

# Hard Choices About Dialysis



DECISION AID FOR SERIOUSLY ILL PATIENTS

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# Introduction

Many people face hard choices about health care. This booklet is for seriously ill patients who are facing a choice about using dialysis. It explains kidney failure and lists treatment options for these patients.

You or someone you know may be seriously ill and in kidney failure. You may be on dialysis. You might be thinking of stopping or changing treatment. Or, you might not be on dialysis and wonder if it is right for you.

In any case, use this booklet as a decision aid. Sections are provided to help you explore your feelings about treatments and the illness. This can help guide talks with doctors, caregivers, and family.

You have a right to know about your treatment options. You have a right to choose your care. Call us if you need help. We are your care team. We are here to support you.

It is important for all seriously ill kidney failure patients and their families to talk about the use of life-prolonging treatments like dialysis.

## Setting Your Goals of Care

Set your goals of care before choosing a treatment. This is important for kidney failure patients. Possible goals of medical care:

- **Cure.** Most health care is focused on the cure. We get sick. The doctor treats us. We hope to be cured.
- **Stabilize.** There is no cure for some health problems. Treatments (like dialysis) may “stabilize” the disease — or keep it from getting worse for a while. In this case we might choose treatment even though it won’t cure us.
- **Prepare for comfort at the end of life.** Some health problems cannot be cured or stabilized. End-of-life care may be best. This goal of care takes planning. We should all try to talk about this choice as early as we can.

Goals can be combined. An end-stage patient might cure a case of pneumonia and prepare for the end of life.

A care plan can be based on the goals of care. Talk to doctors and family about your goals of care often. Goals can change over time.

When setting goals of care, ask,  
“What outcome can we likely expect  
from treatment, given the patient’s  
current condition?”

# About Kidney Failure

The kidneys are 2 bean-shaped organs. They filter waste, salt, and extra water from the blood. These are all passed out of the body through urine. Kidneys also help with other body functions. They play a big part in keeping us healthy.

Kidney failure is when there is less than 15% of kidney function. This causes waste to build up in the blood.

Symptoms of kidney failure are:

- Sleep problems, feeling tired
- Feeling weak/worn out
- Numbness
- Confusion, trouble with focus/memory
- Headaches
- Nausea, vomiting
- Weight loss
- Shortness of breath
- Swelling or stiffness
- Pain
- Itching
- Problems with blood pressure
- Changes in urine

Kidney failure often happens slowly over time. This is known as chronic kidney disease. It can be caused by high blood sugar (diabetes), high blood pressure, other diseases, or long-term drug use.

Chronic kidney disease can lead to ESRD, or end-stage renal disease. (“Renal” is a word doctors use for “kidney.”) **There is no cure for ESRD.** Most ESRD patients will have it for the rest of their lives.

Kidney failure can also happen quickly. This is known as acute kidney injury or acute kidney failure. It can be caused by kidney damage, low blood pressure, or blocked urine flow. Some of these patients may get better.

# About Dialysis

Dialysis (dahy-**al-uh**-sis) is widely used to treat kidney failure. The process filters (cleans) waste from the blood. This can ease some symptoms of kidney failure.

There are 2 types of dialysis. Peritoneal dialysis filters blood inside the body with the lining of the patient's belly. Hemodialysis filters blood outside the body with a machine. This is by far the most common type of dialysis.

Dialysis may help some patients live longer and feel better. This depends on the patient's age and if they have other health problems. **Dialysis is not a cure.** One day patients will need to shift to other treatments.

Some patients might be able to try dialysis for a while. This is called a "time-limited trial." The patient can stay on dialysis if it seems to help. The patient can stop if it is not helping or making them feel worse.

## Dialysis and seriously ill patients

**Some patients might not live longer *or* better with dialysis.**

**They include:**

- Seriously ill patients (who have a high chance of dying within a year from the illness and low quality of life)
- Older patients (65 years and over)
- Frail patients (tired, weak, not active, or losing weight)
- Patients who need help with daily care (feeding, bathing, dressing, walking)
- Patients who have more than one major health problem

These patients should also keep in mind:

- Dialysis can put some seriously ill patients in worse physical shape.
- Treatments may add stress for the patient and family.
- Dialysis can lead to hospital or intensive care stays for frail, older patients in the last year of life.
- Heart disease or infection is a common cause of death for many dialysis patients.
- Many older end-stage patients decide the burdens of dialysis are too great. They choose to stop treatment and prepare for the end of life.
- End-stage kidney failure patients live an average of 8 days after stopping dialysis.
- Stopping dialysis may be a lot harder emotionally than not starting it for some patients.

“Many dialysis patients are willing to trade off quantity of life for quality of life. In the U.S., not many doctors recommend conservative management without dialysis. But this is often the best option for seriously ill patients who are concerned about the quality of their lives. Dialysis is most likely to increase suffering for these patients.”

