

Advance Directives



History

In 1991, the Patient Self-Determination Act became a federal law. The act was signed into law to help ensure that patients' preferences about medical treatment would be followed when they could no longer speak for themselves.

Types of Advance Directives

An advance directive is a written document that is prepared by the patient that states how he/she would want medical decisions to be made in the event that he/she would lose the ability to make those decisions. There are two types of advance directives:

- 1 **Living Will** – A Living Will generally states the kind of medical care that an individual wants or does not want, in the event that he/she is unable to make those decisions. It is called a Living Will because it takes effect while the individual is still living. A Living Will can be completed in a variety of ways such as:
 - The use of a pre-printed Living Will Form that is completed and signed by the individual.
 - Composition of a unique form - the individual may draw up his/her own form and sign it or may just write a statement of preferences for treatment.
- 2 **Durable Power of Attorney for Health Care** – A Durable Power of Attorney for Health Care is a signed, dated, and witnessed paper naming another person as an authorized spokesperson to make medical decisions for an individual. It will become effective only when and if the individual becomes unable to make decisions for himself/herself.

An individual may have one type of advance directive or may have both. They may also be combined in a single document.

An individual may change or cancel an advance directive at any time. It may be changed in writing or verbally. It is important that the individual be certain when communicating his/her wishes verbally, that the receiving party is clear on his/her intentions.

Location of Advance Directives

It is important that someone be made aware that a patient has an advance directive. It is the individual's responsibility to notify a lawyer, family member, friend or physician that he/she has an advance directive and where it is located. Some other areas of location should be considered:

- Physician should have a copy as part of the permanent medical record.
- A copy should be kept in a safe place where it could easily be found.
- An individual should keep a small card in his/her purse or wallet stating that he/she has an advance directive and where it is located.

Nuts and Bolts of Advance Directives

Introduction

- Right setting: appropriate people
- Explain why this is being brought up now
 - May relate to ultimate prognosis of illness, recent hospitalization, fact that you always do this, etc.
- Explain purpose is to respect patients' "wishes"
- Reassurance that death is not believed to be imminent

Information

- Make sure patient understands course of illness and prognosis – achieve shared understanding
- Explain any treatments which are discussed in terms of patient experience and outcome – when these may be relevant to patients' decision

Elicit Preferences

- Gain an understanding of patient's goals for treatment, what makes life worth living, etc. This may be asked explicitly or it may be elicited in process of asking specific treatment preferences

- Ask about specific clinical conditions (scenarios) – not just “being stuck on a machine” or “permanent unconsciousness”
- Ask about probability, uncertainty
- Ask about artificial nutrition and hydration, specifically if patient indicates that he/she would not want treatment in any given situation
- Give positive options – discuss what you WILL do, even if life-sustaining treatment is forgone

Proxies

- Determine identity of preferred proxy
- Urge patient to discuss wishes with proxy; offer to discuss with patient and proxy

Documents

- Provide an opportunity for documentation, by carefully describing the discussion in the chart
- May discuss pre-printed forms

Communication

- Attend to the emotional content of the discussion
- Avoid vague terms or define them immediately
- Ask for questions
- Tell patient that (s)he can change the directive in the future
- Ensure shared understanding of conversation
- Provide opportunities for patient to talk (actively encourage, if needed)

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References

Emanuel, L.L., Danis, M., Pearlman, R. A., Singer, P. A. Advance care planning as a process: structuring the discussions in practice. *J Am Geriatrics Soc* 1995;43:440-446.

Teno, J.M., Lynn, J. Putting advance-care planning into action. *J CI Ethics* 1996;7:205-213.

You may choose to provide your patients with a form such as the one on this Web site that can be ordered from the Allegheny County Medical Society or you may desire to use a form of your own choice or development.

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Advance Directive Questionnaire

Ideally, an advance directive discussion should take place with every patient; however, due to various reasons, this might not be possible. In order to help you make a decision regarding the advance directive discussion, consider the following:

- Would I, as this patient's attending physician, be surprised if this patient died during the next year?
- If you answer “no” to the above question, then consider the following:
 - Does this patient and the patient's family know and understand the prognosis?
 - Does the patient have an advance directive and proxies?
 - Do you know your patient's values and priorities?
 - Help your patient customize his/her care, reflecting their preferences.

The following outlines a possible discussion a physician may have with a patient. Only some questions are appropriate at a single visit. These are meant to be illustrative of the kinds of things one might talk about.

- 1 As you know, when people come into the hospital, doctors do everything they can to keep patients alive—they use breathing machines, artificial kidney machines, attempt to restart the heart if it stops, etc. Usually, the patient agrees with these efforts. However, in certain circumstances, some patients wouldn't want doctors to use these aggressive measures to try to prolong their life. For example, some patients would not want life sustaining treatment if they were in a coma or had a very poor quality of life. I try to talk to patients about these issues so I can respect your wishes. Have you thought about this issue? Do you want to talk about your wishes?
 - a. If the patients say s/he “want everything done,” SAY, “even if you were in a coma and not going to wake up?”
 - b. If the patient says s/he “would not want machines, SAY, “even if you had a pneumonia and we thought if we put you on a respirator for a short time you would get better and go home (in your current state of health?)”
 - c. What circumstances would make your life not worth living? What things make your life worth living?
 - d. REMEMBER ALWAYS ASK WHY?
 - e. REMEMBER THE PATIENT CAN CHOOSE NOT TO TALK.
- 2 What do you fear most about dying?
- 3 If you were terminally ill and permanently incompetent, would you want any life sustaining treatment to be continued?
- 4 Whether terminally ill or not, if you were permanently unconscious, would you want any other life sustaining treatment to be continued?

Advance Directive Questionnaire (continued)

- 5 Whether terminally ill or not, would you want to be kept alive if you were unconscious and had very little chance of ever recovering consciousness, and would almost certainly be very brain damaged if you did recover consciousness?
- 6 Whether terminally ill or not, would you want to be kept alive if you were gravely ill, had only a very slight chance of recovering (<5-10%) and would probably require weeks or months of future treatment before it was clear whether or not you would recover?
- 7 If you chose to have life support discontinued in any of the above conditions, would you desire, in addition to discontinuing any other life support measures, that fluids and nutrition be discontinued? Also ask questions about respirators.
- 8 If you came into the hospital and could not talk to me about what you wanted done, who would you like me to talk to about your views and your care? Have you talked to anyone about your views concerning life supports?
- 9 PROCESS – Remind the patient that we can talk about this more in the future. People, can, and often do, change their mind.
- 10 Any questions?
 - a. If your family and I thought that following your advance directive was not in your best interest, what would you want me to do?
 - b. If you said that you did not want life sustaining therapy continued, but your family wanted the doctor to continue treatment because of their emotional needs, what would you want me to do (i.e., do what the family wants and override your wishes or do what you said you wanted and override the family's wishes?)
- 11 So far, we have talked about the things you would not want done if you became really sick.

Some people have strong views about the way they want to spend their last days. What will be most important to you when you are dying (e.g., physician support, no pain, family members present, etc.)?
- 12 Where would you prefer to die?
- 13 What is your attitude toward dying?
- 14 What is the role of religion in your life?

Modified from Culver 1990

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