

The Role of the ACP Facilitator

An excerpt from “Having Your Own Say: Getting the Right Care When It Matters Most,” edited by Bernard J. Hammes, Respecting Choices

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these contributors and editors have given us a fresh and illuminating perspective.*

I would encourage every state and federal lawmaker interested in informed health policy to read this book carefully.”

—Former Sen. Tom Daschle

Chapter 3: Helping Individuals Make Informed Healthcare Decisions: The Role of the Advance Care Planning Facilitator By Linda A Briggs, MS, MA, RN, Respecting Choices

Like most Americans, you probably know what a living will is. This type of advance directive (AD) allows you to provide instructions for life-sustaining treatment only when you are terminally ill or permanently unconscious. The other (and preferred) AD is a power of attorney for healthcare, which allows you to appoint a trusted individual (e.g., an agent or proxy) to make healthcare decisions for you if you become unable. Despite your awareness of your rights to complete a written plan, only 18% to 36% of you have participated in this activity.¹⁻³ Moreover, only one in three people living with serious, advanced illness (and at risk of imminent complications) have created plans regarding future treatment decisions.⁴

There are many reasons why you have not exercised your legal right to complete an advance directive.⁵ You may feel that you can wait until you are older, or become sick, or get “sicker.” You may believe that your loved ones know what kind of care you would want if you could not communicate and feel no urgency to act any further. Some of you may want to talk about these issues with your family but fear that you will upset them. On a more emotional level, you may not know how, where, or when to bring up the subject of “dying.”

On the other hand, some of you will say, “I’ve already done that,” meaning you have completed an AD. You may have a sense of security that it is done, placed in a safe place (e.g., file cabinet or safe deposit box) and out of sight. You hope to never have to use it. However, how confident are you that it will control the kind of care you

receive in your last weeks, months, or years of life? Does it say what you want it to say? Are you comfortable that your loved ones and healthcare providers will follow your decisions? What kind of conversations have you had with your loved ones about your personal goals and values?

Perhaps you are waiting for your doctor or other healthcare provider to talk to you about ADs. After all, if they were that important, surely your doctor would inform you and help get you started? There are many reasons why doctors and other healthcare providers do not initiate planning conversations. Many feel unskilled and uncomfortable initiating discussions.⁶⁻⁹ Others may assume that patients are not interested in these types of discussions, or they fear that they will cause anxiety and stress.^{10,11} Additionally, practical challenges, such as insufficient time and reimbursement, make it difficult for busy healthcare providers to focus on planning discussions in their daily work.^{12,13}

In the 1980s, people living in La Crosse, Wisconsin, held similar concerns and beliefs about the value of ADs. The culture in this Midwestern community has changed dramatically since that time. In the early ‘90s, the leaders of the La Crosse advance care planning (ACP) program decided to take a unique approach to the completion of ADs. They rejected the belief that this was a simple activity based only on an individual’s legal right to complete a planning document. Instead, a robust and patient-centered planning process was designed that focused on quality discussions initiated by qualified

healthcare professionals. A cornerstone of the program's success was the creation of a new healthcare role, the ACP facilitator. These individuals receive training in the necessary communication skills to assist people in making informed healthcare choices in light of personal goals, values, and beliefs. Working in partnership with physicians, trained facilitators make it possible to realistically deliver a consistent and reliable ACP service to individuals at all stages of illness and in a variety of outpatient and community settings. This ACP service has features that are distinctly different from typical AD programs.

Advance Care Planning Versus Advance Directives: What's the Difference?

It is understandable if you are unaware of the differences between "advance care planning" and "advance directives." In fact, the literature often uses these terms interchangeably. The distinction between them is critical and at the heart of wide variation in the quality of care planning services available to consumers. ACP and AD services vary in their goals, content, and outcomes.

Advance Directives: What is involved?

