of life and quantity of life.[31] Individuals can articulate values over time to guide decisions, including discussing whether certain health states would make life not worth living. Even when older adults have advance directive documents, many individuals have not had substantive conversations about their values and often have not considered how their values may be influenced by likely future medical circumstances, given their illnesses. Clinicians can teach older adults to ask questions to help make informed medical decisions based on identified values (eg, "What are the risks? What are the benefits? What are the burdens?").

### *Documenting Advance Care Planning Preferences*

Clinicians have 2 major roles in supporting the documentation of ACP preferences. First, clinicians need access to advance directive forms to enable patients to formally identify a surrogate decision maker (ie, medical power of attorney) or preferences for future medical care (ie, living will). The American Bar Association has developed a Consumer's Toolkit for Health Care Advance Planning that includes a free, nearly universal Power of Attorney for Health Care form and links to state-specific forms.[32] Baseline knowledge of each form is important, including content and state-specific requirements for witnesses or notarization. Clinicians should emphasize the importance of discussing the contents and sharing copies, especially with surrogates. Second, in the medical record, clinicians should document the content of ACP discussions and communicate with other health care team members. Advance directive copies should

be officially added to the medical record. Ideally the medical record, whether electronic or paper, has specific mechanisms to highlight ACP discussions and documents promote easy retrieval and updating both across and outside of the patient's health care system.[33]

### *Translating Preferences into Medical Care Plans*

Translation of individual preferences into medical orders that direct medical treatments is especially important in the care of older adults with serious illness or frequent care transitions. Out-of-hospital medical orders, variously called POLST, Medical Orders for Scope of Treatment (MOST), or other names, serve as legally approved forms to document and communicate specific life-sustaining treatment wishes of seriously ill patients.[34] Clinicians will frequently need to translate preferences or advance directives into a medical care plan if appropriate in the context of the patient's current medical condition. Examples of common treatment planning that involves translation of the patient's values and existing advance directives include:

- General scope of care options: life-prolonging (ie, CPR and life-sustaining treatments), limited interventions (ie, hospitalization with limitations in the extent of medical intervention), or comfort care (ie, symptom relief)[34,35]
- Role of artificial nutrition and hydration
- Role of hospitalization and/or outpatient services such as hospice[11]
- Role of CPR, including recommending for or against this procedure[36]

**Table 2** provides examples for talking with older adults and translating preferences into current medical care plans, such as CPR directives, do-not-resuscitate orders, and out-of-hospital medical orders. Specifically, clinicians can use POLST forms to translate ACP preferences into medical orders, including CPR, scope of treatment, artificial nutrition by tube, and, in some states, antibiotic use, based on conversations with patients or surrogates.[37] As they generally limit medical interventions, these orders are primarily used in patients with advanced illnesses and limited life expectancies. These medical orders are legal documents that should be followed in any setting (ie, home, hospital, and nursing home).

## SPECIAL CONSIDERATIONS FOR ADVANCE CARE PLANNING IN THE ELDERLY

As clinicians and the outpatient care team undertake ACP, there are special considerations to account for in the older adult, such as:

- Presence of cognitive impairment, suggesting the need to assess decision-making capacity[38] related to ACP and to involve surrogates if available
- Living apart from a potential surrogates (ie, long-distance family member)
- Lack of available surrogates owing to absent or fractured relationships or the death of loved ones
- Prior ACP, especially advance directives that are no longer accurate or accessible
- Multiple health care providers related to multiple medical conditions and/or care transitions resulting in a fragmented ACP process
- Need for hearing aids, pocket talkers, and/or glasses because of sensory impairments

## TEAM-BASED APPROACHES TO ADVANCE CARE PLANNING

As patients engage in ACP, clinicians and the outpatient care team can work together to support ongoing values: clarification discussions; education and counseling about

risks, benefits, and burdens of medical treatment options; and communication with patients, surrogates, and the health care system as patients' health status, needs, and preferences change over time. The multidisciplinary team can use the key concepts as guides to identify how patients may have engaged in ACP or brief counseling opportunities that they can help with (**Box 2**).

Clinicians and the outpatient care team can seek to address clinical and health care system barriers to ACP by systematically identifying barriers and incorporating ACP over multiple visits. A structured, systems-based approach can be used to identify opportunities for improvement.[39,40] Existing clinic programs can be modified to support ACP. For example, ACP interventions (ie, counseling, education, support, and patient-centered ACP tools [see next section]) could be added to existing programs that address other behavioral health needs, such as tobacco cessation or chronic disease management; or routine preventive care, such as the Medicare Annual Wellness visits and programs related to maintaining healthy lives as older adults (ie, driving, exercise, nutrition). Alternatively, the team could systematically incorporate the use of patient-centered ACP tools to help prepare patients before they come into the office to partake in these conversations.

## NEW PATIENT-CENTERED ADVANCE CARE PLANNING TOOLS

Recent advances in ACP include the development of accessible tools to assist patients with knowledge and decision making related to ACP. Because ACP can be a personnel-intensive and time-intensive process, helping patients and families begin this process on their own is useful. In a randomized controlled trial, a patient-completed preference form increased ACP communication from 11% to 30%.[41] Although not all tools have been formally tested in research settings, various tools offer practical benefit for patients and their families.[42]

- PREPARE (https://www.prepareforyourcare.org/)[43] is an ACP Web site with videos that focuses on preparing patients for communication and decision making.
- ACP Decisions (http://www.acpdecisions.org/) presents ACP videos describing how overall goals of care, CPR, and mechanical ventilation can influence patients' and surrogates' preferences for end-of-life care.[35,44]
- The Conversation Project (http://theconversationproject.org/)[45] provides a written toolkit with values-based questions to help individuals start ACP conversations.
- The *GO WISH* Card Game,[46] a set of cards that describe potential quality-of-life values, may facilitate conversations among older adults with cognitive impairment.

**Box 2**
**Examples of multidisciplinary team-based approaches to ACP**

- Front-desk staff can ask patients to bring advance directives to clinic, inform the clinician, document their presence, and copy for medical record
- Medical assistant can prescreen the medical record for evidence of prior ACP and highlight the opportunity for the clinician to initiate/update during visit
- Staff member with ACP counseling training can ask about prior ACP, especially potential surrogate decision makers, and document and communicate for the clinician to follow up

- Making your Wishes Known (https://www.makingyourwishesknown.com/)[47,48] and MyDirectives (https://mydirectives.com/)[49] are tailored Web sites that provide video instructions and explanations to complete advance directives.

## SUMMARY

Clinicians who care for older adults can engage older adults in ACP through multiple brief discussions over time. ACP emphasizes choosing a surrogate decision maker, identifying personal values, communicating values and preferences with surrogates and clinicians, documenting preferences for future medical care, and appointing a surrogate decision maker in advance directives in addition to, when appropriate, translating preferences into specific medical treatment plans or medical orders. While older adults, clinicians, and health care systems face specific needs and barriers related to ACP, multidisciplinary teams can incorporate key ACP concepts into brief clinic visits. In addition, several patient-centered ACP tools are available to support ACP in the outpatient setting.

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