

Getting Ready to Make Your Plan

A Guide to Help You Prepare for
Your Advance Care Planning Appointment



I will meet with my advance care planning facilitator on:

Date/Time

What is advance care planning?

If you suddenly got sick or were in an accident and could not speak for yourself, the people taking care of you would want to know how to make decisions for you. Thinking about how you would want decisions made for your health care, and sharing this with the people who matter (like your doctor or family and friends) is called advance care planning (ACP).

Before you meet with your advance care planning facilitator, read about Taylor, Shauna, and John as they create their advance care plans.

REFLECT

Why are you planning?

I want my doctors and family to respect me if I have an emergency. I'm worried about my family getting into fights or my doctors making decisions that I don't like. I can help make sure that doesn't happen by telling everyone what I want.

I've learned that I know myself best. When my oldest was born, I felt like nobody was looking out for me. While taking care of my parents, I learned that you have to advocate for what you want. I want to make sure that I get the care I want in the future, especially if I can't speak for myself.

I have had diabetes for a long time, and I live by myself. I don't have any close family. I worry that something could happen to me and there would be no one to tell my doctors what I want. I want to have a say even if I can't speak for myself.



Taylor



Shauna



John

Fears & Concerns

Some concerns and emotions that people have about ACP:

The thing about a sudden accident or illness is that it can happen anytime. You can always change your plan.

Do I really need to make a plan?

I feel overwhelmed thinking about the future.

Advance care planning starts by talking about your past experiences and your life right now.

I trust my doctors or decision makers to choose for me.

I don't want to talk about this. It seems morbid.

It's OK to tell other people to use their own judgment. However, sometimes it is hard for doctors or loved ones to make choices for us without knowing more about us.

Advance care planning is talking about how you want to live and how you want others to care for you while you are still alive.

I'm afraid that others won't respect my wishes, or that I could change my mind.

A good advance care plan prepares other people to honor your wishes. It's also normal to change your mind over time. You can update your plan when that happens.

REFLECT

What are you feeling right now?

Terms to know:

Advance medical directive

An advance directive lets you list your health care wishes and name a person who can make health care decisions for you.

Living will

A living will lists your health care wishes but does not name your health care decision maker.

Medical power of attorney

A legal document that only names your health care decision maker. It doesn't list your health care wishes.

Health care agent

Your health care agent is your legal decision maker for health decisions. This person or people will only make choices if you cannot make them yourself.



Remember: Your facilitator will talk to you about any concerns you have and help you to feel comfortable during your planning appointment.

Choosing a Health Care Agent

What does a health care agent do?

Your health care agent is a person in your life that you trust to make medical decisions for you if something happens and you cannot make decisions yourself. There is usually a primary agent (main decision-maker) and a secondary agent (back-up). Your facilitator will help you to choose and prepare your agents for their roles.

The four main things your health care agent should be willing to do:

- 1 Talk to you about your goals, values and preferences
- 2 Follow your decisions, even if they may not agree with them
- 3 Make decisions in difficult moments
- 4 Accept this role

Common questions related to health care agents:

“I want more than one person to be my agent.”

It's OK to have more than one person helping to make decisions for you. However, there can be many reasons to choose just one primary agent. Your facilitator can talk about this more with you.

“Do I have to choose my spouse/partner, child, or a family member?”

No; you can appoint anyone you want, except for your personal physician.

“There's no one I trust to be my agent.”

Advance care planning is still important even if you don't choose anyone right now. Your facilitator will make sure your wishes are noted so your doctors will be prepared.

Examples of situations where your health care agent may need to make decisions for you:

- You are in a coma
- You are under general anesthesia during a medical procedure or operation
- You are living with advanced dementia
- You are receiving drugs to keep you sedated to help with your pain or discomfort



Remember: It's important that your health care agents talk to you about your wishes. Bring them, and anyone else you want, to your advance care planning appointment so that your facilitator can help prepare them.

REFLECT

Who do you think would be the best person to be your health care agent?

Primary:

Secondary:

Taylor:

My partner will be my primary agent, and a close friend will be my secondary agent.

Shauna:

My siblings will make decisions together.

John:

No one right now. I will think about asking my neighbor.



Exploring Experiences

Your facilitator will ask you to share what you have learned from your own experiences. Start thinking about:

- Someone (could be yourself) who had a sudden accident or serious illness
- If you are living with a chronic illness: what kind of care have you received? What could happen in the future because of your illness?

REFLECT

What are some of your experiences that stand out?

Exploring Quality of Life

It's important for your health care agents to understand your personal definition of "quality of life", including physical, mental, social, and other aspects of living.

