

What Happens When We Can't Make Medical Decisions for Ourselves

**Planning for Future Medical Events for You and
Your Family**

At some point in our lives...

Almost all of us will be in a condition where we can't make medical decisions for ourselves. Some of us will be in that condition more than once. The condition can happen gradually and expectedly, as in old age. But it can also happen to people of every age, and sometimes it happens in the blink of an eye. Advance care planning helps us prepare for those times in ways that support our lifestyles, values, and hopes for the future.

Advance care planning is important for every adult, no matter our age. It helps us maintain some control over our healthcare in situations that would otherwise be out of our control. Advance care planning is about maintaining control and about having a voice.

Advance care planning helps us care for the people we love. One of the most difficult situations family members face is trying to figure out what care choices their loved ones would have made if they could speak for themselves. A care plan helps to relieve family members from worrying if they did the right thing.

What is an Advance Directive?

An Advance Directive is a document that makes a person's advance care planning official. Once an Advance Directive is signed and dated by the person making the plan and by two adult witnesses, it becomes a legally binding document.

Making a change to your Advance Directive is as simple as completing a new one. Your Advance Directive with the most recent date is the one that is followed.

An Advance Directive combines two basic pieces of information: It lets you name decision makers (a primary decision maker, and a backup decision maker), and it lets you provide information about the care you want. You can do both of these things in your Advance Directive, or you can do just one of them. It's your choice.

There's one more thing an Advance Directive does. It gives you an opportunity to give a gift to others through organ and tissue donation. There is a section in the Advance Directive that lets you make these decisions or give your decision maker permission to make these decisions on your behalf.

What should I consider when naming a decision maker?

In the language of Advance Directives, decision makers are called Agents for Healthcare Decisions. A person you ask to be your agent should be someone who knows you well, and who is able to represent your wishes even if they might want something different for you. He or she should have a good sense of what is important to you—or be willing to work with you to understand what is important.

It is never a good idea to name someone as your agent without discussing the decision with them, and without their agreeing to take on the responsibility.

It is helpful if your agent is someone who is able to stay calm during an emergency, and who feels comfortable working with your doctors, asking questions and making decisions. It is also helpful if this person is able to communicate with other family members or people who care about you to build agreement about your healthcare plans.

An Agent for Healthcare Decisions is only responsible for medical decision making. He or she is not responsible for your medical bills, or for any other kind of decision making (including financial decision making.) And if a patient should die, the agent's decision making authority comes to an end.

What happens if I don't name an Agent for Healthcare Decisions?

If you haven't named an agent and you are unable to make medical decisions for yourself, Virginia law identifies who the decision maker will be. The decision maker is selected in this order:

- A guardian appointed by a judge or magistrate
- Your spouse (if you are legally married with no divorce actions on file)
- Any adult children you may have (all adult children have the same decision making authority)
- Your parents (both parents are equal decision makers)
- Adult brothers and sisters (again, all have equal decision making)
- Other relatives in descending order of blood relationship
- Other adults based on their relationship with you

Decision maker(s) selected from this list do not have all the same authorities as an agent you have named in your Advance Directive. But they are asked to make very important decisions about your care.

How do I begin the conversation with my loved ones about my wishes?

When it comes to advance care planning, we make the plan by talking, by just beginning. Talking is often how we figure out who and what we want in our plan.

It can be helpful to begin by talking about how difficult the conversations can be—and to agree on a future time and date to talk. “I know talking about this is hard, but it is important for us to do this. I want to let you know what I want, and I want to do it to ease the burden for you.”

How and when we start can be influenced by many things:

- A new medical condition or medical concerns
- Our religious and spiritual beliefs
- Our age
- Changes in our family situation or support network
- A recent death that has had an impact on us
- A story on the news or something that has happened in our community that touches us

It is sometimes helpful to think about “good deaths” we have experienced or heard about, deaths that were an affirmation of the individual, or that were filled with blessings. What were the things that made those deaths “good”, in spite of the losses involved? Which of those things would we want at the end of our own lives?

For some of us, it may be too hard to have these conversations on our own, even though we really want to do that. If you think that you and your loved ones can use some help with your advance care planning discussions, you can ask your UVA doctor or medical professional to help you make an appointment with a social worker or chaplain. They can help you start the process.

Your medical provider can also talk to you about any medical conditions or concerns that might impact your advance care planning. Medical providers can also help you get more information about medical treatments or interventions, like resuscitation, intubation, tube feedings or dialysis.

When you have a medical appointment, the clinic staff are likely to ask about your Advance Directive. That can be a good reminder that you need to review your Advance Directive from time to time. Our planning decisions will change over time. A care choice that makes sense when we are 50 may not be such a good idea when we are 75.

Where can I find an Advance Directive form?

You can get a copy from your doctor's office or clinic. Just about every hospital website offers a link to an advance directive form. Other places where you can get an Advance Directive form include:

- Your local Department of Social Services
- The Charlottesville Free Clinic, or other free clinics
- Public libraries
- www.caringinfo.org has forms and instructions from all 50 states

What should I do after I have completed an Advance Directive?

Put it in a place that is safe but easy to get to. And tell your loved ones where to find it. Do not put it in a safe deposit box, or other location where only you can get to it. It is a good idea to bring a copy to your doctor's office so they can include it in your medical record. You should also give a copy to your primary agent and your back-up agent. And you may want to bring a copy of your Advance Directive with you if you are admitted to the hospital for a planned procedure.

Many Advance Directive forms include a wallet card that you can cut out and keep in your wallet. This card has a space where you can write in the names and phone numbers for your agents, plus the name of the hospital or clinic that has your advance directive on file. Also, the Virginia Department of Health has a state registry where you can record this same information. The registry is available to healthcare providers across the country.

It is a good feeling to know you are prepared

The medical teams that treat our patients seek to know and honor their wishes. And they welcome the clear direction that an Advance Directive can provide.

Advance Care Planning, made official in a completed Advance Directive, helps you to know that you have done what you can to prepare for your future medical care decisions, and that you have done what you can to care for the people you love.

Resources for additional information:

The National Healthcare Decisions Day website provides links to a variety of resources to help make, discuss and document future healthcare wishes and decisions. Visit www.nhdd.org

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