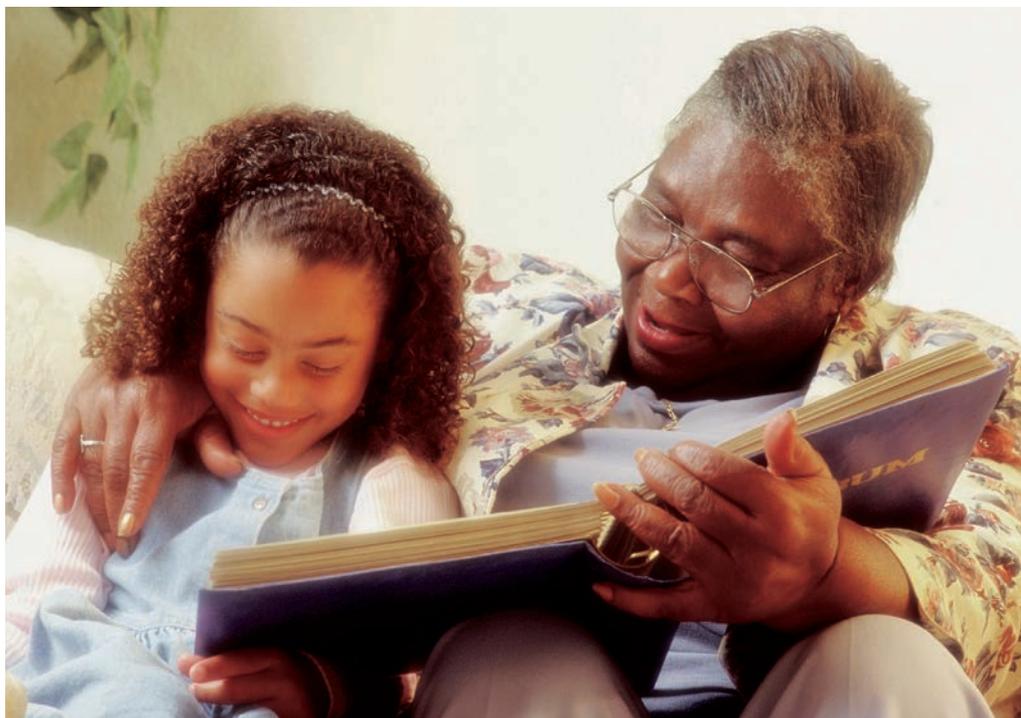


HOME HEMODIALYSIS

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.

What is your stage 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
3	Moderate decrease in GFR	30 to 59
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

Home hemodialysis	4
Different schedules of home hemodialysis	9
Deciding if home hemodialysis is right for you . . .	11
Preparing for home hemodialysis	15
Insurance coverage for home hemodialysis	17
Key points to remember	19
For more information	21
True or false quiz	24

Home hemodialysis

When you are told that you have kidney failure and need treatment to stay alive, it can be a difficult and challenging time in your life. You may have many concerns. These concerns can be physical, emotional, and financial. If your kidney disease diagnosis is recent, you may feel overwhelmed, confused, and angry. You may worry about how kidney failure and dialysis will change your future and your quality of life. But there are some important things you can do to help yourself. Learn all you can about your treatment options. Take an active role in decisions about your care.

Kidney failure can be treated with hemodialysis, peritoneal dialysis, or kidney transplantation. Reviewing the pros and cons of each of these options can help you and your healthcare professional decide what is best for you.

This booklet is about a special type of hemodialysis—hemodialysis done at home, or “home hemodialysis.” See page 21 for a list of resources on the other treatment options.



How hemodialysis works

Hemodialysis is a treatment that replaces some of the work of your own kidneys. Hemodialysis clears wastes and extra fluid from your blood. Your blood is cleaned by a part of the dialysis machine called the artificial kidney or dialyzer. For blood to flow through the dialysis machine, you need to have an access, or entrance, to your bloodstream. This is created by minor surgery, usually to an arm. (See “Getting an access” on page 15.) At each dialysis treatment, two needles are placed into the dialysis access site in your arm; one needle carries your blood through sterile tubing to the artificial kidney (dialyzer), and your cleaned blood is returned to your body through the second needle.

Hemodialysis: At a center or at home

You can do hemodialysis at a dialysis center where a nurse or technician is present to perform the treatment. You will make appointments and travel to the center where you will receive treatment, usually three times a week for three to four hours or longer each session. In-center treatments are performed at a pre-scheduled time. (For example, at 1 pm on Monday, Wednesday, and Friday.) In addition to travel time to and from your home, and dialysis treatment time, there is also some preparation and recovery time to factor into the time you are at the center.

