

10

Psychosocial Guide for Patients, Families, and Dialysis Partners

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CONTENTS

- 3 Introduction
- 3 How Will My Lifestyle Be Affected by Home HD?
- 4 Will Home HD Be a Burden for My Care Partner?
- 4 I'm concerned about Dealing with the Machine. Will It Be Hard for Me to Adjust to Home HD?
- 5 What Will My Home HD Training Consist of?
- 6 How Much Will Home HD Cost?
- 6 How Do I Manage Supplies at Home?
- 7 What Kind of Support Can I Find as I Go Through My Home HD Treatment?
- 7 Summary
- 8 References

This module was predominantly authored by Kamal D Shah, a dialysis patient since July 1997. Kamal lives in India and has been on home hemodialysis (HD) since May 2006. He does nocturnal HD 7 hours each night, 6 nights per week, assisted by a trained dialysis technician. Kamal works full-time, blogs, swims every day, and travels regularly— things, he says, have been made possible only due to his home HD! A video describing his experience can be found [here](#).

Introduction

Home hemodialysis (HD) is far more than a medical treatment: it is a lifestyle. To ensure success, you, your care partner (if you have one), and your family must think through home HD therapy and the impact it will have not only on your daily life, but on the lives of your support team as well. In this module, we answer some common questions asked by home HD patients:

- “How will my lifestyle be affected by home HD?”
- “Will home HD be a burden for my care partner?”
- “I’m concerned about dealing with the machine. Will it be hard for me to adjust to home HD?”
- “What will my home HD training consist of?”
- “How much will home HD cost?”
- “How do I manage supplies at home?”
- “What kind of support can I find as I go through my home HD treatment?”

No doubt, other questions will arise as you start home HD. Never hesitate to ask your doctor, nurse, or dialysis care team for help about any questions you may have.

How will my lifestyle be affected by home HD?

Home HD is convenient. Gone are the days of fitting your life into the clinic’s schedule. At home, you can dialyze when you want. Occasionally, you may choose not to dialyze on a given day. If, for example, you stay late at work and need to start dialysis an hour later, no problem! You are free to fit your home HD treatment around your busy life.

Better social life. When you are home, you can choose when to dialyze—during the day or overnight. The prescription can be tailored to what you prefer. Some people choose to dialyze for 2.5 to 4 hours each day, and can choose which hours. When you do your home HD treatment every day, there is less time for toxins and fluid to build up in your body. This means you can have a little more fluid and a more normal diet.¹

Some people choose to dialyze longer—7 to 9 hours each night while sleeping. If you choose this method, your days and evenings are free to spend time with your family and friends. Doing home HD longer at night also lets you remove most limits on your fluids and diet, so you will have more options when you plan social events with friends and family.

Few limits on travel. Home HD can allow you the flexibility to travel more. Some machines are smaller than the standard ones you might see in a clinic. These are reasonably portable. They can be carried with you in a car, plane, boat, or train. Most

airlines now take the machines as essential medical equipment, at no extra charge. (Airlines will also accept about 2-days’ worth of dialysate fluid. Just make sure the fluid is in its original box and clearly labeled.)

Less time wasted. If you dialyze each night while you sleep, you will not waste any of your waking hours during the day. You can work full-time, complete tasks, socialize, and just be more productive overall.²

Fewer complications. The more you dialyze—during the day or at night—the less fluid you need to remove at 1 time. People who do home HD say that they don’t have the “washed-out” or “energy-drained” feeling they had when performing standard in-center HD. With nocturnal home HD, blood pressure drops are rare and your heart is less strained.^{3,4} Nocturnal home HD uses blood flow rates that are much lower than those used in-center, so you feel more like yourself during and after the session.

Most people who do daily or nocturnal home HD say that they feel much better and healthier.⁵ They have more energy, better appetites, fewer hospital stays, and more active sex lives. In general, they are living fuller, productive lives.

Will home HD be a burden for my care partner?

A care partner is someone who helps a person with home HD treatment, often a family member or friend. Not everyone needs a care partner, and home HD does not have to be a burden for a care partner if you have one. Some countries, such as the United States, require training with a care partner for most people who do home HD. Others, such as Australia and New Zealand, will NOT train a partner! They expect you to do your treatments yourself. Because the number of people who perform home HD in these countries is larger than the number of people who perform home HD in the United States, it's apparent you don't have to put a big burden on a partner, even if you do have one. The key is to learn to do your own treatments and do as much as you can yourself.

