

**Advance Care Planning: Novel Approaches
and Resources to Reach a Broader Population**



Context of Trend

An increasing number of individuals will face decisions about end-of-life care for family and friends as the population ages and advances in medical care prolong life. More than one in four Americans will face decisions about treatment at a time when they are medically-incapable of deciding.¹ Advance care planning (ACP) and advance directives are designed to inform end-of-life care, but are not used by the majority adults. In the United States, approximately 18 to 36 percent of adults have completed advance directives to inform the course of their medical care if they become incapacitated.²

Advance directives serve to legally document a patient's wishes for end-of-life care, but are often insufficient in addressing all the decisions that need to be made. Advance directives often focus on a narrow set of procedures intended to prolong life, such as cardiopulmonary resuscitation (CPR) or artificial nutrition and hydration, and they typically do not cover other complex medical decisions, such as weighing the risks and benefits of a new treatment or deciding on long-term or hospice care. Thus, it is important to have conversations with trusted family or friends about broader treatment plans and decision making.

Many adults are uncomfortable with discussing end-of-life decisions, do not know how to start the conversation, or are unaware of the most important topics to discuss. Although tools and resources exist to support ACP, use of ACP varies widely. Factors associated with participation in advance care planning include older age, greater disease burden, white race, and higher socioeconomic status. ACP tools accessible to a variety of age groups, races and ethnicities, and socioeconomic groups are needed.

¹ National Institute on Aging. *Advance Care Planning*. <https://www.nia.nih.gov/health/publication/advance-care-planning>

² U.S. Department of Health and Human Services. *Advance Directives and Advance Care Planning: Report to Congress*. 2008. Office of the Assistant Secretary for Planning and Evaluation (prepared by RAND Health, contract #HHS-100-03-0023). <https://aspe.hhs.gov/basic-report/advance-directives-and-advance-care-planning-report-congress>

Description

Advance care planning (ACP) is an interactive process between an individual and their family, friends, and health care providers to inform care if the individual becomes incapacitated. Done effectively, ACP involves learning about the types of decisions that might need to be made, considering one's preferences regarding those decisions, and letting others know about those preferences. Ideally, others are made aware of your preferences in a conversation and in a written advance directive. Advance directives are legal documents that include a living will (specifies wishes for future medical care if an individual becomes incapacitated), durable power of attorney for health care (appoints a proxy to make medical decisions on an individual's behalf), and other specific wishes as desired (e.g., organ donation, autopsy).

Initiatives to support ACP may include written or video educational materials, practice exercises for engaging in care planning conversations, and one-on-one or group discussions. Additional engagement opportunities might be available in the community or area health care settings, and focus on improving communication skills, engagement in care, and promoting behavior change in support of one's advanced directive.

Impact

A long-term, multi-component intervention for seriously ill patients has increased advance directive completion rates by 45 percent, compared to a streamlined, single component intervention.³ Interventions that included policy changes, such as the Respecting Choices initiative in Wisconsin and Physicians Orders for Life-Sustaining Treatment (POLST), were effective at increasing congruence in decision making between patients and caregivers and translating the patient's wishes into actionable medical orders.² Initiatives focused only on

³ Guo B, Harstall C. Advance Directives for End-of-Life Care in the Elderly: Effectiveness of Delivery Modes. Alberta, Canada: Alberta Heritage Foundation for Medical Research. 2004; Information Paper #IP 20.

Trends to Watch

building consumer awareness had no effect on ACP completion rates. It is important to note, however, that multiple component interventions, especially those requiring policy changes, are challenging to scale to a broad audience.

The projects described as trends to watch reflect innovations that aim to expand the reach of advance care planning, in general, and to support populations with special needs.

Trend Watch: University of California Project PREPARE

Project PREPARE is designed to help individuals communicate their care goals with surrogates and participate in advance care planning (ACP) with health care providers. Individuals with chronic illnesses face many complex decisions about health and health care over the course of their care, but many people are not prepared to make choices about ACP because they may not be aware of the types of decisions needed, have the skills to communicate their preferences, or have the knowledge to understand complex legal forms. The PREPARE website (<https://www.prepareforyourcare.org/>) provides education and support for individuals as they engage in a broad range of ACP behaviors.

The PREPARE website is widely accessible, relatable, and useful to individuals of different cultural, religious, and educational backgrounds. The website includes easy-to-understand communications and training on five steps:

Step 1: Choose and ask someone to be a surrogate for medical decision making;

Step 2: Clarify and communicate values and preferences regarding care;

Step 3: Discuss how surrogates should use their best judgment if unexpected decisions need to be made;

Step 4: Tell health care providers, family, and friends about your wishes;

Step 5: Ask your clinicians for information to help make the right decisions.

