

Advance Care Planning along the Continuum

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What will happen if you experience a sudden illness that prevents you from making your own medical decisions? How will you ensure that you will receive the kind of care you want? Will your family or loved ones know enough about what you value and believe to feel comfortable making decisions about your care?

To adequately address these questions, everyone 18 or older should discuss his end-of-life wishes with his physician and family members and put it in writing with an advance care directive (ACD). This discussion and documentation process is known as advance care planning (ACP), which helps you prepare for an unexpected illness from which you expect to recover, the dying process, and, ultimately, death.

ACP is not solely for the elderly or the seriously ill, as illustrated by the case of Terri Schiavo, the 40-year-old Florida woman in a persistent vegetative state. She is caught in an ongoing legal battle between her husband and her family over her future care. Her tragic case demonstrates all that can go wrong when we are faced with an unexpected injury or illness and are unable to speak for ourselves and when different values exist among loved ones as to what course of treatment should be undertaken. The case highlights the need for

written advance directives, and, more importantly, the need to discuss our individual preferences on life-sustaining medical treatments and interventions with our family and physician.

These conversations should begin when individuals are young, healthy, and independent, and should continue along the health/illness continuum (Fig. 1), recognizing that goals of care and preferences may change as individuals develop chronic illness and functional decline, advancing disease, and frailty. The people we were at 18 are not the same as we become in later stages of our lives. Life experiences transform our views. Family, personal, and work responsibilities mold and change us as we grow older. There is a continual change in our perception of what is important and what we are willing to undergo in terms of medical treatments and interventions to be faithful to our own sense of self. What is good for me may not be good for you.

Advance Care Planning: More than a Document

ACP is a process of:

- Becoming educated about the topic, including understanding the documents, the process, and the benefits
- Exploring, clarifying, and documenting an individual's values, beliefs, goals of care, and expectations
- Understanding how to choose the best spokesperson (surrogate or agent) who is named in the state's legal document, who will work best with physicians and health care providers to make decisions on the patient's behalf, then discussing wishes with the chosen spokesperson and alternate, family, physician, attorney, and spiritual advisor, as needed
- Understanding various life-sustaining treatments beyond cardiopulmonary resuscitation (CPR)
- Recognizing practical issues related to maintaining document accessibility and the need to periodically review and update the documents



Figure 1. The Health/Illness Continuum

The Benefits

ACP is a gift to both you and your family. You are taking steps to spare them the doubt, the guilt, the emotional burden, and the turmoil that come with trying to guess what their loved one's wishes might have been, particularly during a medical crisis. ACP helps remove uncertainty and ensures that your wishes about treatment are met in the event you are unable to speak for yourself. Realizing that your preferences will be honored will provide you with peace of mind and a sense of control. The benefits are clear.

ACP includes having conversations among families and other trusted individuals, such as friends, physicians, and so forth. The process builds trust and establishes relationships among family, close friends, health care professionals, and others who will care for you or who will be with you as you approach death.

We all have a personal sense of who we are, what we like to do, the degree of control we like to have, goals for our lives, and things we hope for. Many have strong opinions about what would be imperative at the very end of their lives; others wish to be sure that certain things they dislike or fear will be avoided. Therefore, it is important to clarify personal values and beliefs.

Staging Questions: Health Care Proxy Readiness

- Formally designating a person to speak for you about your medical care should you become unable to speak for yourself is called designating a health care proxy. The best way to designate the person to speak for you is to complete a Health Care Proxy form. Which answer best describes your level of readiness to fill out a Health Care Proxy form?
 - I see no need to fill out a Health Care Proxy form.
 - I see the need to fill out my Health Care Proxy form, but I have barriers or reasons why I have not done it.
 - I am ready to fill out a Health Care Proxy form or I have already started.
 - I already filled out my Health Care Proxy form and it reflects my wishes.
 - I already filled out my Health Care Proxy form but it needs to be changed.

We are interested in knowing if age, ethnicity, gender, education, or health care background affects people's attitudes about health care proxies. We would appreciate your help in answering the following questions. Response is voluntary and all information will be kept confidential.

