Advance Care Planning: Advance Healthcare Directives

What Are Advance Care Planning and Advance Healthcare Directives?

› Advance care planning (ACP) is a process through which a person explores the values, beliefs, and experiences that guide his or her goals for medical treatment, including but not limited to the end of life. This planning is sometimes accomplished with the help of a facilitator, who may be a social worker, geriatric case worker, nurse, or community volunteer. Many advance care planning programs utilize techniques that take the person through a series of questions regarding his or her experiences, values, and beliefs. Values and beliefs can be culturally, spiritually, or ethically based. Responses to these questions contribute to the person’s understanding of what living well or quality of life means to him or her and can shape healthcare goals in the event of a crisis.

› Advance care planning is best done when a person is healthy and feeling well. It is most effective when the person’s designated healthcare agent is present throughout the conversation and the plan is communicated to the wider care team (e.g., primary care physician, specialists, family members). Studies have shown that healthcare agents and caregivers who participate in advance care planning have less complicated grief, guilt, and insecurity regarding their choices about continuing or discontinuing life-sustaining interventions in a crisis or at the end of life. The healthcare agents and caregivers felt that they were more confident and knowledgeable about the choices their loved one would have made had he or she been able to.

› The goal of ACP is to not only communicate one’s wishes but also to create an advance healthcare directive, otherwise known as an advance directive (AD), that can guide a patient’s healthcare agent and care providers. An AD is a legal document that can include one or more of the following parts: a living will, designation of medical power of attorney (healthcare proxy), and choices about medical or psychiatric interventions.

› In 1990, the United States Congress passed the Patient Self-Determination Act, which gave people the right to participate in and direct their own healthcare decisions, the right to accept or refuse medical or surgical treatment, and the right to prepare an AD.

› It is important to remember that each jurisdiction (e.g., state, province, nation) has its own requirements for advance healthcare directives and psychiatric advance directives with regard to witnesses, notaries, and time limits.

• What: An AD can include several different types of documents: living wills, medical power of attorney (healthcare proxy), general ADs, psychiatric advance directives (PADs), durable do not resuscitate orders (DDNR), and physician orders for life-sustaining treatment (POLST).
  – A living will is a document that defines the level of intervention a person would desire should he or she be determined to have a terminal illness by the attending physician, or death is imminent.
  – A medical power of attorney (also called healthcare proxy or healthcare agent) designates a person(s) to act on behalf of another in regard to medical decisions in the event that the person loses capacity. Medical decision-making capacity (often referred to simply as “capacity”) is a determination of a person’s ability to understand the benefits and burdens of his or her own medical decisions. Medical powers of attorney are initiated if a person is determined to lack capacity, or is unable to speak for him- or herself.
– General ADs provide instructions regarding desired interventions or prohibited interventions (for example, the use of blood products in an emergency)
– A PAD instructs mental healthcare providers on intervention preferences and treatments such as medications and modalities should a person experience a mental health crisis
– A DDNR order alerts care providers and emergency response workers to not perform cardiopulmonary resuscitation (CPR) should a person’s heart stop beating or breathing stops
– POLST, also known as medical orders for life-sustaining treatment (MOLST), medical orders for scope of treatment (MOST), or physician orders for scope of treatment (POST), address a person’s desired level of medical interventions at end of life. A POLST form may contain a DDNR order within it
– Any of the above documents can also provide information about a person’s desires concerning organ, tissue, or whole-body donation
– ADs are also called advance care plans. An AD does not come into effect until a person loses capacity or the ability to communicate. ADs can be written or oral. Oral ADs are difficult to substantiate; each jurisdiction has its own determination of what constitutes a legal oral directive. Generally speaking, a written directive is recommended

**How:**
– Forms and directions for ADs are available through local and national health departments, local and national mental health providers, healthcare agencies, online, or through specific instructions laid out in legislation (often known as a healthcare decisions act)
– Once completed, forms should be stored in a person’s medical record and in a central registry. Many jurisdictions have registries or a centralized storage system to which people can send their AD and have it accessible to multiple medical facilities. Copies should also be provided to the care team (including mental health team, primary care physician, and designated healthcare agent). Each jurisdiction and medical facility has its own means of storing medical records. Therefore, it is imperative that persons take the responsibility to ensure that their care team and family have copies of their latest directive