REFLECT

What gives your life meaning?

Shauna:

"For me, quality of life means family and faith."

John: "Quality of life means being able to take care of myself and keeping my brain active."

Taylor: "Quality of life is about being in my community, having relationships with others, being able to get outside, travel, and read."

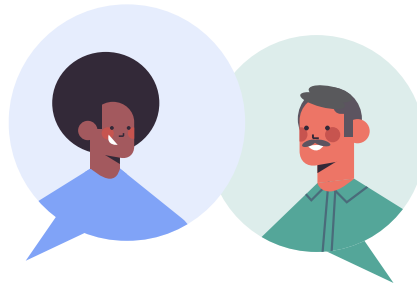
Exploring Beliefs

Part of ACP is reflecting on any other beliefs you have, or other things that are important for your medical care.

REFLECT

What are some of your beliefs?

Taylor: “I consider myself to be spiritual and want to respect my body’s natural healing ability and dying process.”



John: “I don’t have any strong beliefs. However, I do not want to be a burden to society or the health care system.”

Shauna: “I have a strong faith and a big family that makes decisions together and cares for each other. It’s important to me to be here while my children are growing up.”



Exploring **Goals of Care**

Your facilitator will talk to you about the care you would want if you were in a persistent vegetative state or nearing death, and it was unlikely you would recover. In both of these scenarios, you could be receiving life-sustaining treatment. Many people have questions about these situations:

What does nearing death mean?

Nearing death means that your body is showing a pattern of symptoms that often comes days before death.

What if my doctors are wrong about my chance of recovery?

While modern medicine is very advanced, there are always unknowns. You can tell your decision makers how much to defer to your doctors' judgment.

What does “unlikely” mean?

Unlikely means that there is a five percent or less chance of recovery.

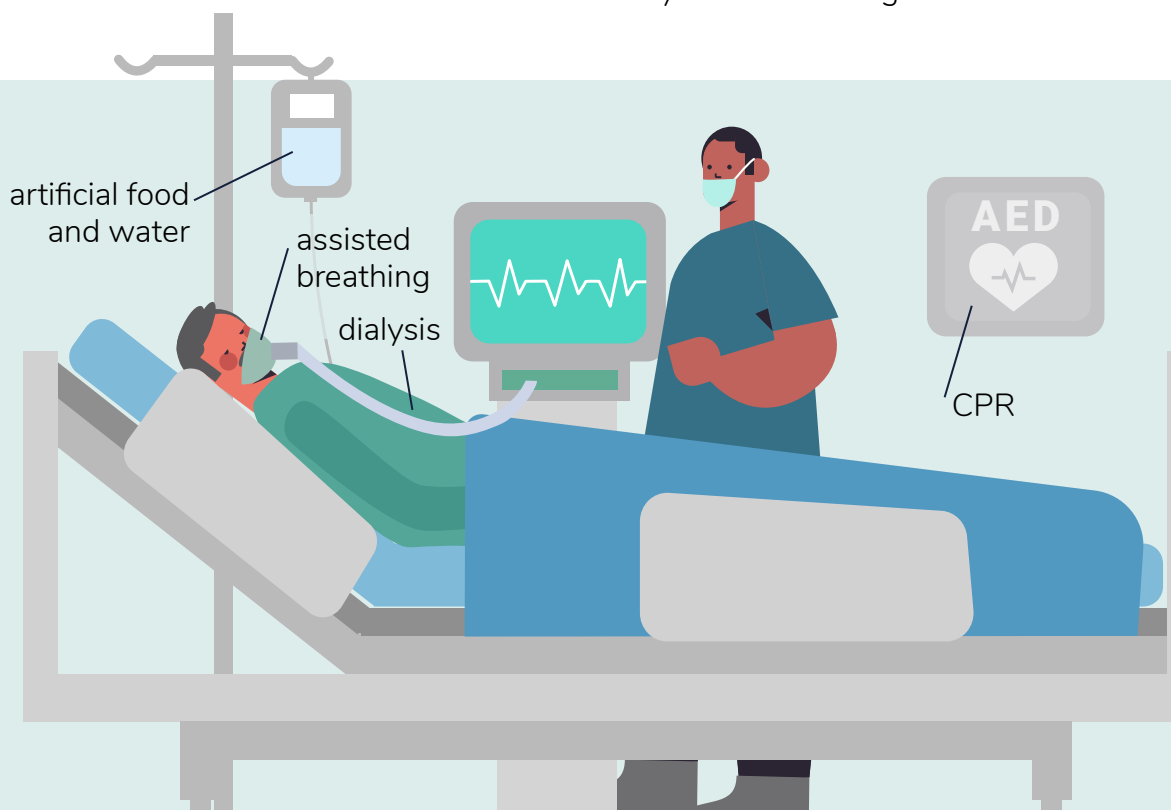
What is a reasonable trial of treatment?

