

Advance Care Planning for Patients with Alzheimer's Disease as a Public Health Issue

Advance care planning and end of life care are increasingly being considered public health issues in the United States.¹ People can develop advance care plans at any point in their lives and update them as their health status and living circumstances change. Advance care planning helps ensure that an individual's preferences and values related to end of life care are understood and honored in the event that he or she is unable to make healthcare decisions.² Advance care planning involves discussing and documenting choices about future medical care in the event that a person is sick, injured, cognitively impaired, or unable to make his or her own healthcare decisions.³

The Alzheimer's Association recommends that patients with conditions such as dementia and Alzheimer's disease initiate advance care planning at an early stage.^{4,5} Alzheimer's disease is the sixth leading cause of death in the country, making early financial and legal planning important for both patients and their families.⁶ [The Healthy Brain Initiative's Road Map for State and National Partnerships](#) specifically addresses this point in action item E-07, which emphasizes the need to promote advance care planning among care providers, family members, and patients before cognitive and physical functions decline due to dementia.

Role of Public Health Agencies

- Train and educate healthcare professionals on advance care planning.
- Create a registry portal to make advance directives readily available to healthcare providers.
- Tailor approaches to advance care planning to meet the diverse needs of people.
- Initiate conversations about advance care planning at an early stage, particularly with people with Alzheimer's disease.

Types of Advance Directives

Patients, family members, and healthcare providers are often involved in the process⁷ and discussion among these parties ensures that a patient's preferences for end of life care are known and entered into a legal document called an advance directive.⁸ The directive is a living document that can be updated at any time a patient wishes to make changes, for personal reasons or due to a medical condition. This document is used only if a patient becomes incapable of making decisions about medical treatment. Healthcare facilities within some states have also used the Physician Orders for Life-Sustaining Treatment (POLST) form to document patients' care preferences. Healthcare professionals often complete this form, which serves as a medical order to administer specific treatments during an emergency **Error! Bookmark not defined.**

Most states recognize two general types of advance directives:

- A living will, which can be used to document an individual's preferences for medical treatments and life sustaining measures if he or she is incapacitated.⁹
- A durable power of attorney, which can be used to establish a surrogate decisionmaker who will be responsible for all medical decisions.

States began sanctioning the durable power of attorney in the 1980s.¹⁰ In addition to outlining the patient's preferences related to end of life care, this legal document gives authority to the

decisionmaker for circumstances beyond those listed in the document. The surrogate decision maker is often a family member, friend, attorney, or someone who shares and respects the patient's values. New York and Massachusetts also have health proxy laws allowing patients to appoint a surrogate decisionmaker.^{11,12}

Although the two documents may be used separately, advance care planning encourages people to consider both. There are other documents that may be used to indicate preferences for specific conditions or issues not covered by advance directives, such as organ and tissue donation and do not resuscitate orders.**Error! Bookmark not defined.**

Advance directives often include decisions related to:

- Cardiopulmonary resuscitation.¹
- Ventilator use.**Error! Bookmark not defined.**
- Artificial nutrition (tube feeding) or artificial hydration (intravenous fluids).ⁱ
- Comfort care or services provided for pain relief.
- Participation in research and clinical trials.

Findings to Date

More Americans are completing advance directives compared to previous decades**Error! Bookmark not defined.** and studies show that patients 65 years and older who are actively involved in advance care planning are more satisfied with the healthcare services they receive.¹³ Some patients are more likely to complete an advance directive, such as those with a higher socioeconomic status and level of educational attainment, as well as those who are older, facing a greater disease burden, or have a history of chronic disease. White patients are also more likely than other racial and ethnic groups to have an advance directive.^{14,15} While these studies highlight the socioeconomic and racial disparities surrounding advance directives, they also present an opportunity to use a health equity lens to devise more targeted approaches to promote the role of advance directives in facilitating end of life healthcare decisions.

According to the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine (formerly the Institute of Medicine), while many patients who indicate their preferences for end of life care choose measures focused on alleviating pain, the majority end up receiving acute hospital care.¹⁶ Therefore, to ensure that patients receive care consistent with their wishes, the report recommends establishing evidence-based standards for advance care planning across healthcare facilities and facilitating patient-physician communication.¹⁶

Barriers

Even though more people are completing advance directives, several barriers remain at the clinical and community levels, such as:

ⁱ Supplying nutrition artificially in cases where patients have difficulty consuming food has been a concern for surrogates of patients with late stage Alzheimer's disease with no advance directives. This is due, in part, to the lack of evidence indicating improvement in nutritional status of Alzheimer's patients with feeding tubes, compared to those receiving assisted oral feeding. The Alzheimer's Association recommends assisted oral feeding for all patients with advanced Alzheimer's disease.