- Are you:
 - 1. Male
 - 2. Female
3. Into which of the following age groups do you fall?
 - 18 – 25
 - 26 – 33
 - 34 – 41
 - 42 – 49
 - 50 – 54
 - 55 – 59
 - 60 – 64
 - 65 – 69
 - 70 – 74
 - 75 – 79
 - 80 – 84
 - 85 and over
4. What ethnic group best describes you?
 - African American, not of Hispanic origin
 - American Indian/Alaska Native
 - Asian/Pacific Islander
 - Puerto Rican
 - Mexican
 - Hispanic, not of Mexican or Puerto Rican origin
 - White, not of Hispanic origin
 - Other _____
5. Which of the following best describes the highest level of education you have completed?
 - Up to and including some high school
 - High school graduate (including G.E.D.)
 - Associate's degree, certificate program, or some college but no degree
 - Four-year college degree
 - Advanced degree (i.e. Masters, Ph.D., MD)
6. Have you ever worked in a health care related job (doctor, nurse, therapist, aide, health insurance worker, etc.)?
 - Yes, I currently work in a health care related field.
 - Yes, I have worked in a health care related job in the past.
 - No, I have never worked in a health care related job.

Figure 2. The Health Care Proxy Readiness Survey

TABLE 1 EXPLORATORY QUESTIONS/YOUR FEELINGS ABOUT END-OF-LIFE CARE

Instructions: For each row, check one answer to express how important these issues would be to you if you were dying.

	Not important	Moderately important	Very important	Extremely important
a. Avoiding pain/suffering, even if it means that I might not live as long				
b. Being alert, even if it means I might be in pain				
c. Being around my family and close friends				
d. Being able to feel someone touching me				
e. Having religious or spiritual advisers at my side when I die				
f. Being able to tell my life story and leave good memories for others				
g. Reconciling differences and saying goodbye to my family and friends				
h. Being at home when I die				
i. Being in a hospital when I die				
j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I'm unconscious				

What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

What are your biggest hopes about the end of your life?

What are your biggest fears about the end of life?

Adapted from Education for Physicians on End-of-life Care, The Robert Wood Johnson Foundation, 1999.

The Barriers

Evaluating potential barriers will help you overcome them. Take time to consider this important civil right now and the barriers that keep you from engaging in the process:

- Are you unwilling to discuss death?
- Do you believe that accepting mortality is giving up hope?
- Are you afraid that discussion will make it happen?
- Are you unwilling and/or unsure how to broach the topic?
- Do you understand ACDs and their benefits?
- Are you able to find reliable resources?

The Documents

An ACD, the central document in ACP, is a legal record and may be called a health care proxy, living will, durable power of attorney for health care, or advance directive for health care, depending on the state in which you reside. State-specific forms can be obtained at www.partnershipforcaring.org.

[org](http://www.Hospiceinfo.org). Although the sponsoring organization no longer operates, the Web site remains for information only. For questions on content, contact the National Hospice and Palliative Care Organization at (800) 658-8898 or visit www.Hospiceinfo.org.

Out-of-hospital do-not-resuscitate (DNR) orders have been developed to provide emergency medical services with written orders regarding resuscitation. The number of states authorizing out-of-hospital DNR orders has increased from 11 in 1992¹ to 42 in 1999.² Despite the growing use and the acceptance of these orders, barriers, including variable implementation, limit their effectiveness.

If you have personally completed an ACD, you have taken an important first step in ensuring that your wishes are honored if you are unable to speak for yourself and that you will receive high-quality palliative and end-of-life care that meets your personal goals. Importantly, you also are in a better position

to understand the process and to assist your patients with ACP.

If you have not completed an ACD, you are not alone. At the time that the Patient Self-Determination Act was enacted in 1991, 20% of Americans had a form of ACD and 75% approved of a living will. Even now the percentage of people with an ACD remains largely unchanged. In 2002, Means to a Better End, the first national end-of-life report card, reported that 15% to 20% of Americans have one.³

Clarifying Values, Beliefs, and Goals

Completing an ACP form is not enough. The form must be part of an ongoing process of planning for future medical care that begins with clarifying values, beliefs, and goals. Table 1 provides a list of issues to consider when helping an individual clarify feelings about end-of-life care. A case manager might ask the following:

- What are some of the things that you hope for that could make your last weeks, days, or hours the most peaceful?

- What are your biggest hopes about the end of your life?
- What are your biggest fears about the end of life?

