

# Home Hemodialysis

A Guide for Patients and Their Families



# National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF-K/DOQI™)

The National Kidney Foundation is developing guidelines for clinical care to improve patient outcomes. The information in this booklet is based on the K/DOQI recommended guidelines. All K/DOQI guidelines provide information and assist your doctor or health care team in making decisions about your treatment. The guidelines are available to doctors and other members of the health care team. If you have any questions about these guidelines, you should speak to your doctor or the health care team at your treatment center.

### **Stages of Chronic Kidney Disease (CKD)**

In Februay 2002, the National Kidney Foundation published clinical care guidelines for chronic kidney disease. These help your doctor determine 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. (See the table below.) 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                      |  |  |  |

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

# **Table of Contents**

| How hemodialysis works  | 4  |
|---|----|
| Hemodialysis: At home or in-center                            | 4  |
| A brief history of home hemodialysis                          | 5  |
| Pros and cons of home hemodialysis                            | 6  |
| Different types of home hemodialysis                          | 7  |
| Added benefits of short daily and nocturnal home hemodialysis | 8  |
| New technology  | 10 |
| Deciding if home hemodialysis is right for you                | 10 |
| Questions to consider   | 10 |
| Finding a center that offers home hemodialysis                | 13 |
| Staying in touch with your dialysis center                    | 13 |
| Preparing for home hemodialysis                               | 13 |
| Your care partner   | 15 |
| Insurance coverage for home hemodialysis                      | 16 |
| Key points to remember  | 17 |
| For more information  | 18 |
| Online information  | 19 |
| True or false quiz  | 21 |
| Important names and phone numbers.                            | 22 |

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 have so much to be concerned about. If your kidney diagnosis is new, 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 different 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 choices can help you and your doctor decide what is best for you.

This booklet is about a special type of hemodialysis—hemodialysis done at home, or "home hemodialysis." See "For more information" on page 18 for a list of resources on the other treatment options.

#### How hemodialysis works

Hemodialysis is a treatment that replaces the work of your own kidneys to clear wastes and extra fluid from your blood. Your blood is cleaned by a part of the dialysis machine called an 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 13.) One needle carries your blood through tubing to the dialyzer and another returns your cleaned blood to your body.

#### Hemodialysis: At home or in-center

You can do hemodialysis at a dialysis center where a nurse or technician is present to perform the tasks required during treatment. In-center hemodialysis is usually done three times a week for three to four hours or longer each session. In-center treatments are done at a pre-scheduled time (for example, at 1 pm on Monday/Wednesday/Friday).



You can also do hemodialysis at home, where you are doing your own treatment. At home, you may be better able to fit your treatments into your daily schedule. If you work, home hemodialysis may make it easier to keep your job. Studies show that the more you know about your treatment and the more you do on your own, the better you are likely to do on dialysis. If you have kidney failure, and your doctor recommended hemodialysis as the best treatment option for you, hemodialysis at home may be a good choice for you.

# 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 did their hemodialysis at home. With the start of Medicare payment 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.

#### Pros and cons of home hemodialysis

Different types of home hemodialysis can be performed (see next section, "Different types of home hemodialysis"). 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
- Convenience of not having to travel to dialysis center three times a week
- Being in control of your own treatments
- Comfort and privacy of being in the home setting
- Having access to telephone, family members and visitors
- Being able to eat and drink when you choose
- Your access (see "Getting an access" on page 13) may last longer

#### Cons

- Training for home hemodialysis is not offered by all dialysis centers
- More space is needed in your home for equipment and supplies
- A trained helper is generally needed to be with you during treatments
- Training may take several weeks or longer
- Some plumbing and wiring changes in your home may be needed
- Electric, gas and water bills may increase slightly
- Most machines are not portable so you may have to do in-center dialysis when traveling
- Loss of social interaction at the dialysis center

#### Different types of home hemodialysis

Three types of hemodialysis can be performed at home. They are:

- Conventional home hemodialysis: You do this three times a week for three
  to four hours or longer each time. You and your care partner are trained
  to do dialysis safely and to handle any problems that may come up.
  Training may take from several weeks to a few months.
- 2. Short daily home hemodialysis: This is usually done five to seven times a week using new machines designed for short daily home treatment. Treatments usually last about two hours each. You and your care partner are trained over several weeks. Because you are doing dialysis more often, less fluid generally needs to be removed each time. This reduces 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 (night-time) home hemodialysis: Long, slow treatments done at night while you sleep. You may do this kind of dialysis six nights a week or every other night. This depends on what your doctor prescribes for you. Treatments usually last about six to eight hours. You and your care partner are trained over several weeks. Some centers monitor your treatments by having information from your dialysis machine sent to a staffed location by telephone modem or the Internet. More hours of dialysis each week can increase waste removal. As a result, many patients report improvements such as those listed in the next section, "Added benefits of short daily and nocturnal home hemodialysis."

