

# Goals Discussion and Advance Care Planning in the Seriously Ill

Health care is grounded in the principle that sentient adults have the right to make their own decisions about the treatments they receive. This acceptance of patient autonomy and respect for the rights of individuals translates into a second principle—that when an adult loses the ability to make decisions, health care should be guided by the values and preferences the patient expressed when he or she was able to do so.

## Advance Care Planning

Advance care planning (ACP) is the term applied to the process by which people who have capacity for medical decision making plan for a future time when this capacity may be lost as a result of neurological complications of chronic illness or primary neurodegenerative disease.

ACP provides information and a clear process, consistent with laws and regulations, that can help health care providers, patients, and families when medical treatments may be appropriate but the patient cannot consent or refuse them. ACP attempts to answer key questions: “Who would the patient want as his or her agent when medical decisions must be made?” “Does the patient have specific preferences for care that should be respected if he or she loses the ability to communicate them?”

It is important to view ACP as a dynamic process, which requires trust between the patient and health professional, honest communication, and a desire to revisit issues as the patient’s situation changes over time. If the promise of ACP is fulfilled, it can increase the likelihood that decision makers comply with patient wishes, reduce hospitalization and intensive treatments

at the end of life, and increase utilization of palliative care consults and hospice referral (1).

Unfortunately, this ideal is seldom accomplished in today’s health care system. In one longitudinal study, ACP discussions were completed in about 37% of patients with advanced cancer (2). Physicians and other professionals must understand the importance of ACP and acquire the fundamental competencies to engage in ACP discussions.

## When to Initiate ACP

There is no ideal time to initiate ACP. Although physicians often choose to bring the topic up when the patient is very sick or is admitted to the hospital, it is better to consider ACP when relatively well and there is both time and energy to consider the issues carefully, discuss them with the doctor or with family members, and ensure that the documentation is consistent with the aims expressed by the patient.

Advance directives take effect when a patient is found to lack decisional **capacity**. This is a clinical judgment based on the assessment of an attending physician. Patients may express global impairment or an inability

to make specific kinds of decisions. The clinical evaluation of capacity requires that the physician evaluate the patient's ability to understand the details of the health care proposed, the possible risks and benefits, the alternatives to treatment, and the consequences of different decisions. In contrast to capacity, **competence** is a legal term, designation of which requires review by a court.

## Common Strategies for ACP

ACP can be accomplished through varied approaches and can yield varied outcomes. A very specific type of ACP is focused on the decision to permit or refuse cardiopulmonary resuscitation (CPR). Other ACP discussions culminate in the patient's selection of a person who would become the patient's *agent* in the event that the patient loses decisional capacity. Yet other ACP discussions may end with clearly expressed wishes about specific interventions, such as hospitalization or artificial nutrition.

**Advance directives (AD)** are **documents** or **witnessed oral statements** through which a person who has capacity expresses his or her wishes about how decisions should be made if decisional capacity is lost.

Written ADs are very useful because they can be reproduced, placed in the patient's medical records at multiple sites of care and kept as copies by the family. ADs may or may not designate one or more agents, and may or may not include specific instructions for specific treatments.

Older Americans are now completing ADs more frequently than in the past; about 70% of older Americans have some type of AD (3). Patient characteristics associated with AD completion include: older age, Caucasian race, history of chronic illness, high disease burden, higher socio-economic and education level, and knowledge about ADs (4). When ADs are up-to-date and contain actionable information—ideally as part of a process of ACP—they offer multiple advantages (5).

## Types of Advance Directives

A **Health Care Proxy (HCP)** or the **Durable Power of Attorney for Health Care (DPAHC)** is a document (which may be considered the AD itself or be part of a larger AD that includes other information) that specifically designates the agent, also known as a surrogate. States have specific legal requirements for this document.

The person who is selected by the patient as his or her agent should be able to make decisions on behalf of the patient based on knowledge of the patient's values and preferences (called substituted judgment), or in the event that these are not known, based on the best interests of the patient. The person who is the agent should know in advance that this role is requested by the patient.

Ideally, the patient's values and preferences should become known to the agent by specific discussions about the type of care that the patient would want in different circumstances. Health care professionals must be able to trust that the agent is able to serve in this role, is available for discussions when needed, and has no conflicts of interest. If there are questions about the ability of the agent to represent the patient, professionals should consider whether help can be obtained from an institutional Ethics Committee.

**If a patient loses capacity and has not designated an agent**, the health care professionals seek guidance about medical decisions from others, typically family members, who know the patient. States have regulations that govern the process by which surrogates are selected and their activities are documented.

In New York State, for example, the **Family Health Care Decisions Act (FHCDA)** stipulates that the health professional attempt to identify surrogates in a defined order if there is no HCP: guardian (appointed by the court), spouse or domestic partner, son/daughter 18 years and over, parent, brother/sister 18 years or over, close friend, or legally separated spouse. If selecting a surrogate results in distress within the family, a family

meeting and good communication are the best antidotes to a difficult situation.

**Living wills (LW)** are documents or witnessed oral statements (which may be considered the AD itself or be part of a larger AD that includes other information, like selection of an agent) through which a patient documents instructions about specific future medical treatments. LWs are legally recognized in most states, and some states have created forms to help residents with documentation.

A **MOLST (Medical Orders for Life-Sustaining Treatment)** is a signed physician's order produced after consulting with the patient, agent or surrogate. It includes specific medical instructions that may focus on cardiopulmonary resuscitation, hospitalization, mechanical ventilation, artificial nutrition, parenteral hydration, antibiotics, or other interventions. The MOLST is legally recognized in New York, and it may be particularly useful for nursing home patients.

As noted, a specific type of AD is a **Do-Not-Resuscitate (DNR)** form. This documentation of the decision to forego cardiopulmonary resuscitation can be completed for any treatment venue, including hospitals and home. In New York, for example, a home DNR form can be completed by the patient's physician and is legally recognized by emergency services and by Emergency Department staff.

## Conclusion

ACP is dynamic and should be considered a process that ideally begins when patients are relatively well and requires periodic re-evaluation. Clinicians have the responsibility to initiate the process, inform the patient and family of the options, and engage in the periodic discussions that yield legal and accessible documentation of the results.

## References

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