You can also do hemodialysis at home, where you perform your own treatment, independent of the center. At home, you may be better able to fit your treatments into your daily schedule. If you work or wish to resume working, home hemodialysis may make it easier. Studies show that the more you know about your treatment and the more you do on your

own, the better you are likely to feel on dialysis. If your doctor recommended hemodialysis as the best treatment option for you, hemodialysis at home may be a good choice.



A brief history of home hemodialysis

Home hemodialysis began in the United States in 1964. By 1973, when Medicare first covered dialysis costs, 40 percent of patients received their hemodialysis at home. With the start of Medicare payments for dialysis, more centers began to open. There was less focus on home hemodialysis, and fewer centers offered it. Now, with new technology and easy-to-use machines, home hemodialysis is regaining popularity. In 2008, new regulations were established by the Centers for Medicare and Medicaid Services (CMS), the government agency responsible for Medicare. Now, dialysis team members are required to inform patients about the option of home dialysis. They must provide you with a list of places that will train you to do it. The regulations require that people with severe kidney disease receive education about all possible treatment options.

Pros and cons of home hemodialysis

Different ways of scheduling home hemodialysis treatments are possible (see page 9). All share some important pros and cons compared with in-center hemodialysis.

Pros:

- Easier to fit into your daily schedule
- Easier to keep working if you have a job or you wish to return to work or school
- Not having to travel to a dialysis center three times a week
- Independence and being in control of your own treatments
- Likelihood of a better health outcome over time
- The comfort and privacy of being in your own home during treatment
- Having access to telephone, family members, and visitors during treatment
- Being able to eat and drink if you choose to during treatment
- Your access may last longer. (See “Getting an access” on page 15.)

Cons:

- Initial fears about duties and caring for the dialysis machine
- Training for home hemodialysis is not offered by all dialysis centers

- More space is needed in your home for equipment and supplies
- A care partner is generally needed to be with you during treatments
- Training may take three to eight weeks or longer, with three- to five-hour training sessions per week
- Some plumbing and wiring changes in your home may be necessary, but newer machines use standard household outlets
- Electric, gas, and water bills may increase slightly
- Some new machines are portable, but you will have to find a dialysis center for support when traveling
- Less social interaction compared with going to the dialysis center
- Your care partner may tire of this role



Different schedules of home hemodialysis

You can do hemodialysis at home using one of three types of schedules. Regardless of which schedule you choose, you and your care partner are trained to perform dialysis safely and to handle any problems that may arise. Everyone is different and training time differs between people, but usually takes three to eight weeks.

1. **Conventional home hemodialysis:** You perform hemodialysis three times a week for three to four hours or longer each time.
2. **Short daily home hemodialysis:** This schedule calls for hemodialysis five to seven times a week, using machines designed for short, daily home treatment. Treatments usually last about two hours each. Because you are receiving dialysis more often, less fluid needs to be removed from your blood each time. This reduces recovery symptoms like headaches, nausea, cramping, and feeling “washed out” after your treatment. (Also see the next section, “Added benefits of short daily and nocturnal home hemodialysis.”)
3. **Nocturnal (nighttime) home hemodialysis:** These are longer, slower treatments done at night while you sleep. You may receive this kind of dialysis six nights a week or every other night. It depends on what your doctor recommends for you. Treatments usually last about six to eight hours. Some centers monitor your treatments by having information from your dialysis machine sent to a staffed location via telephone modem or the Internet. More hours of dialysis each week can increase waste removal from your blood. As a result, many patients report improvements such as those listed on the next page.

It's also possible to combine daily and nocturnal home hemodialysis. Whether you can combine treatments depends on your needs, your health, and your machine.

Whatever treatment schedule you choose, it's important to know if you are receiving the right amount of dialysis. Blood tests are done regularly during the year to check on the amount of dialysis you receive and to help decide if any adjustments to your treatment plan are needed. For more information on how the amount of dialysis is measured, speak with your doctor and your dialysis care team.

Added benefits of short daily and nocturnal home hemodialysis

Having frequent dialysis resembles more closely how your kidneys functioned when they were healthy. Many reports indicate that people who use short daily and nocturnal home hemodialysis:

- Take less medication to control high blood pressure and anemia (low red blood cell count)
- Take less medication to keep high blood phosphorus under control
- Have improvements in blood pressure, nerve damage, and symptoms of restless leg syndrome
- Feel better during dialysis and less “washed out” after dialysis
- Have fewer limits on what they can eat and drink
- Have more energy for daily activities
- Sleep better

- Have fewer and shorter hospital stays
- Have a better quality of life
- Live longer

“With daily home hemodialysis, you don’t have the swings in your blood chemistries and fluids like you do when you don’t dialyze every day, so you feel a lot better. Home dialysis is for people who want to be in control of the process and be in the home setting.”

