



END-OF-LIFE CARE: MAKING ADVANCE DECISIONS

“My husband and I never spoke about our end-of-life care preferences. When he became seriously ill and couldn’t talk, it was difficult for his doctors, our children and me to agree on his medical care. Soon after my husband’s death I discussed with my children and put in writing exactly the kind of health care choices I wanted them to make for me if I was ever incapacitated. Now my children will be prepared to speak for me, if needed.”

— June, 75 year-old-widow

You are not alone if you are uncomfortable thinking about a time when you may be unable to make health care decisions for yourself. Death is a subject that many people want to avoid discussing. However, a life-threatening illness, disability, or accident may strike without warning. Such an event may leave you without the capacity to make your own health care decisions. By documenting your end-of-life care wishes in advance, *you* decide how you would like to be treated, what procedures are acceptable to you, and what values, attitudes, and beliefs are to be followed in case there is a time when you are unable to communicate. There is no right or wrong way when it comes to end-of-life decisions. But it is important that your personal wishes are known in advance so they can be respected and followed.

What Does the Term “Advance Directive” Mean?

Advance Directive (also known as *Health Declarations*) is a general term for any document used to make health care decisions for you when you can no longer do so for yourself. Advance Directives are given to your doctor and loved ones “in advance” so that your end-of-life care choices are clear to them during a time when you are unable to communicate your preferences. Without an Advance Directive, or if family members disagree on a treatment plan when you are no longer able to express your wishes, physicians usually continue life supports. By stating your end-of-life care desires in advance, you take control over your future care and provide yourself and your loved ones with peace of mind.

What is Included in an Advance Directive?

The Advance Directive can include any of your wishes or guidelines for medical decisions and general end-of-life care. Typically it combines several important directions in a single document. These include treatment instructions and the appointment of a person to make health care decisions for you when you cannot. Specifically, an Advance Directive may include the following:

- **Written treatment instructions.** Depending on the form you use and the state you live in, these written health care instructions may be called a *living will*, *directive to physicians*, *medical directive*, *declarations*, *instruction directive*, or *wishes for terminal illness*. The treatment instructions include the care you do or do not want when seriously ill. They become effective after a diagnosis of a terminal illness or if you become permanently unconscious. Medical providers will follow the type of treatments you have designated in writing should you no longer be able to express yourself to them. Review the types of treatments that sustain life and consider under what circumstances and for how long you would be comfortable using them. Some life sustaining methods include:
 - **Artificial Nutrition and Hydration.** Nourishment and water provided by feeding tube or intravenous feeding. Consider under what circumstances and for how long this would be acceptable.
 - **Mechanical Respiration.** Being placed on a ventilator for illnesses such as progressive lung disease, ALS etc. Consider the point at which you would not want the support of the breathing machine.
 - **Cardiopulmonary Resuscitation.** Restarting your heart and breathing, e.g. congestive heart failure. Consider when it would not be appropriate to attempt resuscitation.

Other helpful directives commonly found in Advance Directives that you may wish to include are organ/tissue donation, where you prefer to receive treatment or care, treatment for pain, and the information about your health that you want released to loved ones.

An Advance Directive can also include a DNR order, deciding not to use medical procedures to restart your heart and breathing. If your heart or breathing stops, medical workers will usually attempt some form of Cardiopulmonary Resuscitation (CPR) to revive you if they

can. Some people with terminal illness may want CPR to keep them alive as long as possible. Others, however, particularly those in the final stages of cancer or other terminal illnesses, may not want CPR, and choose to forego it. You can ask that a Do Not Resuscitate (DNR) order be included in your medical record at your physician's office or at your local hospital. If you are terminally ill and are at home, be sure to keep your DNR order available so that Emergency Medical Service (EMS) workers will be able to know your wishes. Some states accept bracelets listing your DNR request as a valid order. For more information concerning this option, contact MedicAlert Foundation. Phone: 1-800-432-5378.

• **Appointment of someone to make health care decisions for you.** It is up to you to determine how much authority the person you choose will have over your medical care when you are no longer able to communicate your wishes. This person can be a close friend or family member but must be over 18 years old. Depending on the state where you live, legally choosing a person to represent your health care may be known as selecting a *durable power of attorney*, *durable power of attorney for health care*, *health care agent*, *health care proxy*, *agent*, *health care surrogate*, or *representative*. Keep in mind that medical conditions can be very complicated and unpredictable. You should choose a person you feel would make decisions based on *your* desires, not his or her preferences. It is critical that you trust the person and provide as much information as possible about your desires, attitudes, values, and beliefs. Also, be sure the person you designate is willing to take on this responsibility.

