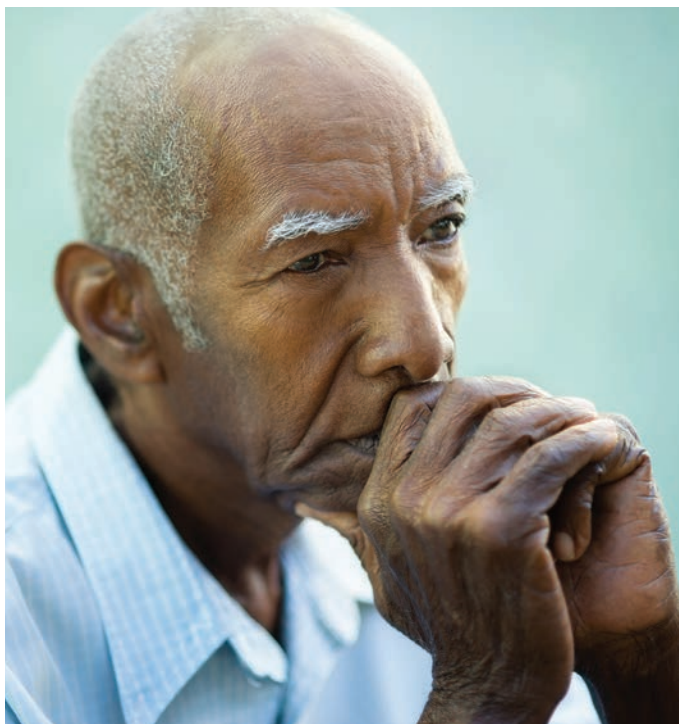


WHEN STOPPING DIALYSIS TREATMENT IS YOUR CHOICE

*A Guide for Patients
and Their Families*



National
Kidney
Foundation™

www.kidney.org

National Kidney Foundation's Kidney Disease Outcomes Quality Initiative

Did you know that the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (NKF-KDOQI™) offers guidelines and commentaries that help your doctor and healthcare team make important decisions about your medical treatment? The information in this booklet is based on those recommended guidelines.

Stages of Kidney Disease

There are 5 stages of kidney disease. They are shown in the table below. Your doctor determines your stage of kidney disease, based on the presence of kidney damage and your glomerular filtration rate (GFR), which is a measure of your level of kidney function. Your treatment is based on your stage of kidney disease. Speak to your doctor if you have any questions about your stage of kidney disease or your treatment.

STAGES OF KIDNEY DISEASE		
Stage	Description	Glomerular Filtration Rate (GFR)*
1	Kidney damage (e.g., protein in the urine) with normal GFR	90 or above
2	Kidney damage with mild decrease in GFR	60 to 89
3a	Moderate decrease in GFR	45 to 59
3b	Moderate decrease in GFR	30 to 44
4	Severe reduction in GFR	15 to 29
5	Kidney failure	Less than 15

*Your GFR number tells your doctor how much kidney function you have. As chronic kidney disease progresses, your GFR number decreases.

TABLE OF CONTENTS

Can I really stop dialysis treatment if I want to?	5
If I decide to stop dialysis, how will my healthcare team respond?	5
How do I discuss my decision with my family and friends?	5
Can any changes be made in my treatment that might improve my quality of life?	6
Will I be asked to speak to a mental health professional?	6
Is stopping dialysis considered suicide?	6
How long will I live if I choose to stop dialysis?	7
What should I expect after stopping dialysis?	7
What type of food and drink could I have?	7
Will my healthcare team continue to help me?	8
Can I choose where I die?	8
Can I get hospice care?	9
If I choose to die at home, can I get a home healthcare worker to help my loved ones?	9
Will I still be covered by Medicare and/or my private medical insurance if I stop treatment?	9
If I change my mind, can I go back on dialysis?	10
Can I name someone to make decisions for me if I am not able to act on my own behalf?	10
Is there anything else I should know about stopping dialysis?	12
What if I have more questions?	14
Glossary	14

There may come a time when you feel you want to stop dialysis treatment. You may feel that dialysis is no longer helping to maintain or improve your quality of life. If this happens, you have the right to stop dialysis. However, before you decide, it is important that you discuss it carefully with your loved ones and your healthcare team. This booklet answers the questions that are most commonly asked about stopping dialysis. If you still have questions after reading this booklet, you should speak with your doctor and other members of your healthcare team.



Can I really stop dialysis treatment if I want to?

Yes. Dialysis patients are allowed to stop their treatment, if they wish. You should discuss your reasons for stopping treatment with your doctor, other members of your healthcare team, and your loved ones before making a final decision.

If I decide to stop dialysis, how will my healthcare team respond?