—David J., patient on daily home hemodialysis

Deciding if home hemodialysis is right for you

Home hemodialysis is not a good fit for everyone. You need to find a dialysis center that offers training and support in home hemodialysis. You need to be willing to be responsible for your own treatment. As long as you and your care partner can pass the training and learn to place your needles, you should be able to do home hemodialysis. The following are questions you may want to discuss with your doctor and healthcare team.

Questions to consider

Your job:

- Can I keep my job and do home hemodialysis?
- Can I get paid time off to train for home hemodialysis?
- If I quit working, how long can I keep my health insurance? Can I get other health insurance?
- How will this change affect my family and me?

Finding a home hemodialysis program

- Does my local dialysis center offer home hemodialysis training? If not, where is the closest center with training?
- Am I willing to change centers, or even doctors, to get home hemodialysis?
- How far would I be willing to go for training that takes several weeks and for clinic visits every four to six weeks?
- How long does training take? What is the training schedule?
- How will I learn to put the needles in my arm for hemodialysis?
- Who will be my trainer? Can I make an appointment to talk with him or her?

Your care partner:

- Who can I ask to be my home dialysis care partner?
- Can my care partner take time away from work or other tasks for the training?
- Does my care partner do what the nurse at the dialysis center does?

Changes at home:

- What will it take to install a dialysis machine in my house?
- Will my landlord allow me to put a machine in my apartment?
- Where can I put the equipment and supplies?
- What are the rules about the disposal of medical waste in my area?

- How much will my insurance pay for home training and home hemodialysis supplies?

Costs:

- What out-of-pocket costs will I need to pay?
- Will insurance pay for any necessary changes in my home?
- How much will my electric, gas, and water bills increase?

Working with the dialysis center:

- How does the dialysis center staff support me once I'm doing treatment at home?
- Who repairs my machine when it breaks? How long do repairs usually take?
- Where can I get dialysis if my machine is broken?
- How often do I need to come back to the center for clinic visits?
- Is transportation assistance available if I need a ride to the clinic?
- Can I see my local doctor monthly, so I won't have to come to the clinic as often?

Long-term concerns:

- What treatment does my kidney doctor believe is best? Why?
- Will I do better long-term with home hemodialysis?

New technology

User-friendly machines are being developed for home hemodialysis. These machines are easier to set up, clean,

and disinfect. They have easy-to-understand alarms to alert you to a problem. With some newer machines, you have fewer supplies to store. If you think home hemodialysis is a good choice for you, ask your dialysis training staff about the best equipment for you.

“With daily dialysis, I’ve noticed that I have increased energy, better sleep, and improved concentration at work. People shouldn’t have to live to dialyze. Daily home hemodialysis on your own schedule makes it possible to live life as best you can.”

—*Bill P., a patient on daily home hemodialysis*

Finding a center that offers home hemodialysis

Your healthcare professional will help you find a dialysis center that has a home hemodialysis program certified by CMS. If your center does not offer home hemodialysis, see page 22 for websites that can help you find centers that offer home hemodialysis. Visit the center. Talk with the home training nurse and other staff. Ask to talk with other people who do their dialysis at home. Two things will ensure your success: 1) a dialysis center and nurse willing to train you and follow your care; and 2) your commitment to learn and do hemodialysis at home.

Staying in touch with your dialysis center

You will need to visit your dialysis center about once a month for a check-up, lab tests, and to see your kidney doctor, nurse, dietitian, and social worker. You may also need to receive some of your medicines, such as intravenous iron, at your center. Between visits to the center, your healthcare team is there to help. If you have a question about your diet or treatment, call your center. When you go home after your

training, your center will give you phone numbers that you can call if you have questions. Some centers monitor care over the Internet. Make a list of important phone numbers and keep them in a handy place. You can use the chart at the end of this booklet.

Preparing for home hemodialysis

1. **Getting an access:** To do any type of hemodialysis, you need to have a way to gain access to your bloodstream. Your access is created by a doctor called a vascular surgeon. There are three types of access:

Fistula: This is the first and best choice for an access for most people. It has fewer problems and lasts the longest, especially if you or your care partner are the only people inserting the needles. A fistula involves surgery to connect an artery and a nearby vein, usually in your arm. Have your fistula created early, so it has time to heal and is ready to use when you need to start treatment.