- **Lack of awareness:** A study conducted among U.S. adults cited lack of awareness as the primary reason for not having an advance directive.¹⁷
- **Lack of clarity about the process:** Healthcare providers express uncertainty about communicating patients' wishes to the right parties in a timely manner. Although a patient may have an advance directive, many healthcare facilities do not have uniform guidance or a communication infrastructure to ensure that the instructions are carried out effectively.¹⁸ One study found that only 12 percent of patients consulted with their physicians when completing their advance directives, which contributes to the limited utilization of directives in guiding end of life care.¹⁸
- **Cultural differences:** People from different ethnic and racial backgrounds have various beliefs about end of life care. For instance, one study found a higher likelihood of using life sustaining technology in terminal illness among Mexican Americans than their European American counterparts¹⁹. Adapting information about advance care planning to reflect different cultural practices and values may encourage more people to develop advance directives.²⁰
- **Lack of knowledge and communication skills among healthcare professionals:** Studies also indicate that general practitioners are less likely to initiate conversations about advance care planning if they feel unprepared to address patients' concerns.²¹

Public Health Opportunities

State health departments have an important role to play in addressing issues related to end of life care and implementing programs that promote advance care planning. The legal landscape around advance directives has progressed significantly over the past several decades. Policymakers have enacted statutes recognizing advance directives and federal agencies have promoted national models for advance care planning, which has helped establish the groundwork for state initiatives.²² However, states can do more to expand the scope and effectiveness of efforts to promote advance care planning.

States can call attention to the importance of advance care planning by incorporating end of life issues in statewide health initiatives, such as cancer control plans.²³ Prioritizing end of life issues as part of the state's public health agenda could play a vital role in guiding efforts around advance care planning. State health departments may also consider identifying a point of contact for end of life issues within the agency, as well as strategies for collecting and analyzing data about end of life care, and educating the public about the importance of advance care planning.²⁴ Advance care planning presents an opportunity for cross-sectoral engagement and public education in order to promote the process both at local and state levels.¹⁶

There are also ethical concerns surrounding advance care planning. Public health ethics supports the integrating principles of advance care planning into existing healthcare frameworks as a means of resolving the ethical dilemmas that healthcare professionals and family members may face, and helping patients preserve their rights and exercise control over their end of life care preferences²⁵.

Opportunities for State Health Departments

- Prioritize end of life issues as part of the public health agenda.
- Identify a point of contact within the health department for end of life issues.
- Educate the public and raise awareness about the importance of advance care planning.

Potential Actions for Health Departments

Although state health departments are vital in promoting advance care planning, healthcare professionals, payer systems, educational institutions, and the general public, especially older adults and their families, must be involved in implementing effective interventions and policies.

State and local health departments may consider the following strategies to support the development and implementation of advance care planning initiatives:

- Train and educate healthcare professionals on advance care planning to enhance their knowledge, communication skills, and capabilities to facilitate the process. In addition to making forms available to patients if they wish to complete advance directives when they are admitted to the hospital, healthcare professionals may also provide information and assistance in completing the document.²⁶ Providers may also seek continuing education through e-learning programs to minimize the logistical challenges of allocating time for in-person trainings.²⁷ CDC offers a three-module introductory [online course](#) on advance care planning, which is geared toward public health and aging services professionals.
- Create a registry portal to make advance directives readily available to healthcare providers, as well as other parties involved in making decisions about patients' end of life care. This portal may improve utilization of the completed directives in a timely manner. Additionally, the portal could improve accessibility if a patient wishes to make changes to the documents.
- Use local and statewide initiatives to bring attention to advance care planning and educate the public.²⁸ CDC has identified existing [resources](#) for public health professionals to use.

Examples of State and Local Programs

- North Carolina's Department of the Secretary of State established the [Advance Health Care Directive Registry](#), which provides healthcare providers and family members access to a patient's advance directive if it has been registered with the department.
- [Coalition for Compassionate Care of California](#) utilizes a coalition-based approach to train community partners to serve as advance care planning facilitators.
- End of Life Washington created the [Alzheimer's Disease and Dementia Mental Health Advance Directive](#), which is the first of its kind, designed specifically for Alzheimer's and dementia patients.
- The New York State Department of Health partnered with the University of Albany to provide free CME [online trainings](#) for primary care physicians, along with tools and informational resources about providing medical care in the advance stages of Alzheimer's disease and other dementias.
- In 2016, the Maryland General Assembly passed [legislation](#) (HB 1385) requiring the state health department to educate the public about advance care planning and make advance directives available online.
- Louisiana created the [Louisiana Physician Orders for Scope of Treatment](#) document after passing legislation in 2010. It is a best-practice model for patients with serious illnesses to state their preferences for end of life care. The document follows patients throughout the healthcare system, enhancing its accessibility across various facilities of care.

- Initiate conversations about advance care planning at an early stage, particularly with people with Alzheimer's disease, to ensure they are involved in the process before their cognitive and communication abilities deteriorate. **Error! Bookmark not defined.**
- Tailor approaches to advance care planning to meet the diverse needs of people with different cultural backgrounds to encourage more widespread acceptance and bridge disparities.²⁹
- Compensate healthcare professionals for providing counseling and services related to advance care planning to incentivize greater patient-provider communication.³⁰

Conclusion

Given the aging U.S. population, the prevalence of conditions leading to cognitive impairment, and the fact that illnesses and injuries are often sudden and unexpected, public health professionals can take an active role in promoting advance care planning and integrating it into routine patient healthcare services. While there has been significant legislative progress since the passing of the Patient Self Determination Act in 1990³¹, state health departments and other partners can focus future efforts on developing programs to improve the effectiveness and timely utilization of advance directives. Developing strategies to promote advance care planning requires assessing the unique barriers within specific settings and cultures. The healthcare workforce needs to be involved in promoting advance care planning, and states should continue to examine health systems and financing mechanisms to support advance care planning efforts.

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