**Where:** AD, DDNR, and POLST forms can be created and implemented in inpatient facilities (e.g., medical or psychiatric hospitals), community programs, and outpatient settings, including physician offices, PACE programs (Program of All-Inclusive Care for the Elderly), and skilled nursing facilities

**Who:** Anyone over the age of 18 who has capacity can execute an AD. Social workers employed in healthcare settings, geriatric, and mental health fields should have a working knowledge of ADs so they can assist their clients in preparing these documents. DDNR and POLST forms are most commonly utilized with frail, older adult patients in the latter stages of a life-limiting illness or clients with a terminal illness

**What Is the Desired Outcome of Advance Care Planning and Completing an Advance Directive?**
– The goal of ACP is that clients’ healthcare agents and families know the client’s wishes and are competent to advocate for them. Planning with clients and their healthcare agents and families helps in decision-making at a time of crisis that adheres to the clients’ values and beliefs. Since no AD can address every health issue that may arise, the process of advance care planning is critical to achieving this outcome
– Through the creation of an AD, social workers help clients have a better understanding of their choices and empower them to advocate for themselves regarding goals for care. This includes helping clients understand and verbalize values and beliefs within the context of medically appropriate care and communicate those values and beliefs to their agents and family. ADs should be reviewed and updated regularly or whenever the client has a change in domestic status (e.g., marriage, divorce, widowhood) or healthcare status

**Why Are ACP and Advance Healthcare Directives Important?**
– When a family is faced with a healthcare crisis, decisions on types and extent of interventions must be made
– Many healthcare professionals are uncomfortable talking about advance care planning and often turn to social workers for assistance. Social workers work in a variety of settings in which they may serve as advocates for advance care planning: hospitals, skilled and long-term care nursing homes, senior centers, elder law offices, senior service agencies, nonprofit agencies, cancer clinics, dialysis centers, shelters, mental health services, etc. They are often direct service providers to clients and are in a position to educate and advocate for their clients concerning healthcare goals. By helping clients complete ADs through ACP, social workers help clients retain their sense of autonomy
Facts and Figures
› Sixty percent of people say that making sure their family is not burdened by tough healthcare decisions is “extremely important”; however, 56% have not communicated their end-of-life preferences(13)
› A survey in California revealed that 82% of respondents believed that it is important to put their end-of-life choices in writing, whereas 23% had actually done so(13)
  • Respondents further reported that if facing a serious sickness, they would like to speak with their doctor about end-of-life care; however, only 7% reported having had an end-of-life conversation with their medical provider(13)
› Results from an end-of-life study indicate that even though 67.8% of respondents expressed concerns about end-of-life, only 26.3% had an AD in place. The most common reason given for not having an advance AD was a lack of awareness about ADs. Respondents who were older were more likely to have an AD in place. Thirty-three percent of respondents with a chronic disease had an AD(17)
› Results from a Pew Research study in 2013 indicate that 66% of respondents stated that a person should be allowed to die under certain circumstances whereas 31% stated that physicians should continue to use all means to keep the patient alive(15)
› Researchers examined personal preferences and found that 57% of respondents believed in stopping all treatment if they had an incurable disease and were in pain, 52% believed in stopping all treatment if they had an incurable disease and were totally dependent upon others for their care, and 46% believed they would stop their treatment if they had an incurable disease and were having difficulty with daily functioning(17)

