

WHEN STOPPING DIALYSIS TREATMENT IS YOUR CHOICE

A Guide for Patients and Their Families



National
Kidney
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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.

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There may come a time when you feel you want to discontinue dialysis treatment. You may feel that dialysis is no longer maintaining or improving your quality of life. If this occurs, it is important to know that you have the right to make the decision to stop dialysis. However, before making this decision, it is important that you discuss it carefully with your loved ones and your healthcare team. This booklet has been written to answer the questions that are most commonly asked about withdrawing from dialysis. If you still have questions after reading the booklet, you should speak with your doctor and the 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 so desire. You are encouraged to 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 have a clear understanding of why you made this decision (for example, worsening health, specific treatment problems, depression) in order for them to determine if there are any improvements that can be made that could affect your decision. Your doctor, social worker and nurse may all want to speak with you and will encourage you to talk openly 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, the best approach is to discuss your feelings openly with your loved ones. You may wish to have members of your healthcare team present during this discussion.

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

If you are thinking about stopping dialysis because of specific issues with your treatment, or due to other medical problems, your doctor might be able to make changes to your treatment or present you with some options, short of ending treatment, that could improve your situation.

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

If members of your healthcare team are concerned that your decision to stop dialysis is the result of a condition such as depression, they may ask you to speak with a psychiatrist, social worker, or other counseling professional. These conversations will help your healthcare team to understand why you're making such a decision. It will also help reassure those around you that you fully understand the impact of stopping dialysis.

Is stopping dialysis considered suicide?

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

What should I expect after stopping dialysis?

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



What type of food and drink could I have?

Typically, there is no reason for you to continue to follow your kidney diet if you end dialysis. Limiting your fluid and salt intake can help lessen any discomfort you experience due to shortness of breath. Your doctor and dietitian can answer any specific questions you may have about your diet.

Will my healthcare team continue to help me?

Absolutely. Your team will remain available to you and your loved ones. Your doctor and primary nurse can advise you about the type of care you might need, and your social worker can help you arrange for care, as well as provide emotional support to you and your loved ones. Your team should also be available to talk to you and your loved ones about any other concerns you might have.

Can I choose where I die?

Your wishes about where you want to die will be honored as much as possible. Many people choose to die at home, in familiar surroundings where they feel more comfortable. If you choose this option, your social worker can assist you and your family in making any special arrangements for your care at home. A nursing home may be another option for some patients. A hospital admission may not be an option. This will depend on the nature of your insurance coverage and your overall medical condition. Your healthcare team can help you decide if hospitalization is an option for you.

Can I get hospice care?

If you choose to stop dialysis, you are considered to be in a terminal state and you are, therefore, eligible for 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 make arrangements 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 that are available to you will depend on your insurance coverage. If you are in a home hospice program, a home health aide may be available to assist. If your insurance does not cover a home health aide, and you and your loved ones wish to pay privately for these services, your social worker can usually assist with the arrangements.

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. Once this is decided, you can 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 make these decisions for yourself. This is done by filling out a form called a health care proxy or a durable health care 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 were 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 documents 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 and Palliative Care Organization, 1700 Diagonal Road, Ste. 625, Alexandria, VA 22314, 800.658.8898 or 703.837.1500, **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 health care 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.
- An inventory 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 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.
- A written statement or a video- or audio-taped message to family members and other loved ones, business associates and friends.



What if I have more questions?

You should speak to your doctor if you have more questions or concerns about medical issues. 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 (see page 9 for contact information).

Fueled by passion and urgency, NKF is a lifeline for all people affected by kidney disease. As pioneers of scientific research and innovation, NKF focuses on the whole patient through the lens of kidney health. Relentless in our work, we enhance lives through action, education, and accelerating change.



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