Caring Conversations®
is designed to guide you, your family and your friends through the process of Advance Care Planning.

An Introduction to Making Your Healthcare Wishes Known

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Advance Care Planning

Advance Care Planning is the ongoing process of discussing personal values, goals of care, determining and/or executing treatment directives and appointing someone to speak for you when you cannot speak for yourself.

Many people are familiar with the names of Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo. The lives of these young women remind everyone of the importance of making our wishes known for our future healthcare and appointing someone to speak for us when we can no longer speak for ourselves.

The U.S. Supreme Court case of Nancy Cruzan not only changed the path of the Cruzan family, it continues to affirm the rights of adults in the United States to make decisions regarding their healthcare wishes. Specifically, the case affirms that adults with capacity:

- May choose or refuse any medical or surgical procedure
- May make advance directives and transfer their decision-making authority.

Preparing an Advance Directive

“Advance directive” is a general term used to describe both the Durable Power of Attorney for Healthcare Decisions and the Healthcare Treatment Directive. It is a term also used to refer to a Living Will as well as informal directives people may set down in letters or conversations. An advance directive allows you to communicate your healthcare preferences when you can no longer make your own decisions.

This booklet includes a Durable Power of Attorney for Healthcare Decisions form to appoint an agent to speak for you when you cannot speak for yourself. Also contained in this booklet is a Healthcare Treatment Directive form. You may complete one or both of these forms. They will be most helpful and informative if you discuss your wishes with your loved ones, friends and healthcare providers as part of your advance care planning.
Conversations

Communicating your wishes for your healthcare is important. The greatest benefit of doing advance care planning and preparing advance directive documents is the power you have to communicate your wishes. Discuss your wishes and share your advance care planning documents with your loved ones, friends, healthcare providers, clergy and your attorney (if you have one) and others whom you trust to carry out your wishes.

Completing the Caring Conversations® Workbook (see page 11) first will make this process easier. It provides an opportunity for you to identify and communicate your values and healthcare goals. You may order print copies of the workbook for a nominal fee at the Center’s website, www.practicalbioethics.org/resources. You may also contact us with questions at bioethic@practicalbioethics.org or by calling 816-221-1100.

Pictures of Illness

When a person is 18 years of age, he or she should complete an advance directive. At any age, the existence of an advance directive can become critical when you have an unexpected traumatic event or a serious health condition. As you consider making your healthcare wishes known, it is helpful to remember that if you are diagnosed with an illness, it will have a path or trajectory that may affect your healthcare wishes and decisions. Below are pictures of four common illness trajectories.

Frequently Asked Questions about Advance Care Planning and Advance Directives

1. What is an advance directive?
Usually an advance directive is composed of two parts: the appointment of an agent to make healthcare decisions for you when you are unable to make these decisions for yourself (a Durable Power of Attorney for Healthcare) and a description of the kind of medical treatment you want when you are facing serious illness (e.g., a Living Will or Healthcare Treatment Directive).

2. Whom should I name as my agent?
It is important that you name a person who knows your goals and values and whom you trust to carry out your wishes as your agent. You may name a family member, but it is not necessary to do so. You might choose your spouse, an adult child, or a close friend or other loved one. Be sure to talk with your agent about your wishes in detail and confirm that he or she agrees to act on your behalf. If you have completed a Caring Conversations® Workbook, share it with your agent.

3. Do I need an attorney to make a Healthcare Treatment Directive or a Durable Power of Attorney for Healthcare Decisions?
No. However, you may want to discuss your advance directive with your attorney, if you have one.

4. Do advance directives need to be witnessed or notarized?
Yes. Witnessing and notarizing requirements vary from state to state and from document to document. States typically require witnessing by two adults and they may limit who may witness. Some states disqualify persons as witnesses who are related to you, who will inherit from you, or for whom you are financially responsible. Because of state-to-state differences, it is a good idea to have your advance directive both witnessed and notarized.