The members of your healthcare team will want to know why you want to stop dialysis (for example failing health, treatment problems, depression) and see if they can make improvements that could affect your decision. Your doctor, social worker, and nurse may want to speak with you and will help you talk about your feelings.

How do I discuss my decision with my family and friends?

Many people find it difficult to talk about stopping treatment and they worry about how others will feel and react. Although you may find it hard at first, it is best to discuss your feelings openly with your loved ones. You may wish to have members of your healthcare team present during this talk.

Can any changes be made in my treatment that might improve my quality of life?

If you are thinking about stopping dialysis because of problems with your treatment, or due to other health problems, your doctor might be able to make changes to your treatment plan or give you some options, other than stopping treatment, that could help you.

Will I be asked to speak to a mental health professional?

If your healthcare team is concerned that you want to stop dialysis as a result of a condition such as depression, they may ask you to speak with a psychiatrist, social worker, or other counseling professional. These talks will help your healthcare team understand why you want to stop treatment. It will also help your loved ones know that you understand what will happen if you stop dialysis.

Is stopping dialysis considered suicide?

No. Many religions believe people have the right to stop medical treatment, including dialysis, if they feel it is no longer improving their quality of life. You may wish to speak with your

religious adviser if you have questions about this.

How long will I live if I choose to stop dialysis?

This varies from person to person. People who stop dialysis may live anywhere from one day to several weeks, depending on the amount of kidney function they have left and their overall condition.

What should I expect after stopping dialysis?

Without dialysis treatment, fluid and toxic wastes will build up in your body, making you feel more and more drowsy. The fluid buildup can make it harder for you to breathe, but your doctor can give you medicines called *diuretics* or a treatment called *ultrafiltration* to remove fluid and make breathing easier for you. Your doctor may also tell you to limit your intake of salt and fluids to lower fluid weight gain. Pain medications can be given if you feel any discomfort.

What type of food and drink could I have?

Typically, there is no reason for you to continue following your kidney diet if you end dialysis. Limiting your fluid

and salt intake can help lessen any discomfort you have due to shortness of breath. Your doctor and dietitian can answer any questions you have about your diet.

Will my healthcare team continue to help me?

Yes. Your team will remain available to you and your loved ones. Your doctor and nurse can tell you about the type of care you might need, and your social worker can help you arrange for care, as well as give emotional support to you and your loved ones. Your team will also talk to you about any other worries you might have.

Can I choose where I die?

Your wishes about where you want to die will be followed as closely as possible. Many people choose to die at home, where they feel more comfortable. If you choose to be at home, your social worker can help you and your family make any special arrangements for your care. A nursing home may be another choice for some people. A hospital admission may not be possible. This will depend on your insurance coverage and your overall illness. Your healthcare team can help you decide if the hospital is an option for you.

Can I get hospice care?

If you choose to stop dialysis, you will be considered to be in a failing state and you are, therefore, able to have hospice care. Hospice services may include nursing care, social work, and chaplain services. The type of hospice care available may be either a home hospice program or a hospice facility. Your social worker can help you and your loved ones plan for hospice care.

If I choose to die at home, can I get a home healthcare worker to help my loved ones?

The types of in-home services you may have will depend on your insurance coverage. If you are in a home hospice program, a home health aide may be available to help. If your insurance does not cover a home health aide, your social worker can usually help you arrange for one if your loved ones wish to pay for these services.

Will I still be covered by Medicare and/or my private medical insurance if I stop treatment?

Your Medicare coverage will not end, even if you decide to stop dialysis. It is important that you and your family speak with your doctor about the type

of care you will need once treatment is stopped. You can then check on whether your insurance will cover this care.

If I change my mind, can I go back on dialysis?

You may go back on dialysis if you change your mind. If you have missed several treatments, you may have some discomfort when you first start dialysis again. You should discuss the possibility of returning to dialysis with your doctor before you make your decision.

Can I name someone to make decisions for me if I am not able to act on my own behalf?

You can ask someone close to you (a spouse, child, or close friend) to make medical decisions for you—such as stopping dialysis—in the event that you are no longer able to decide for yourself.

This is done by filling out a form called a *healthcare proxy* or a *durable healthcare power of attorney*. The person you name to make medical decisions for you is called a *surrogate*. It is important to make sure the person is willing to act on your behalf and that he or she knows your short-

and long-term goals, values, and what treatments you would or would not want to have if you are not able to speak for yourself. It is helpful if you complete a form called an *advance directive* or a *treatment-specific living will*. These are papers that give your surrogate clear directions about your wishes regarding stopping dialysis or other medical treatments.