What You Need to Know Before Assisting a Client with Advance Care Planning and Completing an Advance Healthcare Directive
› Jurisdictional requirements for executing advanced directives vary. In all states in the United States, execution of advanced directives is voluntary
› ADs become active only when a person loses capacity or is unable to speak for him- or herself
› Advance care plans can be voided or changed at any time by the person who executed the plan so long as he or she has capacity
› A person can name anyone as his or her healthcare agent; an agent need not be a relative. One does not need an attorney to complete an AD although it is recommended that a person use a facilitator or partner with his or her care team to assist in completing one
› A person must have capacity at the time of creating an AD. In addition, a person can only write an AD for him- or herself. This is different from a DDNR, which can be signed by a healthcare agent or surrogate
› When care decisions must be made for a person without capacity who has not designated a healthcare proxy, a surrogate decision maker is utilized. A surrogate decision maker is either someone who was appointed by a court as a legal guardian or a spouse or blood relation (in descending order of blood relation). Each jurisdiction’s healthcare decision act legislation contains a hierarchical designation of surrogates. Social workers should be aware of the laws concerning surrogacy. For example, in the state of Virginia if one has not named a healthcare agent and does not have a legal guardian, one’s spouse is the surrogate decision maker (unless divorce proceedings were filed). Even if one is no longer living with one’s spouse, the spouse retains his or her ability to make decisions for one under the laws of surrogacy if one is unable to speak for oneself. Clients need to understand that if they do not appoint someone, the state default to the laws of surrogacy, and the surrogate appointed may or may not be whom they would want making decisions for them
› A DDNR is a physician’s order that is signed by an individual or his or her healthcare agent. A DDNR refers only to a person’s desire to not receive cardiopulmonary resuscitation (CPR) in the event that he or she stops breathing and/or his or her heart stops beating; it is not an AD. A healthcare agent is a person named in a legal AD where legal means that it meets all jurisdictional requirements to render it binding

Social Work Responsibilities in Regard to Advance Care Planning and Completing Advance Healthcare Directives
› ACP is a process that takes clients through a guided conversation about their understanding of their health condition (if they have one presently), their experiences, and their values and beliefs regarding healthcare decisions. This process can be time-consuming; social workers should allocate adequate time for the discussion. The conversation should take place in a room that allows for thoughtful consideration and privacy. Social workers need to use their mediation and active listening skills, as well as skills from solution-focused and strengths-perspective models
The first step in an ACP session is assessing the client’s understanding of ACP. Many people believe that ADs are only for people who are dying or who have life-limiting diseases. In reality ACP is for everyone over the age of 18. There may be decisions that need to be made before someone nears end of life.

The second step is to utilize a model for the conversation. Some models require specific training, such as Gundersen Lutheran’s Respecting Choices Program; others can be found in booklets, such as Five Wishes or the Conversation Project; others are online programs, such as “Making Your Wishes Known: Planning Your Medical History.” Using such tools helps social workers keep the conversation focused and goal-oriented. These models incorporate different scenarios that are intended to help the client think through choices regarding probable treatments and possible outcomes. Other models encourage clients to discuss their personal experiences with loved ones who are seriously ill and needed someone to make decisions for them. Social workers help clients articulate their choices so that they are understood by their healthcare agent, who is present.

The third step is to develop a list of needs or questions the client might have as a result of the conversation. The social worker can assist the client by writing down what he or she might need to ask his or her physician or other services he or she could benefit from, such as home care, meal delivery, or financial or social assistance. The unique quality that a social worker brings to an ACP session is the recognition that the client is a part of many systems. ACP may not seem like a priority to a relatively healthy single mother with diabetes, for example. A social worker could help this client recognize that understanding her condition, caring for her health, and having a good healthcare agent can help her ensure that her values and beliefs are honored should she be faced with a crisis. In addition, the social worker can identify other socioeconomic barriers that may be preventing the client from being an active participant in her health care.

The fourth step is to ensure that the conversation is centered on the client’s beliefs and values and not the beliefs and values of others around him or her. ACP focuses on the client’s beliefs with others present to bear witness. Social workers must recognize, however, that in some families and cultures the input of family members and religious leaders is important and should be respected. If a question arises as to the need for the client to confer with others, a follow-up appointment is recommended to complete the process.

The fifth step is to assist the client in creating an AD or advance care plan that designates a healthcare agent (proxy) and articulates his or her beliefs and values regarding healthcare goals. In the event one is incapacitated from severe neurological damage, for example, choices range from comfort care (no life-sustaining treatments) to full intervention with medically appropriate life-sustaining treatments. In addition, many AD forms provide space to write other wishes.