Is It Common to Avoid End-Of-Life Care Discussions?

Yes, avoiding end-of-life discussions often happens because people may feel afraid, uncomfortable, or overwhelmed discussing this subject. You definitely are not alone if you have been avoiding talking about death and dying. For some, the thought of talking about death makes dying seem more frightening, more imminent, and more real. Yet, often, many people find these end-of-life care discussions helpful. These discussions can bring you peace of mind, comfort, and a sense of control over your own life as well as a sense of connectedness with loved ones. The best way to ensure that your death will occur with dignity is by talking about your end-of-life care choices with the important people in your life.

What Should I Discuss With My Loved Ones?

Planning for how you want to live at the end-of-life is much more than just signing a document. Thinking through the following issues can help you determine the extent of the medical interventions you want at the end-of-life. So before writing an Advance Directive, think about and discuss the topics below with people who are close to you, including your doctors, loved ones, and anyone else whose opinion you trust. This way, no matter what health care situation arises, health care decisions will be based on the wishes you have expressed. Topics for discussion include:

- **Medical Treatment.** Discuss your right to accept or refuse medical treatment. Medical care can be refused even if the treatment could prolong your life. You can also request to have treatments administered for a limited time only so that the decision to continue treatment or explore other options can be based on how you are responding to the treatment.
- **Health Care Proxy.** Consider making you designate as the person to make your end-of-life care choices known to the health care providers. Only one person can be selected to represent you; however, it is helpful to choose a back-up person in the event that the person you have chosen to represent you is unable to do so.
- **Independence/Self-Sufficiency.** Consider how your health status can impact your lifestyle and overall quality of life, then determine if this information will influence decisions you make concerning your end-of-life health care.
- **Religious/Spiritual Beliefs.** Think about your religious, spiritual, and philosophical beliefs as well as the role they play in your life. Consider if these beliefs influence medical treatments you would or would not want.
- **Pain Tolerance.** Think about your comfort and at what point pain and discomfort would overshadow other factors. For example, is being coherent for a conversation more or less important than pain relief? Many patients with terminal illnesses require pain medications that limit their ability to function. Consider how much pain medication you would be willing to take to continue life-sustaining measures.
- **Financial Concerns.** Consider how the costs of end-of-life treatment choices would affect your family. Planning in advance can

prevent financial crises and uncertainty during a time of emotional upheaval.

- **Living Environment.** Consider whether you want to be at home during your final days, in a hospice, or a hospital. If you opt for a hospice or hospital, make sure you specify which one. Clarifying this with loved ones can minimize doubt about your preferences and make it possible for your wishes to be met.
- **Final Days/Memorial.** Discuss who you would like to have with you in your final days and hours. Also, determine a list of people who should be notified after your death. Other considerations include burial location, funeral arrangements, cremation, and the type of memorial service you want. Consider how you want to be remembered and also the costs involved in each of the types of memorials.
- **Organ/Tissue Donation.** Think about whether or not you want any part of your body donated and for what purpose, e.g., transplant, research, or education. You might also want to consider where you want your body to go to after you die (research center, organ transplant organization, etc.)

Based on your decisions about the above-mentioned topics, your end-of life care wishes can be conveyed by writing them on your Advance Directive forms or by attaching handwritten or typed pages to the forms. Some people prefer to write letters to people they care about and attach copies of these letters to their Advance Directive forms.

What Steps Do I Take to Complete an Advance Directive?

The best time to complete an Advance Directive is when you are healthy and able to communicate your wishes. Times of crisis are not the best time to make these decisions because thinking is usually lacks clarity when under stress. A sudden illness, like a stroke, may make you too sick to complete an advance directive—just when you need it most. The steps to take to complete an Advance Directive are as follows:

- **Get an Advance Directive form.** Forms vary by state. It is important that you make sure the form you get is valid in your state. Get a copy and review it. Standard forms will give you a starting point, but you'll probably want to add more detail to specify exactly what you would like. Refer to the resource section of this handout for information on where to get an Advance Directive form, or ask for a form at your local hospital or physician's office.

