An Insider’s Guide to Filling Out Your Advance Directive

What is an Advance Directive for Healthcare Decisions? The Advance Directive is a form that a person can complete while she still has the capacity to think and communicate. This form can be used to indicate *who* should make the patient’s decisions and *what* the patient would want in different medical situations after the patient loses capacity. Each state has a different form to use, so be sure to get the correct form before you start using this guide. Most doctors just hand patients the Advance Directive form and tell them to fill it out. But they don’t help explain how to use the form or what the decisions mean. I am going to help you think through the process of filling out your Advance Directive.

There are two main decisions you need to make when you are filling out your Advance Directive: *who* you want to make decisions for you and *what* you would want. After I help you with these two questions, I will tell you what to do once you have filled out this form. At the end, I have included instructions on how to find a form that would work in your state.

Whom Should You Pick?

Let’s first talk about whom you would want to make decisions for you. In your state, your form might ask you to list your agent, proxy, durable power of attorney for healthcare or surrogate decision maker. (These words all mean the same thing, but different places use different legal terms.) Use the following points to help you make a decision.

1. You should pick someone who is medically literate. What does this mean? The person should be able to understand what the doctor is saying, be able to understand the medical words and be able to understand the medical choices being offered. If the person you thought you were going to pick would be confused by what the doctor would say, then pick someone else.

2. You should pick someone who knows you very well, would know what you would want in a medical crisis and would tell the doctor what you have told her in the past. The person you choose will be asked to listen to medical information and then to use your values to make medical decisions. The decision maker is not supposed to use her own values, but to speak as if she were

you. If the person you thought you would pick wouldn't respect your choices or has very different beliefs from yours, then pick someone else. You want someone who will speak as if she is speaking with your voice, not her own agenda.

3. You should pick someone who won't fall apart in a crisis. It doesn't do you any good if the person is hysterical, can't function or can't stand to visit you in the hospital. You need to pick someone brave enough to be by your side no matter how difficult things get. If the person you thought you would pick doesn't handle his own life very well, then don't have him be in charge of yours.

4. You should pick someone who will do right by you even if it is the most difficult thing she has ever had to do. Sometimes doing the right thing is allowing the person you love to have a peaceful death. Your decision maker needs to be able to live with the difficult decisions she has to make. In reality, she is making the decisions based on what you would want, not what she would want, but that doesn't make it any easier. You have to be able to talk to this person ahead of time about what you would want in different kinds of situations. So if the person you thought you would pick is too afraid to talk about death and dying, then she isn't the right person for this job. Or if she would refuse to follow through with what you have requested, then pick someone else.

5. If you can, pick someone who lives close by or can at least afford to hop on a plane and come to the hospital to talk to the doctor in person. Too often bad decisions get made because people can't understand that their loved one's condition has changed drastically and that the person is no longer as they remember. If the decision maker can't come right away, perhaps a webcam can be used or a picture can be sent to show what is happening to the patient's body.

6. You can also write down those you *don't* want to be involved in the decision making. The rules regarding who is in charge of you when you are unconscious or incapacitated vary from state to state. You need to protect yourself and choose the person who is right for you.

7. Doctors won't tell you this, but you can pick two or three people to share in your medical decision making. But be careful that you pick people who can work together, who will support each other and who you know won't make things worse for the healthcare team. I had one lady tell me that she picked her two sons to make her decisions and that these two men had never agreed on anything. She is setting herself up for a nightmare, as good decisions won't get made and the doctor will hate having to deal with her sons. You don't want your doctor to hate your

decision maker. Please pick carefully.

8. Some people don’t pick their spouse, significant other or partner because they know that it would be too much for this person to go through emotionally and that he couldn’t make the most difficult decisions. If you do pick your spouse, then you need to be extremely careful about picking alternate decision makers. The alternates will make your decisions if you and your spouse are injured in the same accident. The alternates should be just as qualified as your first choice.

9. The other part of the “who” question is “Whom do you want to be able to receive information about your health?” Because of our HIPAA laws, you now have to state who can and cannot receive your personal information. Unfortunately, the Advance Directive form doesn’t ask this question. I would suggest that you write your choices in the “Other” section of whatever form you are using. Make sure you indicate both those you *do* want to receive your medical information and those you *do not* want to receive your medical information. Next, let’s look at how to tell the doctor what you would want, if you were unable to speak for yourself.

What Would You Want?

1. The first thing to remember is that this form goes into effect when you are unconscious, too mentally disabled or too sedated to speak for yourself. This form will be used when you are injured, sick and/or dying. Too many people, including doctors, think of this form as only a dying form. For some people, this form will be used for years and years because they have become mentally ill or disabled.

2. The next thing to decide is what you would want in certain medical situations. Should you be specific or vague about the specific medical treatments you would want? I would encourage you to be vague. You won’t know the exact medical situation you might find yourself in, and you may guess wrong if you write down “Don’t do this” or “Yes, do that.” Here is an example: You might have written on your Advance Directive that you would never want to be put on a ventilator. How will this statement be interpreted by the doctors? The doctor will not put you on the ventilator. If he does, it would be considered assault and battery because it is against your will. This recently happened to an elderly gentleman. The gentleman wrote that he didn’t want to be hooked up to a ventilator, but what he meant was, he didn’t want to live on a ventilator. This became a problem when he needed to be hooked up to a ventilator for four days in order to recover from an infection.

