



# Preparing for End-of-Life Matters: Practical Steps

*What do you want to happen to you if you are in an accident and wind up in a persistent vegetative state? Do you want to remain alive no matter what the cost? Have you filed an advance directive? This session gives you some information to think about in order to prepare for end-of-life matters whenever they occur.*

## The Patient Self-Determination Act

In 1991 the Patient Self-Determination Act (PSDA) went into effect, requiring all health care facilities that receive Medicare or Medicaid to provide written information to every adult patient about state laws regarding the patient's right to have a say in his or her medical treatment.<sup>1</sup> This is why, when you are admitted to a hospital, you receive a copy of the hospital's policy regarding the patient's right to accept or refuse medical treatment. It is also why the person in admissions asks you, "Do you have a living will?" Once you answer this question and your answer is recorded in your chart, chances are no one will ever mention the subject to you again. In the best-case scenario, when asked by the admissions personnel whether you have a living will, you will not only answer yes, you will, in fact, have the document with you, and *you will have talked about your wishes for end-of-life care with someone you have designated to make decisions on your behalf should you become unable to speak for yourself. You will also have talked to your doctor, your pastor, family members, and friends.*

While the PSDA has helped educate patients regarding their right to accept or refuse treatment, it has had limited success in ensuring that patients actually receive the care they want. For one thing, only 30 percent of all adults in the United States have a living will. Also, many of those who do have one have never talked to anyone close about their wishes. Too many people believe that filling

### DEFINITION AND EXPLANATION

An advance directive provides a means to communicate your wishes about your medical care if you become unable to speak for yourself. Technically, the term *advance directive* is more encompassing than the more familiar term *living will*, because it indicates that you have not only signed a document stating your preferences for medical care, but that you have also designated a proxy for making medical decisions on your behalf if you are unable to do so. (A proxy is also known as a surrogate or a durable power of attorney for health care decisions.) Often the written statement is referred to as a living will, but when it includes identifying a proxy, the term *advance directive* is used. The terms *living will* and *advance directive* are used interchangeably here, and they both refer to a document that states your wishes for end-of-life care *and* designates a proxy to be your advocate.

out a living will (the written and signed document) is all that is required to ensure that their end-of-life wishes will be honored. In fact, filling out a document that states your preferences for care is not in itself enough to ensure that you will get the kind of care you want. If your written instructions cannot be easily located or if they are vague or *if there is no one who can interpret them*, others will make decisions about your care that may or may not coincide with what you want. There may even be a family member who knows what you

1. For a copy of the Federal Patient Self-Determination Act see [www.dgcenter.org/acp/pdf/psda.pdf](http://www.dgcenter.org/acp/pdf/psda.pdf).

want but disagrees with your decisions, and this family member may persuade the doctor to ignore what you have written down. If someone took your case to court or even requested that the hospital ethics committee review it, your written statement would most likely

be honored. If, however, no one has been designated to be your advocate in such a situation, then chances are your case would never be brought before a committee or a court, and your wishes may not be honored.

As one health care provider has pointed out, "We have failed in implementing the Patient Self Determination Act because we have allowed documents to speak for us,

and paper can't talk."<sup>2</sup> Therefore, in addition to putting your wishes in written form, *you must designate and talk to someone who will carry out your wishes when you can no longer communicate for yourself. Furthermore, you need to talk to as many people as possible (your family, your pastor, your doctor, your friends) about what you want.*

Since an advance directive takes on the significance of a legal document if a decision about your care goes to court, some people file their advance directives (including the designation of a proxy) with their lawyers. Many lawyers, in fact, provide their clients with such a document when they are filling out their regular will. While such an action is a very good idea, you should not wait to hire an attorney before writing an advance directive. Furthermore, if your advance directive is filed with your lawyer and no one knows about it, it won't be of any use when needed. An advance directive, therefore, should first and foremost be considered an avenue for conversation and second an important legal document. A lawyer can provide you with a document that is consistent with the laws of your state, but as remarked above, you shouldn't wait to hire a lawyer before filling out and signing a living will. The following Web address provides living wills for each state: [http://www.finance.cch.com/tools/poatforms\\_m.asp](http://www.finance.cch.com/tools/poatforms_m.asp). The document consistent with your

state's laws would be a good place to start, but don't hesitate to write down significant things about your values and your wishes at the end of the document. The document should be signed by yourself and witnesses in accordance with your state's laws and filed in a place where someone besides you knows where it is.

