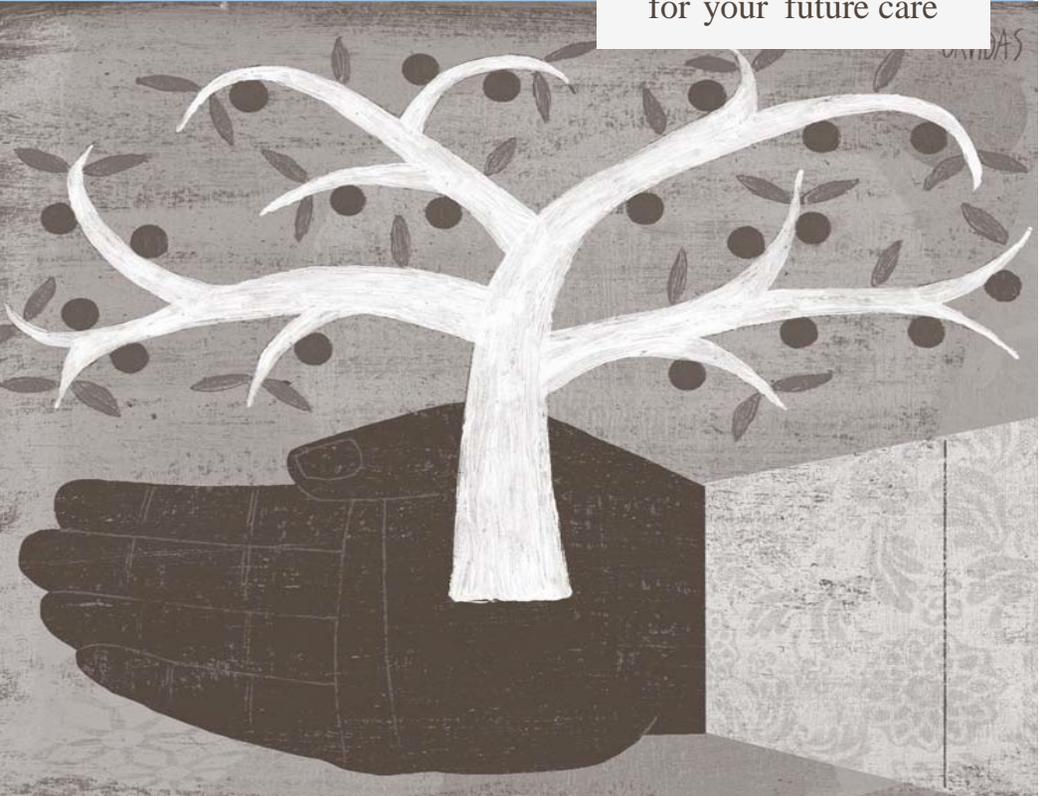




Advance Care Planning: For Dialysis Patients and Their Families

Talking about your
wishes can help you
and your family plan
for your future care



Today's treatments for kidney failure allow you to participate in life and enjoy your family and friends. Dialysis is a life-saving treatment, but it is not a cure. Most people with kidney failure have other diseases or conditions that get worse over time. At some point, you could face failing health and—as all people do, regardless of their health—the end of life.

Looking ahead can be overwhelming and scary to think about. But it helps to take control of your care by telling your health care providers and your family about your wishes and the type of care you want as your disease progresses. This also will make it easier for them to make decisions for you if you become too sick to make them yourself.

Many people on dialysis say they feel better knowing that they talked with their family or social worker about their wishes for the future. They say that they:

- Feel a sense of control over their future
- Have peace of mind
- Know they have made sure that they will be taken care of with dignity, through pain relief and other chosen treatments
- Feel they will be less of a burden to their family, who will not have to make difficult decisions on their behalf

All these decisions are called “**advance care planning**,” which is simply planning for your care before you need it.

Your dialysis facility staff are ready to work with you on putting some of these decisions in writing so you can have peace of mind about your future. You can always change any of your decisions later; they are not set in stone.

Where to start

Many people on dialysis say they don't know where to start when it comes to deciding what should be in their advance care plan. Before you talk about it with your family or social worker, think about what is really important to you about your life and health. Here are some questions to think about:

- How do you feel about your current health and life?

- What do you value about your health and life now?

- How important is it for you to be:
 - > *Independent and self-reliant?*
 - > *Able to recognize family and friends?*
 - > *Able to talk and understand others?*
 - > *Able to live without a lot of pain?*

- Are there any situations—such as permanent unconsciousness, severe dementia or severe stroke—in which you would not want to be kept alive with a breathing machine or a feeding tube, or other measures?

- Are there any situations in which you would want to stop dialysis?

If you feel strongly about any of these issues, talk about it with someone close to you (a family member, social worker, friend or clergy). Then think about including your decisions in your advance care plan.

The hard part is bringing up the subject. Nearly everyone finds it difficult to talk about what the future will bring, especially illness and dying. But here are some things you can try:



Talk with a family member or close friend about your wishes

Tell your family and friends what you would like your life to be and under what conditions you would not enjoy life. This will help them understand what is important to you. Think about some of the questions listed in the “Where to start” section. Your wishes can be as simple as these examples:

- *Whatever may happen to me, I want every procedure done to save my life.*
- *I do not want measures taken to save my life if I will not be able to feed, dress, bathe or use the toilet myself.*

After you have shared your wishes, ask for help in thinking about your options and choices for future treatment. This will help you and your family understand what decisions they might need to make if you cannot speak for yourself.

