

# ADVANCE CARE PLANNING

**Advance care planning (ACP)** is a process of discussions about end-of-life (EOL) care, clarifications of related values and goals, and embodiment of preferences through written documents and medical orders.<sup>1</sup> It is a process that can start at any age or stage of health. It is a process and not a one-time event, and it should be revisited periodically and become more focused as health status changes.<sup>1</sup> The process promotes open, honest, nonjudgmental conversations about values, beliefs, and care goals among individuals, families, and healthcare agents and care providers throughout the life span.<sup>1</sup>

**Advance directive** is a term that is used interchangeably with ACP, which can cause confusion. This is an **individual-initiated** document that records anticipated EOL healthcare goals and wishes, as well as appoints a healthcare agent.<sup>2</sup>

## PATIENT SELF-DETERMINATION ACT

ACP is an important step to ensure each person receives medical care as desired.<sup>3</sup> Congress passed the 1990 Patient Self-Determination Act, which required any federally funded nursing home or hospital to provide a chance for patients and families to complete an advance directive.<sup>3</sup> The law expresses the importance of health care embracing and advocating for the inclusion of advance directives by asking patients about them, providing information and education, and including advance directive forms in the medical record.<sup>4</sup> It requires hospitals, nursing homes, and other healthcare institutions to ask all patients whether they have advance directives upon admission to the facility.

## COMMUNICATION IN ADVANCE CARE PLANNING

Although death is an inevitable consequence of life, it is still not an easy or pleasant topic to discuss in many cultures.<sup>4</sup> High-quality, compassionate, evidence-based care is paramount for individuals with advanced illness who are progressing through EOL.<sup>5</sup> A palliative provider who uses effective conversation promotes respect for individual life choices and supports the individual and family through disease progression. Critical skills include active listening and promoting open, honest, nonjudgmental conversations to elicit goals of care and match medical decisions with patient and family values and beliefs.<sup>2</sup> Most states and healthcare organizations have policies regarding surrogate decision-making for incapacitated patients. If a surrogate is not appointed prior to a patient losing capacity, decision-making will turn to the patient's next of kin according to that state's law, usually in the following order: spouse, adult children, parents, adult siblings, adult grandchildren, or close friends.

## ADVANCE CARE PLANNING BARRIERS

Ideally, ACP conversations are ongoing, established early in the health trajectory, and revisited intermittently or with triggering events such as a hospitalization. A patient or family may or may not embrace the proactive discussion of ACP. Palliative nurses need to identify opportunities to engage patients and families about ACP.<sup>2</sup> This is an essential conversation that can be accomplished during the first meeting with a patient and family, as well as during interdisciplinary team meetings (IDT) to review the patient's plan of care. The conversation aims to help the patient and family understand the whole picture of the patient's illness, which will then lead to a review of options and formal education about the differences between palliative care and hospice care.<sup>3</sup>

Unfortunately, sometimes a patient has an advance directive completed already but no one knows that it exists or cannot locate it when the time comes to use it.<sup>2</sup> It is important to share these documents with family, healthcare providers, and any other individuals who may be asked to support the patient in future medical care so that the directives chosen may be respected and acted upon when necessary. Some other patient barriers to ACP can be low health literacy, English as a second language, poor health, and racial and ethnic barriers.<sup>6</sup> Some clinician barriers may include avoidance of emotions with conversations surrounding ACP, time constraints of care, and inadequate training for open-ended communication to facilitate strong ACP conversations.

## COMPONENTS OF ADVANCE CARE PLANNING

ACP consists of three core elements: identification of a **surrogate decision-maker**, completion of a **living will or advance directive**, and completion of **out-of-hospital orders for life-sustaining treatments**.<sup>2</sup>

## ADVANCE CARE PLANNING TERMS<sup>1,3,7,8</sup>

<b>Surrogate decision-maker (health-care proxy, durable power of attorney for health care, healthcare agent, or healthcare representative)</b>	<p>Someone a patient trusts to make healthcare decisions in the event that person is unable to. This can be in the form of a written document naming an identified person(s) (healthcare agent) who can make healthcare decisions for an individual who is unable to make healthcare decisions for oneself. A durable power of attorney for health care identifies a healthcare proxy, who can make decisions for an individual when that person is not able to make his or her own decisions.</p>
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<b>Living will</b>	A written or video-recorded declaration of EOL care goals and wishes in certain situations, usually terminal illness, when individual independent decision-making is incapacitated. It provides a description of an individual's treatment choices and preferences for life-sustaining measures, such as mechanical breathing, tube feeding, or resuscitation.
<b>Out-of-hospital for life-sustaining treatment</b>	<p>Written orders that document an individual's desire for life-sustaining therapies, such as cardiopulmonary resuscitation, ventilation, dialysis, antibiotics, and nutrition and hydration, created and developed with a healthcare professional (physician, nurse practitioner, or physician assistant, state law dependent) for a seriously ill individual. Medical order sets are portable among healthcare facilities and agencies and require healthcare professionals, such as emergency personnel, to follow the written medical order.</p> <ul style="list-style-type: none"> <li>• <b>Provider/physician orders for life-sustaining treatment (POLST):</b> written medical orders covering a variety of topic areas (including do not resuscitate) generally anticipated for frail, seriously ill individuals in the expected final year of life</li> </ul>
	<ul style="list-style-type: none"> <li>• <b>Do-not-resuscitate (DNR), do-not-intubate (DNI), or do-not-hospitalize (DNH) orders:</b> written medical orders for specific treatments that may be written in a healthcare facility and may or may not be portable, depending on state law. An out-of-hospital DNR order is intended to ensure that an individual will not be resuscitated against his or her will by emergency medical personnel.</li> </ul>

## MODELS FOR ADVANCE CARE PLANNING

The following are well-known models of care that promote a systematic, patient-centered approach to the communication, exploration, and execution of ACP with patients and families.

### 1. Five Wishes<sup>®2,9</sup>

A planning document that guides the individual through completion of advance directives. *Five Wishes*<sup>®</sup> documents 1 and 2 meet legal requirements for advance directives in most states, with several states requiring statutory documents that must accompany the Five Wishes<sup>®</sup> document. <https://fivewishes.org/>

### 2. Respecting Choices<sup>®2,10</sup>

Offers health systems, organizations, or individuals implementation packages for ACP and shared decision-making through virtual courses and certifications. [https://respectingchoices.org/advance-care-planning-courses/?gclid=CjwKCAiA78aNBhAIEiwA7B76p\\_UuyF\\_iiqZqPiHMBVBejFq\\_xJ-iTl8GyLyIk9MXhTa42tXsI7UIURoCnPwQAvD\\_BwE](https://respectingchoices.org/advance-care-planning-courses/?gclid=CjwKCAiA78aNBhAIEiwA7B76p_UuyF_iiqZqPiHMBVBejFq_xJ-iTl8GyLyIk9MXhTa42tXsI7UIURoCnPwQAvD_BwE)

### 3. The Serious Illness Conversation Project<sup>®2,11</sup>

A guide for clinician training to engage patients and families in conversations about their EOL wishes. <https://www.ariadnelabs.org/serious-illness-care/>

### 4. The Conversation Project<sup>®3,12</sup>

A grassroots project for public engagement, housed in the Institute for Healthcare Improvement, promoting expression and honoring individual EOL wishes. <https://theconversationproject.org/>

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