— Alvin H. Moss, MD, FACP, FAAHPM  
Director, Center for Health Ethics & Law, West Virginia University,  
Nephrology, Medicine




# Treatment Options for Seriously Ill Kidney Failure Patients

Most seriously ill kidney failure patients have 2 treatment options: **hemodialysis** or **conservative management**. This section describes these treatments.

Kidney transplant may be an option for some healthier patients. But it is not often suggested for seriously ill patients. Peritoneal dialysis may also be right for certain patients, but is used less often.

Payment is also part of treatment decisions for most patients. Medicare and insurance should cover the costs of these treatments if they are ordered by a doctor. **Ask your doctor about all treatment and payment options in your case.**

To use this section to make a decision between hemodialysis and conservative management:

- 1) **Read about each treatment.** Ask your doctor if you have any questions.
- 2) **Mark how you feel** about each part of the treatment. In the “What to expect” sections, mark the face that is closest to how you feel:
  -  I’m OK with this
  -  This doesn’t matter to me
  -  I’m NOT OK with this
- 3) **If you are OK** with most of the treatment, it might be a good option for you.
- 4) **If you are NOT OK** with most of the treatment, you may need to think about other options.



























## Hemodialysis

This type of dialysis is often done at a treatment center. Some centers offer at-home treatment for certain patients.

Ask your doctor about the options in your case.

What to expect: (Mark the face that is closest to how you feel.)













	I'm OK with this	This doesn't matter to me	I'm NOT OK with this
<ul style="list-style-type: none"> <li>Blood is pumped out of the patient. A machine (a dialyzer) filters waste. The cleaned blood is pumped back into the patient.</li> </ul>			
<ul style="list-style-type: none"> <li>The machine connects to the patient's blood vessels. A needle is inserted in an access. The access is made by joining an artery and a vein in the arm (fistula). Sometimes a soft tube is used in the arm or neck (graft or catheter).</li> </ul>			
<ul style="list-style-type: none"> <li>Surgery is needed to make the access. It must heal before it can be used. The access may look like a large lump (or lumps) under the skin.</li> </ul>			
<ul style="list-style-type: none"> <li>The access must be cared for. The patient must watch for signs of blood clot or infection.</li> </ul>			
<ul style="list-style-type: none"> <li>Treatments are done about 3 times a week. Each session takes about 4 hours.</li> </ul>			
<ul style="list-style-type: none"> <li>Some patients may need to limit (or stop) work, travel, or other activities.</li> </ul>			
<ul style="list-style-type: none"> <li>The doctor may also prescribe medicine and/or lifestyle changes (exercise, changes to diet, or quitting smoking/drinking).</li> </ul>			
<ul style="list-style-type: none"> <li>The patient may feel worse on treatment days. Symptoms of hemodialysis include nausea, cramps, sweating, fast heartbeat, feeling dizzy, and feeling wiped out.</li> </ul>			

## Hemodialysis (continued)













What to expect: (Mark the face that is closest to how you feel.)

I'm OK with this	This doesn't matter to me	I'm NOT OK with this
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### If treatment is done at a dialysis center:

<ul style="list-style-type: none"> <li>The patient must travel to and from the center for each session.</li> </ul>			
<ul style="list-style-type: none"> <li>The center schedules sessions at fixed times. The patient has less control of the schedule.</li> </ul>			
<ul style="list-style-type: none"> <li>Trained staff is there to help the patient.</li> </ul>			
<ul style="list-style-type: none"> <li>The patient has a chance to meet and talk to other patients.</li> </ul>			

























### If treatment is done at home (not for all patients):

<ul style="list-style-type: none"> <li>The patient does not need to travel for treatment.</li> </ul>			
<ul style="list-style-type: none"> <li>The patient has more control of the schedule. But it is up to the patient to make sure all treatments are done.</li> </ul>			
<ul style="list-style-type: none"> <li>The patient <u>and</u> a caregiver must be trained on how to do the treatments. This includes inserting needles in the access. Caregivers will spend a lot of time helping with treatments.</li> </ul>			
<ul style="list-style-type: none"> <li>The patient must store the machine and supplies at home.</li> </ul>			

## Conservative management

This option treats symptoms of kidney failure without dialysis or transplant.

What to expect: (Mark the face that is closest to how you feel.)