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

Whatever treatment option you choose, it's important to know if you are getting the right amount of dialysis. Tests should be done regularly to check on the amount of dialysis you receive. For more information, speak with your doctor and your dialysis care team. Also, see the National Kidney Foundation booklet *Hemodialysis*.

# Added benefits of short daily and nocturnal home hemodialysis

Many reports indicate that people using short daily and nocturnal home hemodialysis:

- Take less medication to control high blood pressure and anemia
- Take less medication to keep phosphorus under control to help prevent bone disease
- Have improvements in neuropathy (nerve damage) and less restless leg syndrome
- Feel better during dialysis and less "washed out" after dialysis
- Have fewer limits on diet and fluids
- Have more energy for daily tasks

- 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



### **New technology**

New, easy-to-use machines are being developed for home hemodialysis. These are easier to set up, clean and disinfect. With some newer machines you have fewer supplies to store. If you think home hemodialysis is a good choice for you, ask your doctor about the best equipment for you.

### 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 you training and support in home hemodialysis. You need to be willing to be responsible for your own treatment. As long as you and/or your care partner can pass the training and learn to place your needles, you should be able to do home hemodialysis. Following is a list of questions you may want to discuss with your doctor and health care 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, can I convince my doctor and center to start a program?

Am I willing to change centers (and my doctor) 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?

Where will I stay while in training (if a place is needed) and can I afford this? What kind of training schedule is offered?

How long does training take?

Who will be my trainer? Can I make an appointment to talk with him or her?

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?

How can I learn to put the needles in my arm for hemodialysis? How long would it take?

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?

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

What out-of-pocket costs will I need to pay for?

How much will my electric, gas and water bills increase?

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 clinic?

Can I see my local doctor monthly so I won't have to come to the clinic as often?

#### About your health and chance for rehabilitation

What treatment does my kidney doctor suggest for me? Why?
Will I do better long term with home hemodialysis?
If my kidney doctor needed dialysis, what type would he or she choose?



"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

Finding a dialysis center that has a home hemodialysis program can be a challenge. If your center does not offer home hemodialysis, see page 19 for Web sites that can help you find centers that offer home hemodialysis. Visit the center. Talk with the home training nurse and other staff. If possible, talk with home patients. Two things are needed for success: 1) a center and nurse willing to train you and follow your care; and 2) your commitment to learn and do home hemodialysis for at least one year.

## Staying in touch with your dialysis center

You will need to visit your dialysis center about once a month for a checkup and lab tests and to see your kidney doctor, nurse, dietitian and social worker. You may also need to receive some of your medications, such as intravenous iron, at your center. Between visits to the center, your health care team is there to help. If you have a question about your diet or treatment, contact your center. When you go home after your training, your center will give you numbers that you can call if you have questions. Make a list of important phone numbers and keep it in a handy place. You can use the chart at the end of this booklet.

### Preparing for home hemodialysis

- Getting an access: To do any type of hemodialysis, you need to have a
  way to access your bloodstream. Your access is placed by a special doctor called a vascular surgeon. There are three types of accesses:
  - 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 person putting in needles. A fistula involves surgery to connect an artery and a nearby vein. Get your fistula early so it has time to heal and be ready to use when you need to start treatment.
  - Graft: If you can't have a fistula, 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. A graft is more prone to infection and clots 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 for long-term use 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 need training. Training can take several weeks or longer, depending on the type of machine you have. Patients and care partners often have concerns about learning how to do home hemodialysis, especially learning 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 and/or your care partner can handle all the steps before they allow you to start performing your own treatments at home.

You and your care partner will learn how to:

- Set up your equipment in your home
- Care for your access
- Insert 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)
- Know how to spot and handle medical and equipment problems that may occur
- Store and order your supplies
- Check your blood pressure
- Follow your diet and fluid limits.

#### Your care partner

Most home hemodialysis programs ask you to have a care partner who is willing to be 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. 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.



#### 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 doing your treatment at home. Medicare pays for part of the cost of home hemodialysis and training. If you are 65 or older or disabled, you should already have Medicare. You can also get Medicare at any age if you have kidney failure and you or your spouse or parent worked long enough to qualify for Social Security. Other sources that help pay for dialysis include:

- Private insurance
- Some managed care organizations
- Medicaid
- Veterans Administration
- Indian Health Service.