Graft: If the surgeon evaluates your blood vessels and a fistula is not possible, a graft is the second best access choice for hemodialysis. A graft also requires surgery. It is made by connecting an artery and nearby vein with a piece of man-made vein. However, a graft is more prone to infection and clotting than a fistula. If that happens, you may need treatment or more surgery to fix or replace the graft.

Catheter: Another way to access your bloodstream is to have a plastic tube called a catheter put into a large vein in your neck or chest. Catheters are only used long-term if no other access can be made. Catheters are more prone to infections and clots. If you have a catheter, you must follow strict catheter care instructions to stay healthy.

2. **Training:** Once your access is ready to use, you will begin training. Training can take several weeks or longer, depending on the type of machine you have. Everyone is different and training time can vary. Patients and care partners often have concerns about learning how to perform home hemodialysis, especially about how to insert the needles. It's not as hard as it may seem. You don't need to have a medical background to learn how to do the process safely at home. Your training staff will make sure you or your care partner can handle all the steps before they allow you to start performing your treatments at home.

You and your care partner will learn how to:

- Set up your equipment in your home
- Insert and remove your needles
- Figure out how much fluid to remove from your blood during dialysis
- Use and care for your dialysis machine and water system (if needed)
- Notice and handle medical and equipment problems that may occur
- Store and order your supplies
- Check your blood pressure

Your care partner

Most home hemodialysis programs ask you to have a care partner who is willing to stay with you to help you during each treatment. Your care partner can be a family member or friend. This person goes through the training with you, so he or she can learn what to do. Sometimes, patients hire a

nurse or technician to be their care partner. But Medicare does not pay for these helpers. Medicare Part B will pay for visits by trained hospital or dialysis care centers to check on equipment, help you in an emergency, or check on your home dialysis technique. Your care partner may insert needles, give you medications, check your blood pressure, and call for help if a problem occurs.

Being a care partner can be stressful at times. Some people on home hemodialysis may decide to have in-center dialysis once in a while, so the family member or friend who assists them can take some time off. It is important to be honest with one another and talk about feelings of burnout or loss of sleep.

Insurance coverage for home hemodialysis

The social worker at your dialysis center should give you information about coverage for home hemodialysis and other costs that may be related to receiving your treatment at home. Medicare pays for part of the cost of home hemodialysis and training. Medicare is not just for people who are 65 and older. The program also helps Americans and legal residents of all ages who need dialysis or a kidney transplant and qualify for coverage.

Other sources that help pay for dialysis include:

- Private insurance
- Some managed care organizations
- Medicaid
- Veterans Administration
- Indian Health Service (IHS)

If you have an employer group health plan, it will be the primary coverage for the first 30 months of your treatment, with Medicare as your secondary insurer. After those first 30 months, Medicare will become your primary insurance.

Your home training nurse will tell you if your home will need plumbing or wiring changes for home hemodialysis. Some of these costs may be covered by private insurance or your center. You may be given the option of receiving your dialysis supplies from your dialysis center or dealing directly with a supply company. You can expect your monthly water and electric bills to increase a little. Speak to your social worker if you have additional questions or concerns about coverage for home hemodialysis.

“I started feeling stronger and more energetic. I had less bone pain, so I was able to walk more and started exercising regularly. I stopped taking some medications and I generally feel good. With home dialysis, you do everything from setting up the machine, connecting and disconnecting yourself to the machine, and disinfecting the machine afterwards. But taken as a whole, the positives far outweigh the negatives.”

—Henry E., a patient on nocturnal home hemodialysis



Key points to remember

- Pros of home hemodialysis
 - It's easier to fit into your daily or weekly schedule.
 - There are fewer restrictions on what you can eat and drink, especially for those doing daily or nocturnal treatment.
 - You are in control of your own treatment and have more independence.
 - Your health over time is likely to be better.
 - Many patients say they feel better and have more energy.
- Three basic types of hemodialysis can be performed at home:
 - Conventional—three times a week for three to four hours or longer each time
 - Short daily—five to seven times a week for about two hours each time
 - Nocturnal—three to six nights a week for six to eight hours each time.

- Talk to your healthcare practitioner about whether home hemodialysis would be a good treatment choice for you. They can also help you choose the best type of home hemodialysis for your needs.
- To perform hemodialysis, you will need to have a permanent access to your blood created. Doctors recommend a fistula for most patients.
- Both you and a care partner (in most cases) will need to be trained to do home hemodialysis. Your care partner may be a family member, friend, or a healthcare worker whom you hire to assist you.
- Medicare, private insurance, and several other sources pay for home hemodialysis. Speak to your social worker if you have any questions.
- Even though you will be at home, you still need to keep in touch with your dialysis center for monthly checkups, questions, and in case of problems.