When you speak to the appropriate people about your wishes for end-of-life medical care, you should also talk to them about things that won't be indicated on most advance directive forms. For instance, if you are unconscious, but there is a possibility that you are still aware of some things that go on around you, would you like certain kinds of music to be played softly in your room? Are there certain aromas, such as those from flowers, that you particularly like or dislike? This would also be a good time to make your wishes known regarding your funeral, for example, favorite Scripture passages, favorite hymns, and so on. Some people write down the entire funeral service. While you may think this is unnecessary, because the funeral is for those who are left behind, most people who have to tend to the details of a funeral are greatly relieved to know the wishes of their loved one. Finally, let people know in writing (as well as by talking to them) your wishes regarding cremation and/or burial.

## Identifying and Talking to Your Proxy for Health Care Decisions

Choose someone you can trust to carry out your wishes, that is, someone who knows your values and is *willing and able* to be your advocate. Talk to this person before you fill out the advance directive (including any instructions regarding your funeral and burial). Make sure that he or she knows where the document is filed. It is also wise to have a second person designated as proxy in case the first person is unable to serve in that capacity when needed. Make sure that he or she knows where the document is.

## Talking to Family and Friends

If possible, speak to family members and appropriate friends in addition to your designated proxy, explaining that you have a living will, telling them the person you

2. Dee Leahman, "Why the Patient Self-Determination Act Has Failed." *North Carolina Medical Journal* 65, no. 4 (July–August 2004): 249–50. Also online at <http://www.ncmedicaljournal.com/jul-aug-04/toc0704.shtml>.

## YOUR FUNERAL?

As you fill out a living will or review one you have already filled out, consider leaving written instructions for your preferences regarding your funeral service (favorite hymns, favorite Scripture passages, and so on). Giving such instructions can be enormously helpful to those who are left to make arrangements.

have chosen to be your proxy for health care decisions, and discussing your values and wishes with them. For some people this may not be possible. Sometimes, however, people hesitate to talk to family members and friends for fear of upsetting them. Filling out the advance directive can be used as a reason to start the conversation.

## Talking to Your Doctor

Your doctor also needs to know your wishes. Under normal medical circumstances your primary care physician should have a copy of your living will. (Be sure to submit a new copy whenever you update the document, and request that the old copy be destroyed.) In case of a serious medical condition that requires a specialist, that physician should have a copy as well.

If your doctor hesitates or directly claims that he or she could not follow your wishes, then you must decide if the disagreement is significant enough for you to look for another physician. (Remember, however, that you cannot expect a doctor to agree to assist you in ways that are illegal; for example, a doctor could not legally agree to assist you in an act of suicide.)

## Talking to Your Pastor

Because your pastor will be seeking to support those who will most likely be taking care of you, it is important that he or she understand your wishes. If your pastor does not agree with some of your decisions, it is important for you to be aware of that disagreement and for you to let your proxy know. (Legally it is your proxy, not your pastor, who will be your advocate.) It would also be good for you to give any written instructions about your funeral to your pastor. If you are uncomfortable initiating this conversation yourself, perhaps a group of people could meet with the pastor together to talk

about advance directives, funerals, and the best way to register specific wishes with the church's staff.

## Medical Situations to Consider

It is impossible to imagine every medical situation that may arise and to state what you would want in those situations. There are, however, some specific cases where people tend to know what they would want, and there are general values and wishes you can make known that can be applied to a variety of situations. For example, if you are especially afraid of a situation where breathing is a struggle, make that fear known. If you would rather experience pain and be alert, or conversely you would rather be unconscious than experience pain, talk to your proxy about those things and to the extent possible indicate them in the written document. Many hospitals as well as numerous Web sites can provide information to help you understand some medical conditions and treatment that you may want to address in your advance directive. Here are a few to consider and study further.