He didn't need it forever—just for a few short days. But because he was too specific and had said to never put him on a ventilator, he was not put on life support and he died. So be careful when you request certain medical choices. Make sure that what you have written would work in different situations.

3. So, now that I just scared you, you are probably worried about what to write in this section. I have a solution. It is called a *meaningful recovery statement*. You need to explain to the doctor what kind of life you would want to live if your mind no longer worked well or if it didn't work at all. Now, for some people, any condition is okay, because they believe it is God's will to determine how we live and when we die. But others can't think of anything worse than living in a nursing home, wearing diapers, having other people feed them and not being able to recognize their loved ones. But how will your doctors know what you would want if you don't tell them? Doctors know how to practice medicine. But what they don't know is what would make for a "meaningful recovery" for you. So you have to tell them.

Here is my meaningful recovery statement:

I value a full life more than a long life. If I have lost the ability to interact with others and have no reasonable chance of regaining this ability, or if my suffering is intense and irreversible, even though I have no terminal illness, I do not want to have my life prolonged. I would not then ask to be subjected to surgery or to resuscitation procedures, to intensive care services, or to other life-prolonging measures, including the administration of antibiotics, blood products, or artificial nutrition and hydration. I also believe that the financial and emotional burden on my family should be considered in making these types of decisions.

A few years ago I added this paragraph to my meaningful statement above when I married my husband. That is the great thing about Advance Directives. Over time, you can write a new Advance Directive and modify your wishes as your life and health condition changes.

In general, I do not want to be a burden on my family. I understand that caring for me may not feel like a burden for my husband, at least for a while. So, if he doesn't consider me a burden, whether financial, emotional or other, and he wants me to live for a while in a non-suffering condition while he makes peace with what has happened to me, then that is okay with me. I realize that everyone comes to terms with a loved one's health crisis in their own time and in their own way. I do not want to increase his unhappiness. So if he wants to care for me for a period of time, because that is less painful than letting me go, then that is okay with me. He is allowed to say, "Enough," when he is ready.

Because I have written this in my Advance Directive, the doctors will know what is important to me. Of course, this doesn't have to be your statement. Write one that is meaningful to you and attach it to or write it on your Advance Directive. One more thing: Please address the issue of terminal versus non-terminal situations. If you are terminal, then it is important your doctors know where and how you would want to die. If you are severely disabled but are not going to die soon, then you need to let them know what kind of life would be tolerable for you. The best way to be protected is to write it down. We have gone over the main sections of the Advance Directive.

Of course, you can write down anything else you want the doctors to know about you. You might want to tell them if you would like to donate your organs or if you are for or against an autopsy. This is your form, so write down whatever works for you. I encourage families to have Advance Directive gatherings where everyone gets together to talk about what they would want while filling out their Advance Directives together. This is a great way to make sure that as a group, your family and friends have heard and understood your wishes.

Now That You Have Filled It Out, What Should You Do Next?

1. Well, the first thing you have to do is sit down with your primary and your alternate decision makers and discuss what you would want if you were injured, disabled or dying. Remember that this form goes into effect when you are unconscious, too mentally disabled or too sedated to speak for yourself.

2. Then, you need to give all of your decision makers a copy of your Advance Directive. You also need to give copies to all your doctors and your local hospital. You should keep a copy at home either by your bedside, taped to the inside of your medicine cabinet or on your refrigerator so the paramedics can find it. You can also keep one in your car or in your purse. You might want to take the form on vacation with you. People won’t know what you want if they can’t find your instructions. Doctors get frustrated when the family says, “The patient has an Advance Directive, but we don’t know where it is.” What I do is keep a paper in my wallet saying where to find my Advance Directive and whom to call in case of an emergency. (Please *don’t* keep your only copy in your safe deposit box, where only you can get it.)

3. The next time you go to your doctor, bring him a copy and discuss what you have written. Ask your doctor if he would be willing to respect your choices. This is where you can really get into trouble. Some doctors won’t follow what people have written in their Advance Directive, so you

better know right now if yours is one of those doctors. Also, some doctors are too afraid to talk about death. If you don't think your doctor will respect your wishes or if he is too uncomfortable talking about dying, then find yourself another doctor. I am serious about this. Doctors go against people's instructions and prolong the suffering and dying of patients in every hospital. If you find yourself in this situation, with the doctor refusing to follow your Advance Directive, then the bioethics committee at the hospital should be able to help you. If you have been chosen as the decision maker and are unwilling to follow what is written in the Advance Directive, then you shouldn't be the decision maker. Remove yourself and have the doctors use one of the alternates.

How to Get an Advance Directive

1. The easiest way to get a free Advance Directive is to go to the front desk of any hospital. Just tell them you need one or more for your family, and they should give the forms to you for free.

