

# Advance Care Planning: Should I Stop Kidney Dialysis?

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

## Advance Care Planning: Should I Stop Kidney Dialysis?

Here's a record of your answers. You can use it to talk with your doctor or loved ones about your decision.

1. Get the facts
2. Compare your options
3. What matters most to you?
4. Where are you leaning now?
5. What else do you need to make your decision?

### 1. Get the Facts

#### Your options

- Continue kidney dialysis, which will allow you to live longer.
- Stop kidney dialysis, which will allow death to occur naturally.

Before you decide to stop kidney dialysis, talk with your doctor about your chances of getting a kidney transplant.

#### Key points to remember

- You may feel better on dialysis than you did before you started treatment. But if you have side effects (such as appetite changes), or if you start to have other problems, you may feel that continuing dialysis is too hard.
- If dialysis lets you do the activities you enjoyed before, you may feel that it hasn't changed your daily life that much. You may feel this way even if you can't do all of your old activities. Or you may feel that your quality of life on dialysis is not good.
- Your diagnosis of kidney failure may force you to rethink your goals for your future. If you feel that your life has been rewarding and that you have met many goals, you may feel okay about stopping dialysis. But if you have goals you have not yet met, you may want to continue dialysis.
- Most people die within weeks of stopping dialysis. If you choose to stop dialysis, you should be ready to put your personal, financial, and legal affairs in order. You may want to continue dialysis if you aren't ready to face these issues.
- Clearly state your wishes to your family. If you decide to stop treatment, will your family understand your reasons? Do they support your decision to continue (or stop) treatment?

#### FAQs

#### What should you know about stopping dialysis?

Dialysis is a process that filters waste from your blood when your kidneys can no longer do the job. When you have kidney failure, you may have either hemodialysis or peritoneal dialysis.

In the United States, 25 out of 100 people with kidney failure end up choosing to stop dialysis. This means that 75 out of 100 choose to continue dialysis.

In a study of people who chose to stop dialysis, 85 out of 100 were judged by their loved ones or caregivers to have had a

good death. About half of the people in the study had pain on their last day of life, and of those people, the pain was thought to be severe in only a small number of them.

Most people who stop dialysis die within a few weeks. As death nears, you may:

- **Feel sleepy and weak.** You may sleep more and need help with walking, bathing, and using the toilet.
- **Have changes in breathing.** You may have periods of rapid breathing and periods of no breathing.
- **See and hear differently.** You may see or hear things that no one else does.
- **Be less hungry.** You may eat and drink less than normal.
- **See changes in your urine and stool.** Your urine may become dark brown or dark red, and stools may be hard to pass. You may stop making urine.
- **Feel temperature changes.** You may sometimes feel very hot and at other times feel very cold.
- **Lose interest in daily life.** You may lose interest in the outside world and the details of daily life, including the day or time.

You may have other changes related to kidney failure. Talk with your doctor about what to expect as your death nears. A dialysis centre can also help with end-of-life planning.

Whether you decide to continue or stop dialysis treatment, take the time to let others know your wishes about your care. You can use a legal document called an advance care plan to make sure that you get the medical treatment you want.

### **What are the benefits of stopping dialysis?**

If you have been getting regular dialysis, and if a kidney transplant is not an option for you, stopping dialysis may:

- Give you more time each day to spend with friends and family instead of going to regular dialysis treatments.
- Allow you to eat and drink what you want in the time you have left. You may welcome this if your diet has been limited while you have been on dialysis.
- Reduce problems that come with regular dialysis, such as infection or clotting of the dialysis access.
- Encourage you to talk with your loved ones about end-of-life goals and wishes.

If you decide to stop dialysis, health professionals who provide end-of-life care can help you have the highest quality of life possible. This may be done through hospice palliative care. Hospice palliative care offers the chance to think about personal goals, relieve pain, and take care of your emotional and spiritual needs.

### **What are the risks of stopping dialysis?**

Most people die within a few weeks after they stop dialysis. Stopping dialysis may force you to think about emotional issues, such as broken relationships, money problems, or a fear of dying. Facing these issues may help you and your family work out problems. But thinking about and dealing with them can be very hard.