5. What do I do with my completed advance directive?
Make copies of your advance directive to provide to any agent(s) named in your Durable Power of Attorney for Healthcare Decisions document and other appropriate individuals (i.e., physicians, family, friends, clergy and attorney), and
- Discuss the details of your advance directive with these individuals.
- Ask your physician to make it part of your permanent medical record.
- Whenever you are hospitalized or go on a trip, take a copy with you.
6. When does my advance directive go into effect?
As long as you can make decisions, it is both your right and your responsibility to make your own decisions. In most cases, therefore, your advance directive goes into effect only when you are no longer able to make or communicate your decisions. If, however, you are concerned about your ability to make reliable decisions, you may give your agent authority to act on your behalf on the day you sign the document.

7. How long will my advance directive be effective?
As a general rule, your advance directive is effective until the time of your death. We recommend that you review your advance directive periodically, especially when there is a change in your health status. Date and initial it following every review and discuss any changes with your family, friends and physician.

If you appoint an agent in a Durable Power of Attorney for Healthcare Decisions document, your agent can, in conformity with state law, make a few decisions following your death, for example, decisions about an autopsy, organ and tissue donation, and the disposition of your body.

8. Can I expect healthcare providers to carry out the directions in my advance directive?
Yes, you should expect that your directions will be carried out. Healthcare providers have both legal and ethical duties to respect patient directions, whether verbal or written, within any limitations of state law. However, your directions are more likely to be known and honored if you have named an agent to act on your behalf. If your directions are not being honored, your agent or loved ones should ask for help from an ethics committee, social worker, chaplain, or ombudsman.

9. Will my advance directive be honored in an emergency situation?
If you are living with a life-limiting condition, the best way to ensure that your instructions and values are honored in an emergency situation is to speak with your doctor to determine if specific medical orders should be written for first responders and hospital providers. Your agent should be made aware of any medical orders that address what types of rescue measures should be applied in your situation that coincide with your goals of care, especially as your condition changes. To learn more, see Caring Conversations®…continued on page 11.
10. Can my advance directive or treatment instructions by my agent be overridden by my family members?

You and your agent will not be able to anticipate every clinical situation that may arise and it may not always be clear exactly what you would want. Your agent will need to work with your providers, other caregivers and family members to make sure everyone stays focused on how your instructions should be honored and how to protect your best interests. The more information your agent and providers have, the better equipped they are to make good decisions. You can assist your agent in preventing your wishes from being overridden by making sure family members know how much confidence and trust you place in your agent and your providers to make decisions on your behalf.

11. How can I describe what an “acceptable quality of life” means to me?

There is no right answer to this question; however, here are some things to consider:

- What is your own “bottom line?” Under what circumstances would dying naturally be preferable to sustaining life?
- Do religious values influence your treatment decisions? (If so, how?)
- How important is it for you to be able to care for yourself?
- What kind of living environment would you be willing to accept?
- How important is it to you to be able to engage with family and friends?

We encourage you to begin your Advance Care Planning. It starts with reflection and conversation. Please share your values and wishes with those who care for you. If you have also completed a Caring Conversations® Workbook, indicate that you have done so in your advance directive so that your care providers will know to look for more information.

The more you express your choices regarding medical treatment and end-of-life care, the more confidence and peace of mind you and your loved ones will have in making these important decisions.

Additional Advance Care Planning Resources

To order or download, go to www.PracticalBioethics.org.
Vision
Ethical discourse and action advance the health and dignity of all persons.

Mission
To raise and respond to ethical issues in health and healthcare.

Our Core Value
Respect for human dignity.

We believe that all persons have intrinsic worth.

We promote and protect the interests of those who can and cannot speak for themselves.

We commit to the just delivery of healthcare.

We welcome your interest in the Caring Conversations® program. For more information about Caring Conversations® or the Center for Practical Bioethics, please contact us at 816 221-1100, visit our website www.PracticalBioethics.org, or email us at bioethic@PracticalBioethics.org.