The typical AD service has the goal of helping people complete a written document that meets the state's legal requirements. Such standardized forms are often difficult to understand, written in "legalese" and provide little direction for how to make healthcare decisions. Individuals assisting with the completion of ADs are trained to ensure that such documents have the necessary signatures, dates, and other legal requirements. Healthcare organizations are motivated to comply with federal mandates and regulatory agencies. Therefore, when you are admitted as a patient to a hospital, you are asked if you have an AD and, if so, where it can be found. If you have not completed an AD, you are asked if you would like more information or assistance in this activity. Through this series of yes or no questions, organizations comply with federal regulations; however, the timing of these questions is not ideal. As a newly admitted patient, you are ill, uninterested, and unmotivated to participate in planning discussions. AD services may also be provided by an attorney as part of estate planning, but in a setting disconnected from your doctors and from the medical care you receive. AD

services often have a just-get-it-done attitude that gives individuals a false sense of security that what is "done" will be effective at a future point in time. Tools that have been developed to assist with the completion of ADs include brochures, videos, computer-based tutorials, educational presentations, and workshops. These single-modality interventions have not proved effective in helping individuals make informed healthcare decisions or, more importantly, in ensuring that their decisions will be honored when needed.^{14,15}

If you are among the minority of Americans who have completed a written AD, the research on the effectiveness of these documents may surprise you. The existence of a planning document does not ensure you will receive the care you intend if you become seriously ill. For example, in a study of bereaved family members where 70% of patients had completed an AD, significant gaps in end-of-life care were found.¹⁶ There are typically two reasons why written plans are not helpful: (1) chosen agents/proxies are unprepared to make healthcare decisions for another person, resorting to more aggressive care than the patient would choose; and (2) the written plan contains instructions that are too vague or ambiguous to guide clinical decision making.^{17,18}

ADs don't work the way most people intend them to work. They fall short of providing the type of planning discussions that allow patient choice, comfort, and control in the last weeks, months, and years of life.

Advance Care Planning: What's involved?

As the term "advance care planning" implies, it is a process and not an event. The La Crosse Respecting Choices ACP program has developed and tested a robust planning approach that involves patient-centered discussions and has broad and comprehensive goals:

- To provide qualified assistance to individuals in making informed healthcare choices appropriate to their stage of illness, goals, values, and beliefs;
- To create plans that will be effective in providing personalized care—plans that ensure that individuals receive *all* the treatment, and *only* the treatment they desire; and
- To develop strategies to communicate these choices to those who need to know (e.g., healthcare agent, family, physician, other healthcare providers).

To reach these goals, ACP requires communication. ACP is an interactive process of understanding, reflection, and discussion.

1. Understanding. While ADs focus on the completion of a planning document, ACP begins with the information individuals need to make personal healthcare decisions and motivate them to participate. Basically, individuals need to understand *why* ACP is important, *what* is involved, and *how* to begin the process. For healthy adults, the planning process is fairly straightforward; however, individuals living with advanced illness face complex and confusing choices. Treatments have benefits and burdens that must be understood and balanced against individuals' goals and values. Alternatives to treatments, including options for comfort care, must be explored. For example, if an individual chooses not to go back on a breathing machine for a lung complication, how will their symptoms be managed and where will they be cared for? Contrary to the belief that patients are uninterested in receiving detailed information about the healthcare decisions they are asked to make, a recent survey showed that 75% of Americans are concerned about not having adequate information about treatment options.¹⁹ Individuals desire and have the right to receive facts and medical advice on the critical decisions that will have a profound impact on their quality of life.²⁰

2. Reflection. Healthcare decision making can be complex, especially for those with serious illness. Individuals need time to reflect on their personal goals, values, and beliefs as they relate to the information they are provided. For most individuals, quality of life is as important as length of life. How do you define quality of life? What activities and experiences give your life meaning? What goals are you hoping to achieve? What religious or cultural beliefs do you have? Individuals need adequate time to reflect on these important questions that will ultimately guide their personal decisions.

3. Discussion. Individuals also need time to discuss these issues with others who are important in the decision-making process, such as chosen healthcare agents/proxies, loved ones, doctors, and religious advisors. Without participating in ACP discussions, healthcare agents, for example, are typically unprepared to make critical life and death decisions for a loved one. The responsibility of making healthcare decisions can be overwhelming, causing stress and grief that can last for years.²¹ Additionally, individuals with strong religious beliefs may want to talk with their minister, rabbi, or priest to receive guidance in making treatment decisions.

