Uncovering Myths About Home Dialysis

Myth vs. Reality Toolkit

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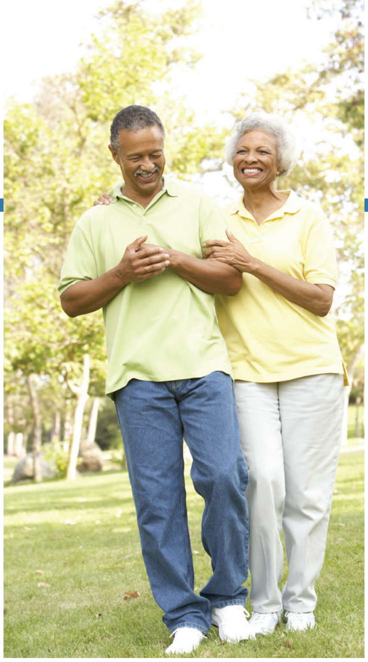


What Members of the Home Dialysis Affinity Group Say About Their Involvement with the NPFE-LAN

- It's impressive how the patient experience is included.
- Making a difference is impactful.
- Being involved adds to knowledge.
- It's important to have a voice for yourself, as well as fellow patients.
- Our involvement enhances quality improvements.

Patients and care partners have reviewed this booklet from their perspective to help you better understand, and potentially make, the personal choice to dialyze at home.

A special **thank you** goes to End Stage Renal Disease (ESRD) Networks 16 and 18 for originally creating the content and providing the opportunity for the **Home Dialysis Affinity Group** National Patient and Family Engagement Learning and Action Network (NPFE-LAN) Subject Matter Experts (SMEs) to review, enhance, and re-package it from the patient and care partner viewpoint.

What are the ESRD Networks?

Eighteen ESRD Networks, organized regionally, serve as liaisons (or links) between the federal government and the providers of ESRD services. The ESRD Networks advocate for quality care for kidney disease patients. To contact your ESRD Network, visit www.esrdncc.org.

What is the NPFE-LAN?

The NPFE-LAN, which is part of the National Coordinating Center (NCC), partners with patients and family members (called SMEs) to enhance national quality improvement initiatives. This is accomplished by bringing together patients from all 18 ESRD Network regions to discuss and achieve patient-led goals. The NPFE-LAN includes patients, family members, and care partners who come together on a regular basis to provide the patient perspective about efforts to improve quality of care designated by the Centers for Medicare and Medicaid Services (CMS).

If you would like to learn more about becoming involved on a national level and making an impact on quality improvement initiatives, please contact your ESRD Network or visit www.esrdncc.org/npfe-lan.

General Information
Hemodialysis (HD) and Peritoneal Dialysis (PD) Home Modalities

Myth	Reality
You must buy the dialysis machine to use at home.	Your dialysis clinic will provide the machine if you need one for home use, as well as the supplies.
You can't just decide to do dialysis at home, right?	Anyone on your care team at the dialysis center can refer you, or you could ask them yourself!
Once you decide to do dialysis at home, you can begin right away.	There's a lot to learn and arrange for when preparing for home dialysis. But you can get started by first speaking up.
If you do dialysis at home, you won't be able to change dialysis types or be a candidate for transplant.	Not at all. You can always switch to another home modality or decide you'd like to go to in-center hemodialysis. Also, doing home dialysis does not make you less likely to receive a transplant.
If you do home dialysis, it costs more than at the dialysis unit.	No, not at all. Both Medicare and private insurance cover the cost of home dialysis.
You can't dialyze at home if you are non-compliant in the dialysis center.	Each individual will be evaluated, but those with a high need to control situations may actually do better at home.
If you do home dialysis, your home must be rewired.	Any required electrical work, if needed, is simple and can often be completed sometime during the training.
You can't do home dialysis unless your plumbing is redone.	It depends. One option uses an adaptor that fits onto the faucet. The other option may require some minor plumbing work to be completed.
You can't do home dialysis if you are afraid to insert your own needles.	Many patients have learned how to self-cannulate (insert their own needles) both for in-center and home dialysis. It can preserve the fistula, hurt less, and result in fewer complications. Patients with a specific kind of fistula (an AV fistula) can use a buttonhole technique, which uses dull needles placed into the exact same hole every time you have dialysis. Ask your nurse to learn how.
You must get rid of your pets to do dialysis at home.	Lots of people dialyze at home and still have pets. Clean well and ensure your pets stay out of the room when you connect or disconnect.
When you dialyze at home, you can eat and drink whatever you want.	Dietary and fluid intake limitations remain in place, but you may have a bit more flexibility with your limits and choices. Always check with your medical team when changing your renal diet.

What patient members of the Home Dialysis Affinity Group say about choosing home dialysis…

- *Flexibility and convenience of setting their own treatment schedule*
- *Choosing a treatment with their doctor that best fits their lifestyle*
- *Less strict dietary limits when dialyzing at home*

Peritoneal Dialysis (PD)