### LIMITS OF LIVING WILL

A living will can accommodate your wishes only within the boundaries of what is allowed by law. Assisted suicide, for instance, is illegal.

## Persistent Vegetative State

A persistent vegetative state (PVS) exists when the upper portion of the brain has ceased to function and only the lower part of the brain, the cortex, which governs breathing, circulation, and basic reflexive movement, is functioning. People in a persistent vegetative state have waking and sleeping cycles, can open and close their eyes, and may appear to give intentional responses to stimuli, when in fact their responses are totally random. People in a persistent vegetative state may be able to hear and see, but they have no capacity to interpret

### THE OTHER SIDE OF LIVING WILLS

A living will is not just intended for people who want to ensure that life-sustaining treatment will be withheld or withdrawn under certain circumstances. A living will also serves those who want everything done to keep them alive that is medically possible.

## HELP THOSE LEFT BEHIND IN GRIEF

Family members can be overwhelmed if they have to make arrangements for buying a cemetery plot in addition to dealing with their grief and preparing for the funeral. If at all possible, purchase a cemetery plot now, letting the appropriate people know that you have done so. Also, discuss with family members your preference regarding cremation or burial.

what sight and sound mean. They may appear to track an object with their eyes, to smile or laugh, but these are cruelly deceptive movements that cannot be purposely repeated. When a diagnosis of PVS is certain, there is no possibility of improvement.

### Nutrition and Hydration

Once someone is diagnosed as being in a persistent vegetative state or in some other form of permanent lack of consciousness, some people believe that the continued use of a feeding tube becomes futile care and it should be removed, especially if there is no reasonable possibility that the person will recover. Others, however, believe that a feeding tube should never be considered “extraordinary” or “futile” care, because it simply supplies the basic necessities of life: food and water (nutrition and hydration). Think carefully about your own evaluation of the use of a feeding tube when all reasonable hope for recovery to consciousness is gone.

### A Respirator

The same kind of consideration should be made regarding a respirator. Often a respirator is used until someone can begin to breathe on his or her own. Sometimes a conscious person chooses to remain on a respirator if doing so will significantly prolong life or add to his or her comfort. If, however, you are not able to speak for yourself, would you want a respirator removed if there is little chance that you will regain consciousness or if there is a chance that you will regain consciousness but with extremely severe disabilities?

### Surviving with a Severe Disability

People with disabilities rightly object to some people’s quick assumption that they wouldn’t want to live “like

that.” While our initial response to the possibility of paralysis may be “Just let me die,” we should think seriously about whether there are aspects of life that would make living even a severely disabled life worth the effort, for example, watching our children or grandchildren grow up, enjoying the pleasures of being with friends and family, reading, writing, and so on. Also, some people believe there is a difference between a severe disability and being “non-abled” such as a person in a persistent vegetative state.

## The Cost

Some people hesitate to consider the cost of treatment versus withdrawing or withholding treatment—and for good reason. We don’t want to place a price tag on the value of a person’s life. Also, in some cultures and for some individuals the danger may be that a decision would be made too quickly for the withdrawal of treatment in order to save the family a drain on its resources. We also want to be careful that poor people aren’t encouraged to withdraw or forgo life-sustaining treatment because they cannot pay, when people with medical insurance and other financial means would be encouraged to live as long as possible. That said, considering medical cost is not out of bounds. It is one among many factors that an individual should consider when filling out a living will. Is there any medical condition (for many people that would be a persistent vegetative state) where one determines that the total lack of awareness and the impossibility of recovering make the thousands of dollars required each day to keep the person alive not worth it?

## Why We Hesitate

If you haven’t filled out a living will (or a regular will for that matter), give some thought to why you have not done so. If you have already filled out a living will you should revisit it every two or three years or whenever there is a significant change in your life situation.

## About the Writer

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