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 Medicare 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 bit. 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 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

| Home hemodialysis has many benefits:  |
|---|
| □ It's easier to fit into a daily schedule  |
| □ There are less restricted diets and fluids, especially for daily or nocturnal treatment |
| ☐ You are in control of your own treatment  |
| □ Many patients say they feel better and have more energy.                                |
| Three basic types of hemodialysis can be done at home:                                    |

- ee basic types ot hemodialysis can be done 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
- Speak to your doctor and other health care team members 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 created. Doctors recommend a fistula for most patients. Other types of accesses are grafts and catheters.
- 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 health care 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 health care team. You may also find these free National Kidney Foundation booklets helpful:

**Hemodialysis** 11-10-0301

What You Need to Know About Peritoneal Dialysis 11-50-0111

Kidney Transplant: A New Lease on Life 11-10-0304

Nutrition and Hemodialysis 11-50-0136

Take Steps to Keep Your Bones Healthy and Strong: For People With

Chronic Kidney Disease (Stage 5) 11-10-0228

Heart Health on Dialysis: How Lipids Can Affect Your Heart

(English and Spanish) 11-50-2107, 11-50-2191

Staying Fit With Chronic Kidney Disease 11-10-0502

Coping Effectively: A Guide for Patients and Their Families 11-10-0503

Planning for Natural Disasters and Other Emergencies:

A Guide for Kidney Patients 12-10-0808

Choosing a Treatment for Kidney Failure 11-10-0352

Working With Kidney Disease: Rehabilitation

and Employment 11-10-0501

*Family Focus* (a quarterly newspaper for dialysis patients and their families)

For order information call 800-622-9010.

#### **Online Information**

National Kidney Foundation Kidney Learning System (KLS)™—Get information about chronic kidney disease and its treatment. www.nkfkls.org

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/esrdcoverage.pdf

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

NKF-KDOQI Clinical Practice Guidelines—Read the guidelines that apply to different aspects of your treatment. www.kdoqi.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

#### National Kidney Foundation Patient and Family Council

Join the National Kidney Foundation's Patient and Family Council, the largest patient organization dedicated to issues affecting patients with chronic kidney disease and their families. Membership in the council is free. For more information on the council and the new People Like Us patient advocacy initiative, and to receive a membership application, call the National Kidney Foundation at 800-622-9010, or go to www.kidney.org/patients/pfc/index.cfm

#### True or False Quiz

Take this quiz and see how much you learned. Check your answers on page 23.

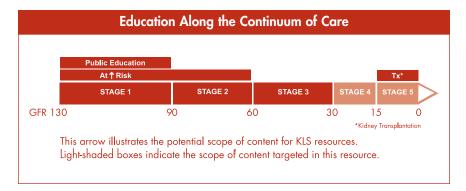
| 1. Conventional home h      | nemodialysis is done every day.                     |
|-----------------------------|---|
| True                        | False   |
| 2. Daily home hemodia       | lysis treatments last about two                     |
| hours each.                 |   |
| True                        | False   |
| 3. Nocturnal home hem       | odialysis is done while you sleep.                  |
| True                        | False   |
| 4. With home hemodia        | lysis, your diet may be more restricted.            |
| True                        | False   |
| 5. In home hemodialysis     | s, you generally need a care partner to help you    |
| with your treatments.       |   |
| True                        | False   |
| 6. Training for home her    | modialysis takes about a year.                      |
| True                        | False   |
| 7. A fistula is the preferr | red type of access for hemodialysis.                |
| True                        | False   |
| 8. In hemodialysis, was     | tes and excess fluid are removed from your          |
| blood by a filter, call     | ed a dialyzer.                                      |
| True                        | False   |
| 9. People on home hem       | nodialysis visit the dialysis center once every six |
| months for a checkup        | ).  |
| True                        | False   |
| 10. With home hemodi        | alysis, your electric and water bills will probably |
| be lower.                   |   |
| True                        | False   |

# Important names and phone numbers

|                     | Name | Phone Number |
|---------------------|------|--------------|
| Kidney doctor       |      |              |
| Home training nurse |      |              |
| Social worker       |      |              |
| Dietitian           |      |              |
| Machine technician  |      |              |
| Supply company      |      |              |
| 24-hour contact     |      |              |

## **Answers to True or False Quiz**

| 7. T<br>8. T<br>9. F | 3 | _<br>_<br>_<br>_<br>_<br>_ | 2. 3. 4. 5. |
|----------------------|---|----------------------------|-------------|
| J . 6                | ) | 7                          | Ϊ.          |



More than 20 million Americans—one in nine adults—have chronic kidney disease, and most don't even know it. More than 20 million others are at increased risk. The National Kidney Foundation, a major voluntary health organization, seeks to prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases and increase the availability of all organs for transplantation. Through its 50 affiliates nationwide, the foundation conducts programs in research, professional education, patient and community services, public education and organ donation. The work of the National Kidney Foundation is funded by public donations.

Made possible through an educational grant from Home feels better. **a K s** 





National Kidney Foundation 30 East 33rd Street New York, NY 10016 800-622-9010 www.kidney.org

#### © 2005 Edition.

All Rights Reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopy, recording or any information storage and retrieval system, without permission in writing from the National Kidney Foundation, Inc. Permission requests should be written and addressed to the publications department of the National Kidney Foundation.