	I'm OK with this	This doesn't matter to me	I'm NOT OK with this
<ul style="list-style-type: none"> <li>Treatment keeps what kidney function is left for as long as possible. The doctor may prescribe medicine, lifestyle changes (exercise, changes to diet, or quitting smoking/drinking), and other therapies as needed.</li> </ul>			
<ul style="list-style-type: none"> <li>Care teams will treat symptoms of kidney failure (see page 3). The focus is on comfort and quality of life.</li> </ul>			
<ul style="list-style-type: none"> <li>Care teams give emotional, social, and spiritual support to the patient and family.</li> </ul>			
<ul style="list-style-type: none"> <li>Dialysis and transplant are not used. Hospital stays are avoided.</li> </ul>			
<ul style="list-style-type: none"> <li>Most care is given where the patient lives. The patient spends less time in doctors' offices or treatment centers. Patients can spend more time on what matters most to them.</li> </ul>			
<ul style="list-style-type: none"> <li>Patients who are not in end stage could live for a year or more with this treatment.</li> </ul>			
<ul style="list-style-type: none"> <li>Most patients choosing this treatment will not live as long as those who go on dialysis.</li> </ul>			
<ul style="list-style-type: none"> <li>The care team can help shift to hospice care if that is the patient's goal.</li> </ul>			

# More Support for Decision Making

Most healthcare decisions are based on how the patient feels about their illness and what they value most. Fill out this page. Share your thoughts with doctors, caregivers, and family. **Ask your doctor to answer questions 1–3. Then answer questions 4–6 yourself. (If you are deciding for someone, try to answer the way the patient would.)**

1) What condition will I most likely be in as my illness gets worse?

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2) What will dialysis most likely do for me?

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3) What will conservative management most likely do for me?

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4) What do you think about the condition you are in now?

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5) What do you think about the condition you will likely be in as your kidney failure gets worse?

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6) What is most important to you right now?

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## Palliative Care

Palliative care (also called “comfort care” or “supportive care”) is physical, emotional, and spiritual care. It is for all patients who have symptoms that disrupt daily life. It can be given at any stage of an illness. It can be given with dialysis. In some cases, palliative care can help dialysis patients get through treatment. Care teams can work with the patient’s doctor.

Palliative care is well suited for kidney failure patients. Kidney failure affects patients physically, emotionally, and spiritually. Loved ones may also be tired and stressed. Care teams can manage symptoms, make care plans, and give support to the patient and family.

You, your doctor, or a loved one can suggest palliative care. Insurance, Medicare, and Medicaid may cover costs if care is ordered by a doctor. Let us know if you have questions about palliative care.

## Hospice Care

Hospice care is physical, emotional, and spiritual care. It is for patients in the last phase of life. Treatments like dialysis are stopped in most cases. Comfort and quality of life are the goals.

Hospice care is well suited for end-stage kidney failure patients. Care teams manage symptoms, make care plans, and give support to the patient and family.

You, your doctor, or a loved one can suggest hospice care. The patient’s doctor and a hospice doctor decide if the person can be admitted. Insurance, Medicare, and Medicaid cover costs if the patient qualifies. Let us know if you have questions about hospice care.

# Final Thoughts

Choosing a treatment can be an emotional and spiritual journey. A healthcare chaplain shares his thoughts below. His thoughts are based on more than 30 years of helping patients with these hard choices.

“Change is part of each phase of life. Having a serious illness like kidney failure is a big change. It reminds us that our lives will not last forever. This could be a time of growth. Both patients and families can learn to let go and let life be.

“Saying ‘no’ to treatments that will not help is being able to let go. **Letting go is not giving up.** It is knowing there is a time when life will end. It is preparing for a more natural, peaceful death.

“Families must always ask, ‘Am I choosing a treatment plan based on *my* feelings? Or is this what the patient would want?’ Working through this can be tough. It’s hard to let go of a loved one. But treatment decisions should not be used to make up for feelings that haven’t been settled.

“Not choosing dialysis is letting the patient die of natural causes. The end of life would have come sooner if treatment had not been started. Kidney failure is the true cause of death.

“When we let go, we can let be. By learning to let be, we can face our own fears about the future. Once we come to terms with the end of life, we can learn to live more fully and freely.”

— Adapted with permission from *Hard Choices for Loving People*, by Hank Dunn, MDiv

What you can do:

- Start talking about your wishes now. Give yourself time to plan.
- Set up an advance directive. These are legal forms to fill out in case you cannot speak for yourself later. You can list your wishes and name a person to speak for you. Ask us if you have questions about advance directives.
- Honor what the patient would want if you are making a choice for someone. If the patient has an advance directive, be sure to honor it.
- Be gentle with yourself as you make healthcare decisions. Do the best you can with the information you have.
- Reach out for help when you need it. Contact us for support. We are here for you.

Helpful links about palliative care and hospice care:

- [www.getpalliativecare.org/whatis/disease-types/kidney-disease-kidney-failure-palliative-care](http://www.getpalliativecare.org/whatis/disease-types/kidney-disease-kidney-failure-palliative-care)
- [www.caringinfo.org](http://www.caringinfo.org)

Helpful links about kidney disease:


- [www.kidney.org](http://www.kidney.org)
- [www.aakp.org](http://www.aakp.org)

What makes these decisions “hard choices” has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual. These are decisions of the heart, not just the head.

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