These answers change with illness. It is the physician's role to clarify the patient's goals and subsequent treatment plan. Case managers and other health care team members support the patient's goals and help the patient recognize options to discuss with his physician. Potential goals of care might include the following:

- Curing disease
- Avoiding premature death
- Maintaining or improving function
- Prolonging life
- Relieving suffering
- Improving or maintaining quality of life
- Staying in control
- Experiencing a good death
- Supporting families and loved ones

Multiple goals often apply simultaneously, occasionally contradict each other, and are sometimes unrealistic. Certain goals may take priority over others. Goals often change over time. Some take precedence, resulting in a gradual shift in the focus of care. This is expected along the health/illness continuum. Goals guide care and are essential in helping to assess priorities and to develop initial and follow-up plans of care. Goals should be reviewed with any change in health status, advancing illness, or transition in setting of care, because it may change treatment preferences.

Choosing a Spokesperson

It is important that our individual voice be heard concerning medical treatment. To that end, finding a spokesperson, whether a spouse, a family member, a friend, or a spiritual leader, who will speak for you, represent what you want, and adhere to your values instead of to his own or someone else's is of prime importance. The alternative is that a stranger or a government representative may end up making medical decisions affecting your life based on their value and background.

When choosing a spokesperson, remember that this person must:

- Meet legal criteria (competent adult at least 18 years old)

- Be willing to speak on your behalf
- Be willing to act on your wishes
- Be willing to separate his or her feelings from yours
- Live close by or be willing to come
- Know you well
- Understand what is important to you
- Be willing to talk to you now about sensitive wishes
- Be willing to listen to your wishes
- Be able to work with those providing your care to carry out your wishes
- Be available in the future
- Be able to handle potential conflicts between your family and friends
- Be able to handle responsibility

Understanding Life-Sustaining Treatments

Helping patients to understand the various life-sustaining treatments beyond CPR is essential. Preferences regarding mechanical ventilation, artificial hydration and nutrition, antibiotics, comfort measures, and transfer to a hospital must be considered and may change over time. When making decisions about life-sustaining treatments, it is important to consider the following:

- Will the treatment make a difference?
- Do the burdens of treatment outweigh the benefits?
- Is there hope for recovery? If so, what will life be like afterward?
- What does the patient value?

Clinical situations are frequently neither black nor white but rather gray.

Clinical situations are frequently neither black nor white but rather gray. Too often, it is difficult to determine when wishes stated in the ACD apply or when stated wishes are vague. Difficulty in decision making arises when recovery cannot be predicted. In this case, a short-term trial of life-sustaining treatment may be desired. These trials must begin with clarifying the patient's goals of care and must require active discussions between the doctor and the

spokesperson about the most appropriate course of treatment.

A distinction often is made between not starting treatment and stopping treatment. However, no legal or ethical difference exists between withholding and withdrawing a medical treatment in accordance with a patient's wishes. If such a distinction existed in the clinical setting, a patient might refuse treatment that could be beneficial out of fear that, once started, it could not be stopped. It is legally and ethically appropriate to discontinue medical treatments that are no longer beneficial. It is the underlying disease, not the act of withdrawing treatment, that causes death.

Physician Orders for Life-Sustaining Treatments

Concerns about the failure of long-term care systems in honoring end-of-life treatment preferences led to the formation of a task force in Oregon in 1991. As a result, a Physician Orders for Life-Sustaining Treatment (POLST) form was developed. A POLST form contains medical orders describing a patient's code status and other aspects of care, including preferences with regard to intubation, antibiotics, CPR, nutrition and hydration, and comfort measures. The POLST form is designed to be an easily identifiable document that travels with a patient across care settings—nursing homes, hospitals, homes—and provides accurate, patient-centered medical orders.

The fundamental philosophy of a POLST form is that individuals have the right to control their own health care decisions, including those pertaining to life-sustaining treatments. This includes the right to withhold and withdraw treatments, to maintain a mechanism for describing preferences to health care providers, and to gain access to health care providers who understand how to provide comfort care while honoring the individual's wishes about life-sustaining treatment.

The POLST form or a similar form (e.g., West Virginia's POST and New York's MOLST) does not replace an ACD. Advance directives still have a place as legal documents that create a founda-

tion for wishes that might be included in a POLST. However, these medical order forms are more consistently followed than previously reported for advance directive forms.

For individuals who are seriously ill, have advanced chronic illness, or are nearing the end of life, ongoing, active conversations regarding care goals and treatment preferences are essential. A decade of research in Oregon has proven the POLST form to be an effective tool for increasing compliance with patients' end-of-life care wishes.⁴⁻⁸ As a result, several states have begun to adopt the principles of the POLST form or have developed similar forms, and a National POLST Paradigm Task Force has been formed. For further details on the National POLST Paradigm Initiative and state-specific contacts, go to www.polst.org.