- **Take time before making any decisions.** Think about the kind of care you want or don't want. Although you cannot foresee every medical decision, you can convey an overall goal for your medical treatment at the end-of-life. One way to think about your end-of-life goals is to ask yourself a question posed by the New Jersey Supreme Court in 1976 in an end-of-life care case. The court asked, "If the patient could wake up for 15 minutes and understand his or her condition fully, and then had to return to it, what would he or she tell you to do?"
- **Discuss end-of-life issues with those closest to you.** Talk about your medical treatment and end-of-life care preferences with family, friends, loved ones, and health care providers. What is written on the form will be more meaningful if these discussions take place prior to completing the form. These conversations can be very emotional and difficult and often the most challenging part of the entire process.
- **Fill out form.** You do not need a lawyer to complete an Advance Directive form. When you have signed an Advance Directive form in the presence of witnesses or a notary public (or sometimes both depending on the state), the directive goes into effect. To find out what specifically is required in the state in which you live, download your State's Advance Directive instructions and forms from Caring Connection's Web site:
<http://www.caringinfo.org/i4a/forms/form.cfm?id=16&pageid=3462>
- **Be Clear.** Use words and terms that clarify your decisions. Many terms, such as "heroic measures," "vegetable state," and "pull the plug" are vague. Your health care provider may be able to help you select the best words that will accurately reflect your decisions.
- **Give a copy of your Advance Directives to your health care provider and to those closest to you.** Keep your Advance Directive in a safe place but somewhere so that others can easily find it, not in a safety deposit box. For example, some people keep it with their personal calendar, address book, or their bills.
- **Revise an Advance Directive as needed.** Review the document to reflect your current health wishes. For example, if you are newly divorced, you may choose someone other than your ex-spouse to make health care decisions on your behalf. Create an up-to-date copy, destroy copies of the old directives, and give out new ones to the appropriate people.

Where To Get Help

National Resources

Aging With Dignity. This national non-profit organization provides practical information, advice, and legal tools needed to ensure that wishes are respected in case of serious illness. This organization has created a document called *Five Wishes* helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. This document is unique among all other living wills and health agent forms because it looks to all of a person's needs: medical, personal, emotional and spiritual. Individual copies are available for \$5.00 online or by phone. This organization also offers a free "Family Resource Guide" on advance care planning topics. Phone: 1-888-594-7437.

Web site: www.agingwithdignity.org

American Bar Association. This professional association's Web site (under "Law for Older Americans) a frequently asked questions section thoroughly covers advance directives issues.

Web site: www.abanet.org/publiced/practical/directive_what.html

For online books and brochures for consumers, go to www.abanet.org/aging.

National Hospice and Palliative Care Organization (NHPCO). This nonprofit organization is committed to improving end-of-life care and has free brochures and state-specific advance directives to provide you with information and resources for advance care planning. If you have questions, call the HelpLine. Phone: 1-800-658-8898.

Web site: www.caringinfo.org

Center for Practical Bioethics. This Center encourages you to share meaningful conversations about your values and wishes with loved ones before you complete your healthcare directive and appoint a durable power of attorney for healthcare. The Center provides a workbook called *Caring Conversations* as well as advance directive forms (downloadable on the site or phone for a hard copy) to guide your planning and discussion.

Phone: 1-800-344-3829. Web site: www.practicalbioethics.org

New York State and City Resources

New York State Department of Health This agency has revised the state's health care proxy form, and by doing so, hopes to encourage more New York residents to use advance directives to enhance their end-of-life care. Web site: www.health.state.ny.us (Go to Topics A-Z. Choose Health Care Proxy)

New York State Office for the Aging. This agency offers an article titled, "Estate Planning Basics: The Health Care Proxy." The article includes information on patients' rights, legal requirements for designating a health care agent, and answers to frequently asked questions.

Senior Hotline: 1-800-342-9871.

Web site: www.aging.state.ny.us/news/letter/an000502.htm

New York City Department for the Aging. This agency offers online courses such as, "*Choices and Decisions I: Planning for the medical issues that come at the end of life*". From the home page, select Planning End of Life Issues under Caregiver Support.

Phone: 1-212-442-1000. Web site: www.nyc.gov/html/dfta

Office of the Attorney General of the State of New York. This office offers a valuable publication, "*Smart Seniors*", which has a section devoted to "Planning in Advance," pp 34-37. NYC Office Phone: 1-212-416-8000.

Web site: www.oag.state.ny.us/seniors/smart_seniors.pdf

The Center for Hospice and Palliative Care. This site provides an Information Guide titled, "*What everyone should know about New York State Law*," which you can order for free or download. The guide includes health care proxy and living will documents, pertinent information, and a health care proxy wallet card and sticker.

Web site: www.palliativecare.org/advancedirectives/nys_law.asp

This resource provides brief, general information about this health care topic. It does not take the place of specific instructions you receive from your health care providers. For answers to other questions consult your physician or other health care provider.

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