As an interactive process of understanding, reflection, and discussion, ACP resembles the familiar informed consent practices used to help patients understand recommended treatments or procedures, such as elective surgery, treatment for cancer, or management of heart failure. Could you imagine agreeing to a surgical procedure that you did not understand, or not taking the time to talk to a surgeon about risks and complications? You have a right to the best medical facts available regarding your treatment choices. Armed with accurate information, you are more prepared to make your own choices and control your destiny. Consider the following example. Patients living with advanced illness are commonly asked whether they would want cardiopulmonary resuscitation (CPR) if their heart or breathing stopped. This question is routinely asked on admission to a nursing home or hospital with the expectation that a yes or no answer will be given. Have you considered this question for yourself? What information would you need to make a decision about CPR? Would you want to know how successful it is at restarting the heart and breathing? Would you want to know the complications that can occur from CPR? Would you like the time to talk to your doctor about his recommendations? If you decided you did not want CPR, what alternative plans would need to be developed? How would you prepare your loved ones to follow your CPR decision? Decisions about life-sustaining treatments do not have simple yes or no answers.

This approach to ACP makes a difference for patients and families. Studies evaluating the impact of facilitated ACP discussions have demonstrated improved quality of life for patients, reduction in stress and anxiety for healthcare agents, and increased satisfaction with overall medical care^{22,23}

To achieve these outcomes, an ACP service requires skill, time, and organizational support. A core component of the success of the Respecting Choices ACP program is the creation of the role of the ACP facilitator, trained to assess individual planning needs, fears, goals, values, and beliefs and craft a patient-centered planning approach. The ACP facilitator provides this service as a member of the healthcare team, making referrals to others as needed and involving physicians whenever necessary.

The Team Approach to ACP and the Emerging Role of the ACP Facilitator

There is a tendency to assign the sole responsibility of ACP to the patient's physician. While there may be some advantages to this approach, there are significant barriers that make this assignment unsustainable. In a small quality improvement study conducted at Gundersen Health System, several physicians were interviewed regarding their ACP practice for patients with advanced illness. Most physicians acknowledged the importance of initiating ACP discussions but admitted that they rarely had the time to do this consistently and focused on patients perceived to be at highest risk for complications. Physicians who had access to non-physician ACP facilitators were more likely to rely on this member of the team to make referrals. Even if physicians feel prepared, motivated, and willing to initiate ACP discussions, they will face challenges delivering this service to all patients who need it due to increasing demands on physician-dependent services and lack of adequate reimbursement. This physician-based model of providing ACP is unsustainable and unreliable in delivering a consistent ACP service as a routine of care.

Respecting Choices advocates a different model—one that integrates a team approach to ACP and includes the physician but supports the training of nonphysicians in the role of ACP facilitator. A facilitator's role is to make it *easier* for you to make healthcare decisions, to *support*

you in getting the information you need, to *help* you develop questions for your doctor, and to *guide* the creation of your personal healthcare plan. An ACP facilitator

- Initiates opportunities for ACP discussions at multiple encounters and throughout the lifespan of an individual;
- Assesses the needs of the individual seeking ACP assistance;
- Designs a patient-centered approach to planning based on the patient's illness, readiness to participate, fears and concerns, and religious or cultural beliefs;
- Makes referrals to other resources, as needed;
- Assists patients in making informed healthcare decisions based on facts, understanding, reflection, and discussion;
- Prepares the patient's healthcare agent and loved ones to understand and honor choices that the patient has made;
- Assists in the development of a plan that honors the patient's goals, values, and beliefs for future medical care; and
- Develops strategies to effectively communicate the plan to those who will be responsible for interpreting it and making decisions (e.g., healthcare agent, physician, and other healthcare providers).

The ACP facilitator cannot work alone. The delivery of quality healthcare services to patients is often complex, requiring a multidisciplinary team approach to achieve maximum outcomes. Using the expertise, background, and availability of a variety of qualified professionals, the patient is more likely to receive comprehensive and consistent care. There are many clinical examples of the effectiveness of this model. Consider the patient with chronic heart failure who suffers a heart attack. While the internist or hospitalist may initially diagnose the problem, cardiologists are consulted to assess the treatment options and make recommendations for a medical plan of care. The patient will be assisted by a rehabilitation team of nurses, physical therapists, and others who will design a plan for recovery and return to an active lifestyle. Additionally, a clinic heart failure team may be used to educate the patient in self-care, such

as diet, exercise, and medication guidelines, as well as provide psychological and spiritual support.

Another common example is a newly diagnosed patient with diabetes. While the medical plan of care is designed by the patient's physician and a pharmacist is consulted on the options for delivery of medications, the services of a diabetes educator are used for patient education and ongoing support in managing this chronic illness. This familiar team approach to quality patient care is effective for delivering a reliable ACP service, as well. The beneficiaries of this team approach to care are obviously the patient and family, but professional satisfaction also increases as interdisciplinary respect and collaboration result in improved patient outcomes.