Most importantly, you should always cannulate yourself (ie, put in your own needles), if at all possible. Asking a partner to do this scary task may be one reason why assisting with home HD does not always work out for the partner. If you put in your own needles, you always have your own best cannulator with you. Self-cannulation not only helps a fistula or graft last much longer, but it frees you up to travel.

Do you have other disabilities and need total care? If so, it may be less of a burden for a partner to learn to do your home HD than to help you get to and from a clinic 3 times per week for standard treatments. Be sure to let your care partner know often how much you appreciate his or her help.

I'm concerned about dealing with the machine. Will it be hard for me to adjust to home HD?

You won't need to make many changes to fit home HD into your life. Home HD machines have been designed to give you the freedom you want without sacrificing safety. Some machines may require some minor updates to your home's plumbing and wiring. If you rent your home, many landlords will allow the changes, but some will not.

Choose your home treatment room. Living area or bedroom, the choice is yours. Some who do daily home HD prefer to sit in an easy chair in their living room. If you do nocturnal home HD, you can sleep in the room you chose as your treatment room. In fact, couples can even sleep in the same bed. Whichever option you use, you will need to keep your treatment room clean and safe. More information, including a checklist of home infrastructure requirements, can be found in the "Infrastructure, Water, and Machines in the Home" module.

Pets. If you have pets, watch them closely if you want to have them in your treatment room during home HD. Many people have said that they do their home HD with their pets sitting on their laps, but this may not work with all pets. Some pets may be startled by the machine's alarms and sounds. Other pets may play with or bite the hoses or blood tubing, which can result

Psychosocial Guide for Patients, Families, and Dialysis Partners

in damage or cause an infection for you. If you dialyze at night while you sleep, it is best to keep pets out of the room.

Infection. Dialysis at home or in the clinic always comes with a risk of infection, which can require treatment in the hospital. You can help prevent infection by regularly washing your hands, using a sterile technique to insert needles, and keeping your home HD room clean. Your clinic training program will teach you how to avoid infections and make sure you feel safe at home.

There is no infection risk for families living with patients who do home HD. When you use the sterile techniques your clinic will teach you, there is no chance a family member will get an infection simply by being with you as you dialyze.

What will my home HD training consist of?

Training will be performed by a training nurse or other dialysis staff at your clinic. You will be trained to use the machine you have chosen and the prescription your doctor wrote for you. The time required for training will be based on your machine. Training for small portable machines that have been designed for easy use may take 2 to 4 weeks. Training for larger, more complex machines may take 5 to 8 weeks. During this time, you will learn how to place the needles, set up and run the machine, fill out treatment forms, and track your supplies. You won't take the machine home and begin home HD until both you and your trainer are confident that you can succeed. Your trainer may come to your home to support you during your first treatment to ensure your peace of mind. In most countries, your clinic will give you 24/7 phone support in case you have questions. Be sure to ask your trainer how your clinic will support you at home.

It's normal to worry about things that can go wrong during home HD. Your trainer will teach you how to have a comfortable, safe, and successful treatment. Here are some key facts to keep in mind while you are training:

Home HD is much gentler than in-center HD. Home HD is less stressful on your body than in-center HD. Much less fluid is removed at a time. This means you have a much lower risk

of blood pressure drops and cramping. These are common problems in-center, but are very rare with home HD.

Putting in your own needles hurts less than having someone else do it for you. People who do home HD say that they focus so intently on placing their needles correctly, they feel much less pain than they do when a care partner or nurse does it. Also, when you are able to place your own needles, your access can last much longer.⁶ For more information, see "The Care and Keeping of Vascular Access for Home Hemodialysis Patients" module.

Good taping and alarms keep you safe. If you dialyze at night, you will learn how to tape the needles securely and safely so they won't come out as you sleep. If you use an alarm (like a bed wetting alarm) you will have even greater peace of mind. With an alarm under your access arm and one under the dialyzer, you can sleep without fear that you will bleed and not know it.

Fewer clinic visits. You will still need to meet with your nephrologist, but less often than if you were getting your treatments at a clinic. During the visit with your doctor, you will review your prescription, medicines, and blood test results. It is helpful to set up a fixed schedule for your visit. For example, you may want to set up your visits on the first Monday of each month. That way, you can plan around the visit. You can draw your blood samples, deliver or send them to your lab, and have the results in time for your visit.