For more information

If you have questions, speak to your doctor and other members of your healthcare team. You may also find these National Kidney Foundation (NKF) booklets helpful. To order a free copy call the NKF Cares Patient Help Line toll-free at **855.NKF.CARES** (855.653.2273) or email **nkfcares@kidney.org**

Hemodialysis: What You Need to Know

Order# 11-50-0214 [Spanish #11-50-0219]

Peritoneal Dialysis: What You Need to Know

Order# 11-50-0215 [Spanish #11-10-0221]

Kidney Transplant Order# 11-10-0304

Nutrition and Hemodialysis Order# 11-50-0136

Hemodialysis Access: What You Need to Know

Order# 11-50-0216 [Spanish #11-50-0220]

Take Steps to Keep Your Bones Healthy and Strong:

For People with Chronic Kidney Disease (Stage 5)

Order# 11-10-0228

A Guide to Heart Health for Dialysis Patients

Order# 11-50-0218 [Spanish #11-50-0222]

Coping Effectively: A Guide for Patients and Their Families

Order# 11-10-0503

Planning for Natural Disasters and Other Emergencies:

A Guide for Kidney Patients Order# 12-10-0808

Choosing a Treatment for Kidney Failure Order# 11-10-0352

Dialysis Patients' Bill of Rights and Responsibilities
Order# 11-65-1639

Getting Ready for a "New Normal": A Helpful Guide for Starting Dialysis Order# 11-10-0306

A "New Normal": Life on Dialysis—The First 90 Days
Order# 11-10-0307

Working with Kidney Disease Order# 11-10-0501

Online Information

Dialysis Facility Compare—Find information about dialysis centers that offer home hemodialysis training programs.
www.medicare.gov

Home Dialysis Central—Learn about home dialysis options, talk to other patients, find out if a dialysis center near you offers a home hemodialysis program. **www.homedialysis.org**

Medicare—Read a patient booklet about coverage for kidney failure treatment. **www.medicare.gov/publications/pubs/pdf/10128.pdf**

ESRD Networks—Find out who oversees dialysis quality and collects data, and learn about your own Network at the Forum of ESRD Networks website. **www.esrdnetworks.org**

American Association of Kidney Patients (AAKP)—Learn about kidney disease and treatment. **www.aakp.org**

U.S. National Kidney and Urologic Diseases Information Clearinghouse—Download or order booklets on kidney disease. **<http://kidney.niddk.nih.gov/kudiseases/pubs/kidneyfailure/index.htm>**

RenalWEB—Find resources on home hemodialysis.
www.renalweb.com/topics/homedialysis/homedialysis.htm

The National Kidney Foundation's Patient & Family Council

Join the National Kidney Foundation's Patient & Family Council, the largest patient organization dedicated to issues affecting patients with chronic kidney disease and their families. Membership in the Council is free. To sign up, visit **www.kidney.org/patients** and click on "Join the NKF Family," or call the NKF Cares Patient Help Line toll-free at **855.NKF.CARES** (855.653.2273).

True or false quiz

Take this quiz and see how much you learned. Check your answers on the next page.

1. Conventional home hemodialysis is done every day.
True _____ False _____
2. Daily home hemodialysis treatments last about two hours each.
True _____ False _____
3. Nocturnal home hemodialysis is done while you sleep.
True _____ False _____
4. With home hemodialysis, your diet may be more restricted.
True _____ False _____
5. In home hemodialysis, you generally need a care partner to help you with your treatments.
True _____ False _____
6. Training for home hemodialysis takes about a year.
True _____ False _____
7. A fistula is the preferred type of access for hemodialysis.
True _____ False _____
8. In hemodialysis, wastes and excess fluid are removed from your blood by a filter, called a dialyzer.
True _____ False _____

9. People on home hemodialysis visit the dialysis center once every six months for a checkup.

True _____ False _____

10. With home hemodialysis, your electric and water bills will probably be lower.

True _____ False _____

Answers to true or false quiz

1. F 2. T 3. T 4. F 5. T 6. F 7. T 8. T 9. F 10. F

IMPORTANT NAMES AND PHONE NUMBERS

Kidney doctor:

name: _____

phone: _____

Home training nurse:

name: _____

phone: _____

Social worker:

name: _____

phone: _____

Dietitian:

name: _____

phone: _____

Machine technician:

name: _____

phone: _____

Supply company:

name: _____

phone: _____

24-hour contact:

name: _____

phone: _____

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**



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