If you choose to stop kidney dialysis, you may need the support of a team of end-of-life care professionals, such as a hospice palliative care team. But you may not want to have a lot of people involved in your care. If this is the case, allowing others to help may be hard for you.

### **What are the risks of continuing dialysis?**

Dialysis will keep you alive, but it is not a cure for kidney failure. Dialysis affects:

- **What you eat.** If you are on peritoneal dialysis, you may need to eat a high-protein diet. If you are on hemodialysis, you may need to eat less salt and limit foods with potassium and phosphorus. You may also need to drink less water and other fluids if you have a low level of sodium in your blood.
- **Your time.** Dialysis affects how you spend your time. Your activities must be scheduled around your treatment. Hemodialysis must be done 3 times a week for 3 to 4 hours each time. Peritoneal dialysis must be done daily.
- **Your freedom.** You may become dependent on others to help with your dialysis treatment. If you are getting hemodialysis at a dialysis centre, you may have many health professionals working with you to provide your treatment. You may need family or friends to take you to or help you with your treatments.
- **Travel.** When you're on dialysis, travel needs to be carefully planned. If you are on hemodialysis and plan to travel, you will need to find a dialysis centre away from home.

Problems linked to peritoneal dialysis may include:

- Infection of the skin (cellulitis) or the stomach wall (peritonitis).
- Low levels of protein in the blood. This can lead to fluid retention and swelling.
- Scar tissue around the dialysis access that can lead to a bowel blockage, but this is rare. Other rare problems include hypothyroidism, seizures, high blood sugar, and hernias.

Problems linked to hemodialysis may include:

- Low blood pressure.
- An abnormal heart rhythm.
- Fever.
- Allergic reactions.
- Bleeding problems caused by the blood-thinning medicines.
- Infection or clotting of the dialysis access.

## 2. Compare your options

	<b>Continue kidney dialysis</b>	<b>Stop kidney dialysis</b>
<b>What is usually involved?</b>	<ul style="list-style-type: none"> <li>• You continue to get dialysis treatments every day or several times a week.</li> </ul>	<ul style="list-style-type: none"> <li>• Your body will start to shut down, and you will experience normal changes from the dying process.</li> <li>• You may need the support of a hospice palliative care team.</li> </ul>
<b>What are the benefits?</b>	<ul style="list-style-type: none"> <li>• Dialysis keeps you alive longer so you don't have to deal with dying yet.</li> <li>• You may feel better physically while you're on dialysis than you did before dialysis.</li> <li>• You may be able to return to normal activities.</li> <li>• Treatment may allow you to meet goals you have set for yourself.</li> </ul>	<ul style="list-style-type: none"> <li>• You no longer have side effects or problems from dialysis.</li> <li>• You no longer need to limit what you eat and drink.</li> <li>• The time you have left is your own to spend with friends and family, not on dialysis treatments.</li> <li>• Your quality of life may be better.</li> </ul>
<b>What are the risks and side effects?</b>	<ul style="list-style-type: none"> <li>• Dialysis won't cure you.</li> <li>• Dialysis may involve frequent travel to and from where you have treatments.</li> <li>• Dialysis takes a lot of time and can affect your quality of life.</li> <li>• Dialysis has risks, including infection, low blood sugar, allergic reactions, fever, abnormal heart rhythm, and low levels of protein.</li> </ul>	<ul style="list-style-type: none"> <li>• You will probably die within a few weeks.</li> <li>• As you near death, you'll face end-of-life issues that may be hard to deal with.</li> </ul>

### Personal stories

#### Personal stories about kidney dialysis

These stories are based on information gathered from health professionals and consumers. They may be helpful as you make important health decisions.

"I've been on regular hemodialysis for the past 5 years. When I first started, I felt good and my activities were not limited. I was diagnosed with heart failure 2 years ago. Since then, my physical health has deteriorated. My doctor and I have discussed the possibility of kidney transplant, but because of my deteriorating health, we feel this would not be a good option. My preference is to stop dialysis and receive hospice palliative care. I'm tired of not feeling good and want to die comfortably."