2. You can go online to caringinfo.org for a free, state specific form. These forms are also available on many other organizations' websites. Just type in the words ‘‘Advance Directive” and the name of the state where you live, and plenty of options should appear.

3. You can also order an Advance Directive form called Five Wishes from agingwithdignity.org. This is a very good document for explaining what you would want in certain situations. There are forms in twenty-three different languages, including Braille, and they are valid in forty states. The document costs $5 and can be ordered in bulk (twenty-five copies or more are $1 each) at 888-5-WISHES or agingwithdignity.org.

4. Your doctor's office should have Advance Directive forms available, but unfortunately, many doctors don't keep them in their offices.

Do You Want to Make Your Own Decisions Even When You Have Capacity?

Now that your Advance Directive is complete, you may want to tell your doctor whether or not you want to make your own medical decisions starting right now, while you still have capacity. For some people and in some cultures, the patient would like to have someone else make the decisions even though the individual has full capacity and the ability to make his or her own decisions. If this is important to you, you will want to answer the question below and then use one of the three options on the following pages to document your wishes. Copy the option page that is right for you; then fill it out and give it to your doctor.

Do you want to make your own medical decisions?

•• Yes, I want to be in charge of receiving my medical information

and making my own decisions.

•• Yes, but I don’t want to make the decision alone:

•• I will make the decision together with other people.

(Use Option 1 to clarify your wishes.)

•• I will make the final decision, but I will want advice

from other people. (Use Option 2 to clarify your wishes.)

•• No, I don’t want to make my own medical decisions. I

want someone else to handle the decision making starting

now, even though I have the ability to decide for myself.

(Use Option 3 to clarify your wishes.)

Option 1

Yes, I want to make my own medical decisions, with the help of the following people (write in the names of those you will consult):

My spouse

My significant other

My partner

My family

My doctor(s)

My religious leader(s)

My community leader(s)

My friends

Others

The following people should *not* be involved in my medical decision making:

Signature

Date

Option 2

I will make all final medical decisions, but I will want advice from other people, including (write in the names of those you will consult):

My spouse

My significant other

My partner

My family

My doctor(s)

My religious leader(s)

My community leader(s)

My friends

Others

The following people should *not* be involved in my medical decision making:

Signature

Date

Option 3

No, I do not want to make my own medical decisions. I want someone else to handle the decision making for me, even though I have the ability to decide for myself (have capacity). I realize I can get back the power to make my own decisions just by telling my doctor, as long as I still have decisional capacity at that time. I want the following person/people to make my decisions for me starting now:

My spouse

My significant other

My partner

My family

My doctor(s)

My religious leader(s)

My community leader(s)

My friends

Others

The following people should *not* be involved in my medical decision making:

Signature

Date

[Note: This next section is optional. I am including it here for the sake of your doctors. Some healthcare professionals are not used to people not wanting to make their own decisions while they can think for themselves. Personally, I have met lots of people who have asked someone else to make their decisions for them, even while they could still speak for themselves. This information will help the doctor respect your wishes. (Even though the doctor should respect your wishes without you explaining, we might as well make it easier for him or her.)]

Here are some of the reasons I would like someone else to make my decisions (circle all the answers that apply):

I don't want to worry about making the decisions.

I want to focus on getting better.

This is the way we do things in my culture.

This is the way we do things in my family.

This is the way we do things in my religion.

I don't have the energy to do all the necessary research to make a good decision.

I don't think I would be a good decision maker.

I just don't want to make the decisions.

I don't want to tell you why.

Other

Signature

Date

Quick Tips for Filling Out Your Advance Directive Form

Whom should you pick?

1. Pick someone who will understand what the doctor is saying.
2. Pick someone who knows you well and has listened to what you want.
3. Pick someone who won't fall apart in a crisis.
4. Pick someone who will do what you have asked, even if it difficult to do.
5. Pick someone who is close by geographically.
6. Write down whom you don't want to be involved in the decision making.
7. You can pick two or three people to work together as your decision makers.
8. Your spouse, significant other or partner may not be your best choice, and you may want to choose someone else.
9. In the "Other" section of the form, state whom you do and don't want to be told your medical information.

What would you want?

1. This form goes into effect when your brain isn't working anymore, not just when you are dying.
2. Don't be too specific about the particular treatments you want or don't want, because you don't know what the medical situation will be when you need this form.
3. Write out a meaningful recovery statement describing what kind of life you would want if you were disabled and couldn't think anymore.
4. Tell the doctors what they should do if you were going to live in a terrible condition, as well as what you would want if you were dying.
5. Write down anything else you want your doctors and loved ones to know about where or how you want to die, organ donation preferences or autopsy instructions. Make sure that your decision makers, your doctors and the hospital get copies of your form and that you talk about it with those who will be involved in your care.

Have a kind and respectful day!

Excerpt from *The Caregiver's Path to Compassionate Decision Making – Making Choices for Those Who Can't* Viki Kind – viki@kindethics.com – KindEthics.com