How much will home HD cost?

In countries with national healthcare systems, you may not have to pay for dialysis no matter which type you choose. In some countries, like the United States, you may pay the same amount out of pocket for home HD as you would for in-center HD (you do not have to buy the machine). In other countries, you will have to pay for home HD yourself. If you live in a country that does not cover home HD, you will need to buy the machine and the water treatment equipment. Or, you may be able to pay a monthly rental fee to a clinic that will set up the machine and water treatment system and maintain the equipment for you. You and your dialysis care team will need to find out what your insurance or national healthcare service will cover. Here are some costs you may have:

Cost of the machine. In most cases, you will have a choice of home HD machines. You and your dialysis staff will discuss the costs of each brand of machine, compare ease of use, and look at maintenance costs.

Costs for water treatment. You and your dialysis staff will look at the volume of water your machines will need and calculate how this will affect your water bill.

Cost of supplies. You will need supplies for home HD. Your center may provide these. Ask your dialysis staff for an estimate of the monthly costs for supplies (see the “Supplies” section for more details).

Cost of maintenance. Normally, your center will provide the fittings and arrange for an electrician to do the wiring, a plumber to do plumbing fittings and install piping, a biomedical waste disposal service to handle waste products that are generated by dialysis, and a technician to clean your water tank and pipes and maintain your machine. Ask your dialysis staff how this is set up and whether you will have any costs.

How do I manage supplies at home?

Some clinics will keep track of the supplies you need and send you more before you run out. Others will require you to order what you need when you need it. Either way, keep track of supplies you are using and budget enough time to get more supplies before you run out. A good rule to follow is to keep 2 to 3 weeks of supplies on hand at any one time.

You will need a fair amount of space to store all of the supplies. You may need to empty a closet in or near your dialysis room, add open shelves or closed cabinets to the room for storage, or store supplies in a dry garage or basement (be sure they won't get too hot or cold). If you do not have space, talk to your dialysis staff. The center may be able to send you supplies for a week or 2 at a time, instead of 1 delivery per month. You will need to keep a close watch on your stock levels to make sure you don't run out.



Practice Tip

To make sure you never run out of any supplies, keep an “emergency” set-up kit for 1 full home HD session in a small bag in a safe, secure place. This way, if you notice just before a treatment that you have run out of an item, you can use your kit. Make sure you review the kit periodically to make sure you replace things that are about to expire.

What kind of support can I find as I go through my home HD treatment?

Peer support. Group support can help you to feel less alone. Your country may have consumer networks and face-to-face peer support groups. Such groups can help you meet others who have similar life challenges. If your area does not have support groups, you may wish to start one of your own. You might form a group of other home HD patients that meets outside your clinic in a social setting (eg, restaurant, library, place of worship, or your home). Your care partner, if you have one, might want to form a group for other care partners. You may want to ask professionals to be guest speakers or facilitators. One-on-one “buddy” support can also be helpful, and may be easier to arrange than group support. Such one-on-one support can also be done via telephone or the Internet. Talk to your dialysis staff to see if they know of any buddy support programs or might be willing to start one. An example of a buddy support system can be found [here](#). This system could be set up in your own program, region, or country.

Web-based support. If you have Internet access, you can find online support in the form of Facebook groups, message boards, email listservs, chat rooms, and others. For example, a Facebook group for home dialysis can be found [here](#). You could also search Google (<http://www.google.com>) for “dialysis support”. Remember to check with your care team before you follow any medical advice discussed on any sites.

Useful Resources

If you want to start a peer support group, we recommend the following websites:

- » [The Community Toolbox. Creating and Facilitating Peer Support Groups](#)
- » [Manuals and Workbooks for Starting and Running Support Groups](#)

Summary

We have given you some general information about the impact of home HD on your lifestyle. We haven't touched on every issue, but we hope that this module will act as a springboard to stimulate other questions you may have. ***Never hesitate to contact your dialysis staff with any questions you may have about your home care.*** Many people around the world who do home HD have reported great success. They have been able to fit dialysis into their lifestyles rather than letting dialysis limitations dominate their lives. We wish you every success as you think about doing treatment with home HD.

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