A trial of treatment can be used to see if your health condition changes. The amount of time that is “reasonable” can vary. It may be hours or several weeks.

What is a persistent vegetative state?

Sometimes an injury or illness can cause damage to your brain. Doctors look at your brain function using different tests to tell whether you are in a coma, brain dead, or in a “persistent vegetative state”. A persistent vegetative state means that your body is alive, and you may be awake, but you do not know who you are or have awareness about your surroundings.

Life-sustaining treatments keep your body alive when your body is too sick to support itself. It can include:



What if I choose to stop treatment?

Life-sustaining treatments keep your body alive when your body is too sick to support itself. Stopping treatments may lead to death. Either way, you will be kept comfortable.

What if I choose to continue treatment?

You may choose to continue life-sustaining treatment under medical recommendation. In this case, you may need to be transferred to a long-term care facility.

On a scale of 1-5 circle the number to best describe how important the following is to you:



Have medical treatments that focus on giving you **longer to live.**

equally important

Have medical treatments that focus on giving you **quality of life** for as long as you live.



Have all of the possible medical treatments, including machines, to **keep you alive for as long as possible.**

equally important

Have a **natural death without machines.**

REFLECT

What questions do you have about these situations?

Organ and body donation

On an advance medical directive, you can choose if you want to donate your organs or body when you die. Your facilitator will talk to you about this choice.



1

There are three choices you can make:

"I would like to donate my organs, eyes, or tissues."

If you choose to donate your organs, eyes, or tissues, they will go to other living people in need or be used for research. You can choose which organs you want to donate and how you would like your organs used.



2

"I would like to donate my whole body."

If you choose to donate your whole body, it will be used for medical research and education. The program cannot promise where your body will go. In Virginia, you must make plans ahead of time with the State Anatomical Program. Not all bodies are accepted because of their condition or current program needs.



3

"I do not wish to donate."

If you do not wish to donate your organs or body, you can make this choice on your advance medical directive. You can also leave this decision up to your health care agent to decide later.

Questions and concerns about organ and whole body donation

If I am sick or very old, can I still donate?

Yes, it may still be possible. If you choose to donate your organs or whole body, you are giving permission to be considered as a donor. The people who work on organ and whole body donation will figure out if it possible for you to be a donor when you die.

Does it cost money to donate?

Donating your organs or body will not cost money. However, if you want to donate your whole body, there may be related transportation or funeral home costs, depending on your final plans.

Can I still have a funeral if I donate?

You can donate your organs and still make any funeral arrangements you want. If you choose to donate your whole body, your body will be cremated once it is no longer needed. Your family may request the return of your remains. However, it may take six months to several years before your family receives your remains. Sometimes, an organ or part from a body may still be kept for a long time.

I am afraid that someone will donate my organs or body even though I don't want them to.

Nobody, even your health care agent, can change your decision once it is written in your advance medical directive.

I am afraid that if I choose to be an organ donor, I will not receive very good care.

This is a very common concern. Doctors and nurses are not able to see the list of people who say they want to be organ donors. And, someone can only be approved as an organ donor after their doctor has announced their death.

REFLECT

What questions do you have about these situations?



Making Your Advance Medical Directive

Your facilitator will help make sure that your most important values and choices are written in your advance directive. The advance directive may not include everything that you talk about.

What kinds of things might not be written in your advance medical directive:

*I do not want
CPR to be
attempted for
any reason.*

Some preferences require extra steps, like a conversation with your doctor.

*I never
want to be
in a nursing
home.*

Some preferences can be tough to honor.

*Please take
care of my pet
if I am in the
hospital.*

Some preferences are not appropriate to write in an advance medical directive.

Whenever you're ready to review or update your plan, contact us to make an appointment with an advance care planning facilitator.

Explore other planning needs you may have.

Download the Because I Love You guide:
www.honoringchoices-va.org/learn/resources

Your support makes a difference.

Consider making a tax-deductible donation to Honoring Choices® Virginia. HCV is a nonprofit organization whose vision is for every Virginian to have access to quality advance care planning that is honored in the delivery of care. Your donation helps us to provide advance care planning services free of charge.



804-622-8141

honoringchoicesvirginia@ramdocs.org

www.honoringchoices-va.org