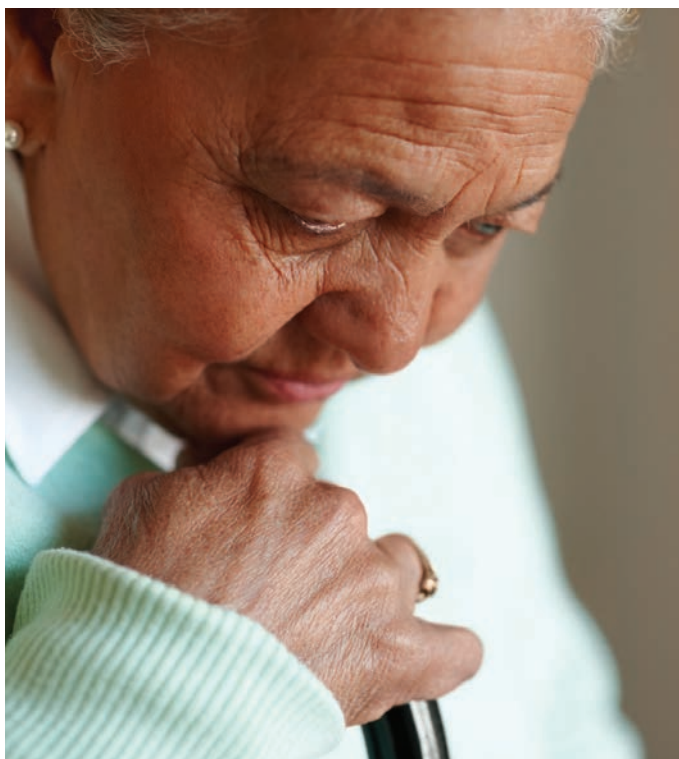
The role and responsibilities of the surrogate, as well as the types of decisions the surrogate may make, vary from state to state. Generally, the surrogate must follow your wishes. For more information about naming a surrogate and about the laws in your state, speak with an attorney or the social worker on your healthcare team. To obtain copies of the forms used in your state, contact your local or state bar association or The National Hospice & Palliative Care Organization, 1731 King Street, Suite 100, Alexandria, VA 22314; 800.658.8898; **www.nhpco.org** (also see the National Kidney Foundation's booklet *Advance Directives: A Guide for Patients and Their Families*).

Is there anything else I should know about stopping dialysis?

If you decide to stop your dialysis treatment, you or your surrogate may want to make sure the following items are in order:

- Your will.
- A signed advance directive (living will, durable healthcare power of attorney, or healthcare proxy) that complies with your state's laws.
- A durable power of attorney naming someone to act on your behalf in all nonmedical matters (e.g., legal, financial, banking, and business matters). Your power of attorney must be “durable” in order for it to stay in effect even if you become unable to make your own decisions or if you die.
- A list which includes information about the location of your bank, brokerage, and any other financial institutions with which you do business; any stock and bond holdings; any real estate and business records; copies of your medical and other insurance policies; and any paperwork pertaining to pension plans and other legal papers.

- Contact information for your family, friends, and other loved ones, as well as your attorney, accountant, and any other business associates, who should be notified of your death or who may have information that will be helpful in dealing with estate affairs.
- A statement about your preferences for funeral or memorial services, burial or cremation instructions, and decisions about organ and tissue donation.



What if I have more questions?

You should speak to your doctor and other members of your healthcare team if you have more questions or concerns. Additional information about living wills, healthcare proxies, or durable healthcare powers of attorney can be obtained from your attorney, your state or local bar association, or by contacting The National Hospice and Palliative Care Organization at **www.nhpc.org**. You can also contact the Kidney End of Life Coalition; **www.kidneyeol.org**; 866.651.6272.

You can also call the NKF Cares Patient Help Line toll-free at **855.NKF.CARES** (855.653.2273).

Glossary

The following is a list of terms that are found in this booklet:

Advance directive: Legal papers that state your decisions about end-of-life care ahead of time.

Diuretics: A medicine to get rid of excess fluid in your body.

Durable healthcare power of attorney: A legal paper that lets someone other than you make decisions about your health and medical care.

Healthcare proxy: A legal paper that lets someone other than you make decisions about your medical care.

Healthcare team: A group of healthcare workers including your doctor, nurse, dietitian, and social worker.

Hospice care: Care for those who are dying. Helps with physical, emotional, and spiritual needs.

Quality of life: General well-being.

Surrogate: The person you choose to make medical decisions for you.

Treatment-specific living will: A legal paper that states your decisions about end-of-life care ahead of time.

Ultrafiltration: A treatment to remove extra fluid from the body.

The **National Kidney Foundation** is the leading organization in the U.S. dedicated to the awareness, prevention, and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of Americans at risk.

Help fight kidney disease.

Learn more at **www.kidney.org**



National
Kidney
Foundation™

30 East 33rd Street
New York, NY 10016
800.622.9010



Awareness. Prevention. Treatment.
