VNS Health

Guide to Advance Care Planning

What you need to know and do to make sure you get the care you want.

Although many people put it off, thinking about your future health journey — or starting that conversation with an aging parent — is important.

Advance care planning might seem scary or like tempting fate. In fact, it's better to talk about care plans long before you need them. It's easier to talk about difficult topics when they are hypothetical what-ifs, rather than during a crisis.

Starting early, while you or your loved one is in good health and able to make decisions, can make the process less stressful. And it can start with a simple conversation.

What Is Advance Care Planning?

Advance care planning is a way of planning for the what-ifs in life. Having a plan lets you make sure that the medical care you receive is what you want if you are unable to speak or make decisions about your care.

Advance care planning includes thinking about who you want to make health care decisions for you if you can't make them, thinking about what kind of care you do — and do not — want, and putting those choices down in written documents called advance directives.

Advance care planning is often associated with old or sick people, but it's actually important for healthy people of all ages. By planning ahead, you can have peace of mind, knowing that your wishes will be respected if you're in an accident, if you develop a sudden and serious illness like COVID-19, or as you age.

When Is It Time to Think About Advance Care Planning?

It’s never too early to think about advance care planning. Everyone over the age of 18 should have a plan, and it’s especially important if you have a disability or a chronic or progressive illness.

A plan means your family doesn’t have to wonder whether they did the right thing. It avoids confusion, arguments, or disagreements among family members trying to decide what to do if you cannot speak or make your wishes known.

Advance directives let your family and your medical team know what your wishes and preferences are — and can ensure that those wishes are honored.

Writing a plan and sharing it with your loved ones *and* your doctors can help relieve or prevent unnecessary suffering, improve quality of life, and help you and your loved ones better understand the decision-making challenges you face.

What Does Advance Care Planning Include?

Advance care planning is a five-step process. The steps are not complicated, but they do take time and careful thought.

Step 1. Think about your wishes.

Think about what kind of care you would want in a specific situation. You can ask yourself questions like:

- What tests, procedures, life-sustaining measures, treatments, or medications do I want?
- Which do I not want?
- What might make me want to stop a certain treatment or medication? For example, some treatments may cause painful side effects. You may decide that you would rather not live with that pain, even if stopping the treatment could mean you don’t live as long.
- Will a certain procedure allow me to continue an activity or meet a goal?
- How likely am I to recover fully? What will my life be like?
- Where do I want to receive care? (You may want to avoid hospitals when your illness reaches a certain stage.)
- What is important to me ?
- Who do I want to speak for you or make decisions on my behalf?

Thinking about the future in this way might bring up all kinds of feelings. You might feel peace planning things out, or you might feel nervous about getting older. All of these feelings are normal.

Remember that by thinking about advance care planning now, you are saving yourself and your family members from worry and doubt in the future. You're making it easier for family and friends, for your doctors, and for yourself.

Step 2. Talk to your family and your doctor.

Advance care planning can feel overwhelming, but you don't have to do it all by yourself. When you talk with your loved ones or your doctor, you can get their insights. They may bring up things you hadn't thought of.

As part of you annual exam, you doctor might ask if you have advance directives. If you don't, you can make an appointment to discuss care options. Medicare now covers advance care planning appointments between doctors and patients and their caregivers.

When you make an appointment, let the office staff know you wish to discuss advance care planning. These appointments may take longer than other office visits, so the staff may want to block out more time so you and your doctor are not rushed.

If you are a caregiver and you want to talk about advance care planning with your aging loved one, these conversation starters might help.

Step 3. Choose a health care proxy (or agent).

An important element of advance care planning is naming a health care proxy, sometimes called a health care agent. A health care proxy is a person you choose to make decisions about your care if you are unable to do so. Your proxy should be:

- Someone you trust, like a family member or close friend
- Someone you have discussed your health care wishes with
- Someone who has agreed to be your health care proxy
- Someone who is named in writing on your health care proxy form

Step 4. Create written documents.

After talking with your family and doctors about your wishes, it's important to put them down in writing. Documents that include decisions about your future care are called advance directives.

Every state has different rules about advance directives, so be sure to check what documents are recognized in your state. In New York, these documents include:

- **A health care proxy**: A document that names someone you want to make health decisions for you if you are unable to.
- **A living will**: A written document that states your wishes for various medical treatments in advance.
- **A do not resuscitate (DNR) form**: A medical order issued by a doctor, at your request, that tells medical staff not to provide CPR (chest compressions) if your heart stops.
- **A do not intubate (DNI) form**: A medical order issued by a doctor, at your request, that tells medical staff not to insert a breathing tube in your throat.

Once you have created your advance directives, be sure to give copies to your doctor, your health care proxy, and your emergency contacts.

Step 5. Review your advance directives as needed

It's important to review your advance directives every so often to make sure they still reflect your wishes. If you created your directives when you were healthy, or before you had children or grandchildren, your outlook and wishes might be different now. Your documents should reflect that.

It's especially important to review your advance care documents:

- Any time you are going into the hospital or having anesthesia
- If your condition or treatment plan changes
- If your goals for treatment change
- If your illness gets worse
- If treatments aren't as effective anymore

How Do I Talk to a Loved One?

Whether you're creating your own advance directives or making sure an aging parent or your spouse has them, talking about the future can be awkward. No one really wants to think about being in a medical emergency or getting older. Parents especially might not want their kids to worry about them or think of them as weak.

But talking about the future with your loved ones is important. It can give both of you a sense of comfort and security to know that wishes will be respected.

Here are some tips that can make the conversation easier:

- Pick a comfortable place, and leave enough time so that you won't feel rushed.
- Respect you loved one's discomfort, but make it clear that this is important and you want to finish the conversation.
- Ask open-ended questions (like the ones in Step 1 above) that can't be answered with just a yes or a no.

Conversation Starters

Although these tips are for walking an aging loved one through this tough conversation, you can also use them to guide your own thinking or family/doctor conversations about your end-of-life wishes.

Topic	Conversation Starter
Getting the conversation rolling…	"Hey, I want to talk about something kind of serious, but I don't want you to feel like you have to have all the answers right now — have you ever heard of or thought about advance care planning?"
What it is…	"It's basically talking about and writing down some of the things you want your family and doctors to keep in mind as you get older — or if you were to have some kind of medical emergency like a stroke or fall."

Topic	Conversation Starter
Why it's important…	"Advance care planning might sound scary, but actually it's really helpful. It can help everyone involved in your care be on the same page — especially if you can't speak or make decisions for yourself — and it can also give you peace of mind knowing your wishes will be respected."
Quality of life…	"Have you ever thought about what you might want to happen if you were in a medical emergency? One thing that can help to think about is how you define your own quality of life. Is it about time or ability — or something else?"
Organ donation…	"Are you an organ donor? There's no age limit for donation, and you can carry around a card in your wallet indicating your preference."
Kinds of treatment…	"There are lots of kinds of treatments and ways a doctor might try to save your life — things like ventilators to help you breathe or CPR if your heart stops. It might be helpful for us to research different things or talk to your doctor so you can make decisions about the kinds of things you might or might not want."
Reminding them they're not alone…	"I know it can be hard to talk about this kind of stuff, but I'm here to help you and be a part of this process. You don't have to do it by yourself."
Putting things in writing…	"There are a couple of different documents we can write so that all of your wishes are on paper and legally protected. How would you feel about starting to write some of your wishes down on paper?"

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