ACP facilitators work in a variety of community and healthcare settings. They are community volunteers, parish nurses, chaplains, social workers, and nurses. Their specific ACP duties will vary with their expertise, background, and the planning needs of the individual.

Advance Care Planning is not a “One Size Fits All” Process

One of the greatest misconceptions about ACP is that it is a static process that ends with the completion of a written document—that it is a one-size-fits-all process. Many AD programs, tutorials, and documents propose a single planning approach for everyone. It is unrealistic and impossible to plan for all possibilities in a single document or at a single point in time. Respecting Choices defines ACP as a patient-centered process of understanding, reflection, and discussion. The content of this process will change over time as an individual moves from a healthy state to one of advanced illness. As goals and values change over the course of advanced illness, specific and timely planning strategies must be available.

To address the changing needs of patients for planning assistance over the course of their lives, Respecting Choices has developed a staged approach to ACP: First Steps, Next Steps, and Last Steps. This approach is based on an individual's stage of health, readiness to learn, and venue of care. This patient-centered and practical approach to planning makes it possible for individuals to take one step at a time, making decisions that are appropriate to their stage of illness and revising plans

as necessary. This staged approach to planning also makes it possible to train ACP facilitators from varying backgrounds and expertise to assist individuals to make appropriate healthcare decisions in the community and healthcare setting.

First Steps Planning and the Role of the ACP Facilitator

While any person over the age of 18 has the right to complete an AD, First Steps planning should be routinely initiated for those between the ages of 55 and 65 years as a component of routine healthcare. The goals of this stage of planning are to

- Introduce the importance of ACP as an ongoing process;
- Assist in the selection and preparation of a qualified agent/proxy;
- Explore the individual's goals for life-sustaining treatment in the event of a severe, neurologic illness where a full cognitive recovery is unlikely; and
- Complete an AD (i.e., power of attorney for healthcare).

A First Steps ACP facilitator would assist you in several ways. You would be provided written information that helps you understand why planning is important, explore examples of situations that require healthcare decisions, reflect on personal goals, values, and religious beliefs, and identify fears or concerns you have about participating in such ACP discussions. The facilitator would help you choose a healthcare agent wisely—one who is willing to talk with you, who will follow your wishes, and who is capable of making decisions under stressful situations. An ACP meeting would be scheduled with you, your chosen healthcare agent(s), and other family members, as desired. The goal of this meeting would be to assist you in talking to your loved ones and to improve your agent's ability to make decisions consistent with your values and beliefs. The facilitator would also be attentive to possible obstacles to making advance care planning decisions. Perhaps you have family members who would disagree with your decisions, or you have strong religious beliefs about withholding artificial nutrition and hydration. The facilitator would help create strategies to address these issues. In helping

you create a written plan that reflects your goals, values, and beliefs, the facilitator will recommend strategies to communicate your personal plan to your healthcare agent, family, doctor, and other healthcare organizations.

First Steps facilitators may be in the community (e.g., senior center staff, parish nurses, volunteers) providing education on the importance of pre-planning, the tools that are available to begin this work, and completing a written advance directive, even when you are healthy. First Steps facilitators are also nurses, social workers, and chaplains who provide ACP services as a component of routine primary healthcare in the clinic setting.

First Steps ACP delivers an important message to patients: planning will be ongoing. It forces you to plan for advanced illness when you are healthy. It sets the foundation for weaving ACP discussions into the routines of care and helps to normalize the conversation.

Next Steps Planning and the Role of the ACP Facilitator

Many Americans suffer from advanced illness, such as heart failure, emphysema, or kidney disease. Due to advances in medical science and technology, such illnesses are well managed for years. Even so, since there are no cures for advanced illnesses, they will progress and eventually cause complications, a decline in people's ability to care for themselves, and repeated emergency department visits or hospitalizations. When these types of changes occur, it is time for a different planning approach—one that is specific to your illness and the real treatment decisions you will need to make when complications occur.