— Georgia, age 81

"I've had family members receive dialysis because of kidney failure. In fact, my aunt told me I would hate dialysis because she saw how miserable my grandmother was when she received dialysis over 30 years ago. Dialysis has changed so much since then. I started hemodialysis 4 years ago and have felt fine. In fact, I feel better than I did before starting dialysis! There certainly are diet changes, and sometimes my dialysis schedule is not convenient. But I feel these are small prices to pay for feeling better. I'm awaiting a kidney transplant. Although I look forward to the day when I won't need dialysis, I wouldn't consider stopping."

— Marco, age 45

"I have diabetes that has been very difficult to control. I received a kidney transplant 20 years ago. Two years ago, my kidneys began to fail and I started kidney dialysis. Even with dialysis, I have not felt good. Even with another kidney transplant, there is no guarantee that I will feel good again. I have had problems with fluid retention and my appetite is poor. I am tired of diet restrictions and the limitations of dialysis. I have discussed my wish to stop dialysis with my family and doctor, and they have been supportive."

— Max, age 49

"I started dialysis 3 years ago when my chronic glomerulonephritis progressed to kidney failure. Even on daily peritoneal dialysis, I lead an active and productive life. I work full time and travel a lot. Even though dialysis requires organization, I don't feel that it negatively impacts my life. I feel good most of the time. At this point in my life, I wouldn't consider stopping dialysis."

— Debbie, age 36

### 3. What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

Reasons to stop kidney dialysis

Reasons to continue dialysis

I'm ready to face my death and let my illness take its course.

I'm not ready to die.

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More important

Equally important

More important

I'm not happy with my quality of life.

I feel that my quality of life is okay right now.

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More important

Equally important

More important

Meeting my remaining life goals is not a priority for me

Meeting my remaining life goals is not a priority for me.

I feel that dialysis can give me enough time to meet my remaining goals.

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- More important
- Equally important
- More important

I don't want to keep relying on others for help with my dialysis treatments.

It doesn't bother me to rely on others for help.

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- More important
- Equally important
- More important

My other important reasons:

My other important reasons:


- More important
- Equally important
- More important

#### 4. Where are you leaning now?

Now that you've thought about the facts and your feelings, you may have a general idea of where you stand on this decision. Show which way you are leaning right now.

Stopping dialysis

Continuing dialysis

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- Leaning toward
- Undecided
- Leaning toward

#### 5. What else do you need to make your decision?

##### Check the facts

1. In some cases, stopping dialysis could improve my quality of life.

- True
- False
- I'm not sure

You're right. If you start to have side effects or other problems, you may feel that continuing is too hard. Stopping may make you feel better.

2. After I stop dialysis, I will have several months to get ready for my life to end.

- True
- **False**
- I'm not sure

You're right. Most people die within weeks of stopping dialysis. You should be ready to put your personal, financial, and legal affairs in order.

3. If I decide to stop dialysis, it's important that my family understand my reasons.

- **True**
- False
- I'm not sure

You're right. It's important to clearly state your wishes to your family, so that they understand your reasons for stopping or continuing dialysis.

**Decide what's next**

1. Do you understand the options available to you?

- Yes
- No

2. Are you clear about which benefits and side effects matter most to you?

- Yes
- No

3. Do you have enough support and advice from others to make a choice?

- Yes
- No

**Certainty**

1. How sure do you feel right now about your decision?

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Not sure at all  
 Somewhat sure  
 Very sure

2. Check what you need to do before you make this decision.

- I'm ready to take action.
- I want to discuss the options with others.
- I want to learn more about my options.

3. Use the following space to list questions, concerns, and next steps.

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**Credits**

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References

Citations

1. Cohen LM, et al. (2003). Practical considerations in dialysis withdrawal. JAMA, 289(16): 2113-2119.

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Note: The "printer friendly" document will not contain all the information available in the online document some information (e.g. cross-references to other topics, definitions or medical illustrations) is only available in the online version.

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