How to bring up the topic

There is no right way to bring up your wishes for the future. Here are some tips that have worked for others:

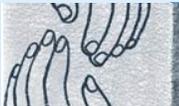
- Ask someone like a clergy member to offer advice or share experiences with you and your family. Use the discussion to talk about how your wishes are different or the same.
- Use a story in the newspaper or on TV to start a discussion. Talk about how you feel about the story and how your wishes are the same as or different from the ones in the story.
- Dialysis patients often know other patients who have died. Talk about the loss as a reminder that you want to plan ahead.
- Share this brochure with a family member and talk about how hard it is to think about the future.



Talk with your doctor about future care

Your nephrologist is responsible for your care for the long term. This means he or she can help you plan for your future care.

Sometimes doctors also have a hard time bringing up the subject of future care. They may not bring it up unless you do. Discuss the topic at your next visit and tell your doctor about your concerns and the care you want at the end of life. This will help him or her understand what treatment is best for you.



Meet with your social worker

Make an appointment with your social worker to get started on your advance care plan. Your social worker will have the necessary information and forms to help you. Your advance care plan can include:

- Who you want to make decisions for you if you become too sick to make them yourself
- Your goals for dialysis and other life-sustaining treatments
- Your wishes for pain relief (palliative care)
- “Do not resuscitate” (DNR) orders
- Advance directives
- Your preferred place to die (such as your home, hospital or hospice center)
- Your wishes for donating organs and tissues like heart, lung, liver, corneas, etc.

(See the Glossary for an explanation of some of these terms.)

You do not have to talk about all of these at once. Just making the appointment to talk about what an advance care plan is and what decisions you want it to include is a good first step.

Glossary

Here are some terms that you may hear when making your advance care plan:

Activities of daily living: Everyday things people need to do to take care of themselves, such as dressing, bathing and eating. When a person can no longer do one or more of these, they may become unhappy with their health or quality of life.

Advance directive: A legal document that tells your doctor and family what treatments you want, in case you cannot speak for yourself. Advance directives can specify life-sustaining treatments that you want to receive to continue life and which, if any, you do not want to receive.

DNR: Short for a “do not resuscitate” order. This legal document tells the medical team not to use CPR or other methods to restore breathing or a heartbeat.

Durable power of attorney: A document in which you appoint someone else to act for you when you cannot act on your own behalf.

End-of-life care: Medical care at the end of a person’s life.

Health care proxy: A family member or close friend chosen by you to speak for you if you cannot communicate.

Hospice: Health care that helps patients at the end of life at home or in a facility. Hospice care focuses on comfort and grieving, not on curing the illness. Depending on their illness, patients can sometimes receive hospice care while continuing dialysis.

Living will: A type of advance directive with instructions that outline a patient’s wishes for medical care in case he or she cannot communicate and is dying or in a vegetative state.

Palliative care: Comfort and pain treatment to ease the effects of a disease.

Power of attorney: Legal right you can give to a friend or relative to make decisions for the you.

Quality of life: A term describing how satisfied a person is with his or her life—including health, relationships, spirituality and financial issues—how active or independent the person is and how well the person can achieve his or her personal goals.



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Get more information when you are ready

These Web sites have a lot of information about the decisions you may want to include in your advance care plan. If you do not have a computer, ask your social worker to print out the information for you, or visit your local library.

Aging With Dignity www.agingwithdignity.org This organization offers a booklet called “5 Wishes” that can help you decide what should be in your advance care plan. ☎ 1-888-5WISHES (594-7437)

American Association of Kidney Patients www.aakp.org Serves the needs, interests and welfare of kidney patients and their families by helping them to deal with the physical, emotional and social impact of kidney disease. ☎ 1-800-749-2257

Coalition on Donation www.Donatelife.net A not-for-profit alliance of national organizations and local coalitions across the US that provides information about organ donations and inspiring all people to donate life through organ, eye and tissue donation. ☎ (804)782-4920

Caring Connections www.caringinfo.org This organization can provide you with advance directives for your state. ☎ 1-800-658-8898

Medicare Medicare covers hospice and other specialty care at the end of life. You can search for coverage benefits at ☎ 1-800-MEDICARE

National Hospice and Palliative Care Organization www.nhpco.org This association of hospices and hospice workers has information on living wills and on choosing a hospice or palliative care provider. ☎ 1-800-658-8898

West Virginia Center for End-of-Life Care www.hsc.wvu.edu/chel/wvi/ The Web site has information about grief, pain management and advance directives for patients and their families. ☎ 1-877-209-8086

Your State Attorney General Your state attorney general’s Web site has helpful information about the laws in your state. For example, Maryland’s site provides a sample living will at www.oag.state.md.us/Healthpol/adirective.pdf You can find your state at www.naag.org/ag/full_ag_table.php. ☎ (202)326-6000



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