Consider the following example. John is a patient with emphysema, a type of advanced lung disease that makes him susceptible to pneumonia and breathing problems. His lung disease has been well-managed until the past several months. His illness has worsened and he has experienced repeated episodes of breathing complications that require hospitalizations and mechanical assistance to help his lungs recover. These episodes have taken a toll on his lungs, and he does not fully recover his ability to do the things he used to do. Life is not the same. As John's quality of life changes, he may begin to wonder, "Do I want to go back on a

breathing machine again?" "Do I have other choices to help me breathe when I have a complication?" "How can my breathing symptoms be managed if I decide not to go back on the breathing machine again?" "How do I help my family understand my fears?" John needs assistance navigating such challenges. Without assistance, John may be unaware of his choices and unable to make decisions. He will experience another medical crisis and his family will be unprepared to make decisions on his behalf. He may or may not receive the care that he wants.

At this critical stage of John's illness, a Next Steps ACP facilitator will schedule a planning meeting with him, his chosen healthcare agent(s), and other family, if needed, in the outpatient setting when he is medically stable. The goals of this planning meeting are to help John understand his disease progression, potential complications, and life-sustaining treatments that may be needed if complications occur. His fears, hopes for living well, and experiences will be explored. While hoping for the best, John will be assisted in planning for worst-case scenarios and identifying the burdens that he is willing (or not willing) to accept. A critical component of Next Steps discussions is the preparation of the chosen healthcare agent to make future decisions consistent with John's goals, values, and beliefs, and to make referrals to other resources that can help John live out the rest of his life with dignity. The planning process results in a disease-specific written plan that will be added to John's AD.

This Next Steps planning approach has resulted in improved understanding of treatment choices between patients and their chosen agents and a high level of satisfaction with the quality of such discussions.^{24,25}

Last Steps Planning and the Role of the ACP Facilitator

As individuals age, become frail, and cope with multiple illnesses, they are at risk of complications that may result in death or disability. These individuals are often living in long-term care facilities and at risk of losing their ability to make their own healthcare decisions. Timing is of the essence. Last Steps facilitators assist individuals to clarify goals of care and made specific decisions about CPR, hospitalization, management of breathing complications, and artificial nutrition and hydration,

among others. Last Steps ACP facilitators are typically nurses, nurse practitioners, social workers, chaplains, and physicians who work in a variety of healthcare settings, such as long-term care facilities, home and hospice care, and palliative care. To ensure that patients' decisions are followed, the Physician Orders for Life-Sustaining Treatment (POLST) form (<http://www.polst.org>) is used to document specific treatment decisions in a system that converts them to medical orders that can be followed throughout the healthcare community.

ACP facilitators have unique roles to play at each stage of planning. By working in partnership with physicians and other healthcare providers, patients are provided the information, support, and the freedom they need to choose the care that matches their goals and preserves their personal dignity. Physicians and healthcare providers know what treatment patients do and do not want. Care is individualized. Everyone benefits.

Advance Care Planning: A Worthy Investment?

Of course, not everyone will agree that the robust ACP service described herein is worth the investment. What is the motivation to support the role of the ACP facilitator? Why should an organization commit the necessary time for ACP? What is the return on investment? After all, reimbursement for ACP planning has met resistance over fears of so-called death panels and rationed healthcare. While these fears are unwarranted, they stem from a lack of consensus about the goals of an ACP service, which are to assist individuals to take control of their own healthcare, to make decisions based on facts and on their personal definitions of quality of life. When there is consensus about this personalized approach to planning, fears diminish and a new paradigm for how to deliver this service emerges. ACP is understood as more than the completion of an advance directive. ACP discussions are patient-centered. Patients' goals and values are revisited at appropriate points in time as they move from a healthy state to one of advanced illness. Written plans become more specific as advanced illness progresses and provide instructions to effectively guide clinical decision making. Loved ones are prepared to make decisions when serious illness occurs. The planning needs of individuals are met by multiple professionals and in different settings of care. A team approach that integrates the role of the ACP facilitator is efficient,

practical, and rewarding for patients, families, and healthcare providers.

Life is precious. Only you can control the kind of care you receive in the last weeks, months, or years of your life. The ACP service described in this article creates a partnership with you, your doctor, qualified facilitators, and your loved ones to help you take charge of your life. ACP discussions promote trust and peace of mind, as depicted in the following message to a facilitator after an ACP discussion:

"I just wanted to thank you again for helping my Dad. The meeting was just what we needed. It would have been difficult to broach those subjects without you there to facilitate. I think his mind was put at ease by getting everything out in the open and it led to some very productive and loving conversations later in the day."

This is the type of human interaction patients expect and deserve. Patient-centered ACP discussions have the power to heal and alleviate the stress and burdens of healthcare decision-making.

Is ACP a worthy investment? You decide.

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