The final step is to ensure that the AD adheres to jurisdictional requirements and is attached to the client’s medical record. Clients should keep the original document and give copies to their primary care physician, their healthcare agent, family members, specialists, and other healthcare (including mental health) providers. Many jurisdictions have storage registries; local health department or healthcare agencies can provide information on these.

Other Interventions That May Be Necessary Before, During, or After Completing Advance Healthcare Directives

Capacity is an important issue for anyone completing an AD. Social workers should seek the assistance of a supervisor, designated primary care physician, or other healthcare official if incapacity is suspected. Each jurisdiction has laws governing capacity.

What Social Work Models Are Used with Completing Advance Healthcare Directives?

Social workers use a combination of models in assisting their clients with completing ADs. In general, a solution-focused model is used with a strengths-perspective model. Both can be incorporated into systems theory that recognizes the complexity of an person’s life and relationships.

Traditional medical models often fail to empower persons to make their own decisions based on their values and beliefs. Social workers are bound by their code of ethics to assist and promote their clients’ sense of self-determination and autonomy.

Assessment of a person’s understanding of his or her illness and illness process is often the first step in providing care to the client. Often, this is done by completing a biopsychosocial-spiritual assessment. This assessment helps to determine not only the client’s understanding but that understanding in the context of the client’s larger environment and how he or she interacts within it.

For others, a psychoeducational approach can be used to help them understand their healthcare choices and their ability to make their own choices. This approach assesses cognitive abilities and breadth of understanding, and can help to identify any barriers to completing an AD.
Social workers should use a culturally competent model and be aware of their own cultural values, beliefs, and biases; they should develop specialized knowledge about the histories, traditions, and values of their clients. Furthermore, social workers must adopt treatment methodologies that reflect their knowledge of the cultural diversity of the communities in which they practice.

**Red Flags**

Clinicians are required to follow the instructions in an AD as long as they do not conflict with standards of care and the clinician is acting in good faith. For example, documents that state that a person wishes that all interventions must be done regardless of expected outcome could be considered inappropriate if those interventions would not improve or sustain life and could cause suffering to the person. Practitioners generally try to adhere to a person’s wishes if they are known and they align with the standards of care.

Clients who decide to void their ADs should strike a line through the document, write “void,” initial, and date. The voided document should be placed in the medical record, especially if the medical record is electronic.

The most recently dated AD is the legal document; therefore, clients are encouraged to ensure that they have their most up-to-date version in their medical record.

Jurisdictions may differ on witnessing requirements, but a common requirement is that the witness cannot be providing care for the client. Thus, in most if not all cases the social worker is not allowed to serve as a witness for an AD but can help the client locate witnesses who meet the criteria of the jurisdiction.

**What Do I Need to Teach the Client/Client’s Family?**

ACP is for everyone over the age of 18 who has capacity. Social workers should emphasize to clients the importance of completing an AD when they are healthy and educate them about the different kinds of ADs.

Choosing a healthcare agent or proxy who is able to make decisions in a crisis and who is willing to adhere to the client’s wishes (regardless of whether the agent agrees with them or not) can be one of the most important decisions in ACP.

ACP is about a client expressing his or her choices about healthcare interventions and treatments based on his or her beliefs and values; it is not about limiting care.

Educate the patient and family on the legal ramifications of each jurisdiction having its own laws regarding ADs (e.g., in the United States adjacent states such as New York and New Jersey may have different legal requirements). Health departments are a source for what is required in each jurisdiction.

Internationally, social workers should practice with awareness of and adherence to the social work principles of respect for human rights and human dignity, social justice, and professional conduct as described in the International Federation of Social Workers (IFSW) Statement of Ethical Principles, as well as the National Code of Ethics that applies in the country in which they practice. For example, in the United States, social workers should adhere to the NASW Code of Ethics core values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence; and become knowledgeable of the NASW ethical standards as they apply to clients and practice accordingly.

**Note**

A recent review of the literature has found no updated research evidence on this topic since previous publication on May 27, 2016.

**References**