**Trend Watch:
Institute for
Healthcare
Improvement
Conversation
Project**

A library of videos and scripts is included on the website with ways to model communication about each step. The videos reflect a range of choices and factors that may influence those choices, such as culture, religion, and literacy. The site also provides tools to develop an action plan to complete each step. In a pilot study of PREPARE, participants increased engagement in ACP behavior within one week.⁴ PREPARE was rated as easy-to-use by older adults from diverse backgrounds, computer literacy levels, and health. PREPARE was also found to be helpful to some participants who had previously engaged in aspects of ACP, inspiring them to recognize the seriousness of the topic.⁵

The Conversation Project provides individuals with starter kits to help families engage in end-of-life care planning, as well as specialized resources for caregivers of pediatric patients and patients with Alzheimer's Disease or other forms of dementia. Three kits support this project:

The Original Starter Kit is designed to support conversations about end-of-life care for older adults, regardless of health condition.⁶ The starter kit outlines four steps, including: 1) assessing readiness to have this conversation; 2) clarifying the patient's values and preferences about care; 3) clarifying who should participate in the conversation, when and where it should happen, and what should be discussed; and 4) next steps for after the conversation.

The Pediatric Starter Kit adapts the four steps of the original starter kit to meet the needs of parents and pediatric patients by acknowledging the special concerns of parents⁷ (e.g., what if I cry in front of my child?, how do I support their siblings?) and adapting the conversation tools for children of different

⁴ Sudore, RL, Knight, SJ, McMahan RD, et al. *J Pain Symptom Manage*. 2014 April; 47(4):674-686.

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4111443/pdf/nihms591676.pdf>

⁶ http://theconversationproject.org/wp-content/uploads/2016/09/TCP_NEWStarterKit_Writable_Sept2016_FINAL.pdf

⁷ http://theconversationproject.org/wp-content/uploads/2016/05/TCP_PediatricSK_Forms.pdf

**Trend Watch:
University of
Colorado School
of Medicine –
Group Medical
Visits**

ages and language abilities. Testimonials from parents who lost children and pediatric health care providers are included throughout the starter kit as examples of how the conversation might play out and how it might feel.

The Starter Kit for Patients with Alzheimer’s or Dementia is similar to the original kit and includes additional content for families of patients who are experiencing cognitive decline.⁸ This kit accounts for key concerns, such as having the conversation at different stages of disease progression and how to advocate for a loved one when they can no longer advocate for themselves. Matching the support in the pediatric kit, the Alzheimer’s kit includes testimonials from caregivers and health care providers to reinforce the importance of having end-of-life care planning conversations, and provides examples of how the conversations may occur.

Many primary care providers seek new ways to engage their patients in advance care planning and, although the Centers for Medicare and Medicaid Services offers reimbursement for counseling on advance care planning, many providers face challenges, such as lack of time, training, and resources, to provide advance care planning to large numbers of patients. Group medical visits, also referred to as shared medical appointments, are typically used to engage groups of patients in discussions of chronic disease management. Previous studies of group medical visits have shown they can increase patient engagement and support for behavior change, which provoke the idea that group medical visits are a good venue for discussing advance care planning. Researchers from the University of Colorado set out to test this idea and soon found that using group medical visits to provide counseling for advance care planning (ACP) offered a promising approach to increasing patient engagement in planning activities.

⁸ http://theconversationproject.org/wp-content/uploads/2016/05/TCP_StarterKit_Alzheimers.pdf

The research team developed the Conversation Group Medical Visit to engage patients in discussions of key topics in advance care planning and to help them develop action plans to carry out their wishes. The Conversation Group Medical Visit consisted of two 2-hour sessions co-facilitated by a geriatrician and a social worker. Facilitators used educational materials from the Conversation Starter Kit and the PREPARE website (both noted above) to guide discussion and provide conversation and plan examples. Patients were referred to the group visit by their primary care providers, and had the option of an individual visit with the geriatrician immediately following the group visit. During engagement on ACP, the implementation of Conversation Group Medical Visits, recommended resources, a class agenda, a facilitator’s guide, and billing recommendations, are made available through the tools available in the Conversation Group Medical Visit team.⁹

In a pilot study of 80 patients, patients reported a significant increase in ACP activities and positive experiences with Conversation Group Medical Visits. After participating in the group visits, 41 percent of participants engaged in conversations with sufficient detail. They reported feeling confident that loved ones knew their wishes, compared to 19 percent before these group visits.¹⁰ Approximately 90 percent of participants agreed or strongly agreed the group visits were better for discussing ACP than the usual clinic visit. During the group visits, patients shared their values and preferences regarding care and discussed a wide range of topics, including advance directives, cardiopulmonary resuscitation (CPR), dementia, organ donation, and emergency, long-term, and palliative care.

⁹ <http://www.annfammed.org/content/14/2/125.full>

¹⁰ Ibid.