Practical Issues

After completing your ACD, it is important to ensure availability of the form. Keep a copy for yourself in a secure but accessible place. Do not put it in a safety deposit box or any other security box that would keep others from being able to retrieve it. Share a copy with your spokesperson and alternate spokesperson, family members, primary care physician, all specialists who participate in your care, and the primary hospital where you receive care. If you enter a hospital or a nursing home, have a copy placed in your medical records.

ACDs should be reviewed and updated periodically. It is important to review them after major life events, such as divorce, birth of a child, and death of a spouse, because you may wish or need to choose a new spokesperson. As noted earlier, it is critical to review your wishes if a new life-threatening or chronic illness develops, as these chronic illnesses progress, and after receiving complicated life-sustaining treatments. Your care goals and preferences may change. If your wishes change after your documents have been completed, a new set of documents must be written, signed, and witnessed.

If you begin to view ACPs as part of preventive health, planned reviews can be integrated with periodic health evaluations. By reviewing ACDs along with nutrition, exercise, smoking, injury prevention, stress management, etc., then the importance of ACDs is clarified and the fear of discussion is demystified. Discussion can be linked with the behavioral readiness to complete an ACD and then can be much more focused.

Measuring ACP Participation

In collaboration with our county department of health medical director, we developed a health care proxy readiness survey (Fig. 2) based on behavioral readiness to change theory and on clinical practice experience. We use the survey to measure the effectiveness of an educational workshop on advance care planning, "Community Conversations on Compassionate Care." Essentially, individuals are staged as follows:

- Stage 1. Precontemplation: See no need to change
- Stage 2. Contemplation: Recognize need but have barriers
- Stage 3. Preparation: Ready to complete
- Stage 4. Action: ACD reflects wishes
- Stage 5. Maintenance: ACD needs update

Individuals in stages 1, 2, and 3 do not have an ACD. Those in stage 1 need education and follow-up, those in stage 2 need to identify barriers as previously outlined and receive assistance in eliminating them, and those in stage 3 need encouragement to finalize the process and commit to review and update periodically. Stages 4 and 5 are self-explanatory.

Conclusion

In summary, everyone 18 and older should discuss their end-of-life wishes with family members and their physician, and put them in writing with ACDs. These fluid instructions are meant to be modified over time to reflect changes in our lives. As serious life-threatening illness, advancing

chronic illness, frailty, and functional decline occur, care goals may shift and preferences for life-sustaining treatment may change.

These are patient-centered decisions. When possible, converting these preferences into specific medical orders may ensure compliance with end-of-life wishes beyond CPR. □

References

1. Adams J. Prehospital do-not-resuscitate orders: a survey of policies in the United States. *Prehosp Disas Med* 1993;8:317-22.
2. Sabatino C. Survey of state EMS-DNR laws and protocols. *J Law Med Ethics* 1999;27:297-315.
3. Last Acts. Means to a better end: a report on dying in America today. 2002 Nov [cited 2004 Nov 5]. Available from: URL:<http://www.rwjf.org/news/special/meansReport.pdf>
4. Dunn PM, Schmidt TA, Carley MM, Donius M, Weinstein MA, Dull VT. A method to communicate patient preferences about medically indicated life-sustaining treatment in the out-of-hospital setting. *J Am Geriatr Soc* 1996;44:785-91.
5. Tolle SW, Tilden V, Nelson CA, Dunn PM. A prospective study of the efficacy of the physician order form for life-sustaining treatment. *J Am Geriatr Soc* 1998;46:1097-102.
6. Lee MA, Brummel-Smith K, Meyer J, Drew N, London MR. Physician orders for life-sustaining treatment (POLST) outcomes in a PACE program. Program of All-Inclusive Care for the Elderly. *J Am Geriatr Soc* 2000;48:1343-4.
7. Hickman SE, Tolle SW, Brummel-Smith K, Carly MM. Use of the POLST (physician orders for life-sustaining treatment) program in Oregon nursing facilities: beyond resuscitation status. *J Am Geriatr Soc* 2004;52:1424-9.
8. Schmidt TA, Hickman S, Tolle SW, Brooks HS. The physician orders for life-sustaining treatment (POLST) program: Oregon emergency medical technicians' practical experience and attitudes. *J Am Geriatr Soc* 2004;52:1430-4.

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