Myth	Reality
You'll get an infection!	Very low rates of PD infection are possible when close attention is paid to the causes of peritonitis (an infection of your abdomen), along with training provided to patients on the procedures used to reduce the risk of infection.
If you had previous abdominal surgery, you can't do PD.	Routine abdominal surgeries, such as hernia repairs, C-sections, and some transplants, do not prevent PD as an option. Your doctor and surgeon will help you evaluate your options.
If you have vision or hearing problems, you can't do PD.	Assist devices are available to help with most tasks involved in doing PD.
You need to have some kidney function to do PD.	Kidney function will always be checked, but PD can be done without any kidney function.
If you are overweight, you can't do PD.	A catheter placed differently into your abdominal cavity may be a better option. PD can still be done.
You need to have a lot of space at home to do PD.	You do need some space for PD, but many people who live in efficiency apartments, trailers, and other small spaces find a way to make PD work if they want it.
Only one kind of PD is available.	While all PD involves having a special fluid in your abdomen, you can choose how to handle the process, for example, manually or automated (while you sleep).
When you do PD, you are free to take either a bath or a shower!	A bath is not permitted unless you have a pre-sternal catheter placement. A shower is permissible, and you will be taught how to care for your catheter site after your shower.
When you do PD, you cannot go swimming.	It all depends where you are swimming. Swimming in a lake, pond, river, ocean, or non-chlorinated pool would not be OK because it increases the risk of infection. Generally, swimming in a chlorinated pool could be OK. Always check with your healthcare team first.

Home Hemodialysis (HHD)

Myth	Reality
You won't have any experts at home to help.	You will learn to be an expert. Plus, your home dialysis facility serves as 24-hour phone backup. You will always be near help.
You could bleed to death very quickly.	No one has ever bled to death on HHD. Machine alarms alert you to the detection of just one drop of blood out of place. You will have time to react and fix the problem.
HHD is a huge burden of extra work for a care partner.	It is best if you do as much of our treatment as you can. Some people do HHD without a care partner.
An HHD care partner needs to have a medical background.	Nope, no medical background is needed. The clinic will train you and a partner (if they require one, a care partner is not always needed).
You can't do HHD with a dialysis catheter.	Some programs allow HHD with a catheter. It is best to trade your catheter for a vascular access due to higher infection chances.
Your house must be perfectly clean at all times.	Your home does not have to be perfectly clean to perform hemodialysis at home.
If you do HHD, you must follow the same scheduled days of the week.	Many different schedules are available and can be arranged at home. For instance, short daily dialysis or extended dialysis. You might also consider nocturnal dialysis if you're interested in dialyzing while you sleep. The purpose of home dialysis is to set your own schedule.
You can't get training to do your dialysis at home right from the beginning.	There must be time for evaluation and practice. Everyone is a little different; both you and staff must be comfortable with your skills.
There's a long waiting list to learn how to do HHD.	This varies among facilities offering a home program. Ask your nurse to be certain.

Is It for Me?

You've had the opportunity to review and uncover some of the common myths related to home dialysis modalities. Now, is an opportunity to consider if this is the right treatment option for you.

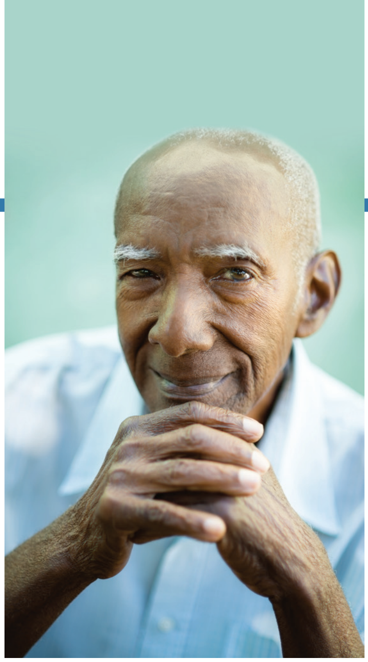
Why should I consider home dialysis?

- More flexibility in my dialysis and daily life schedules
- More normal diet with less restrictions
- May be able to reduce medications
- Less transportation hassles getting to and from a clinic
- Ability to travel more (*depending on your capability with bringing the machine and supplies*)
- I'm interested in managing my own care
- I'd like more energy, both mentally and physically
- I could have better control of my blood pressure
- There would be less stress on my heart and less recovery time after treatment

What type of support would be provided by my dialysis facility?

- The Home nurse will provide one on one training until you are comfortable to dialyze at home.
- Your clinic will be available to you 24/7 either in the facility or by phone.
- You will still have visits to the home facility for labs and evaluations.
- The Home nurse will assist in organizing your home with supplies needed for dialysis.

If you would like to learn more about a home modality option for you, take the next step, research the best options for you and talk with your care team.



Seven Tips Patients Have About Choosing a Home Modality

1. Research your many options.
2. Think about your long-term goals.
3. Involve your care partner in the preplanning process.
4. Consider how you can add home dialysis in your living space.
5. Ask to speak with a patient who is dialyzing at home.
6. Discuss any questions you may have with your healthcare team.
7. Form a partnership with your care team.

Conversation Starter

Below are a few sample questions to start your discussion:

1. I’d like to talk to you about being considered for home dialysis. Where do I start?
2. What are the benefits with dialyzing more frequently at home and what are the choices that are best for me?
3. How long does the training take and what does it entail?
4. Do you have a video I can watch or a web link for more information?
5. Can I talk to a patient who is dialyzing at home?

Add your other questions below:

Home Dialysis Resources

Below is a listing of websites and resources providing you additional information about home dialysis.

Home Dialysis-Related

MyDialysisChoice.org—www.mydialysischoice.org

A program of the non-profit MEI, the "My Life, My Dialysis Choice" website, offers an interactive tool to help you choose the right treatment for you, so you can feel your best AND live the way you want to.

Home Dialysis Central—www.homedialysis.org

A program of the non-profit MEI, the Home Dialysis Central website offers information and education about all types of dialysis.

Home Dialyzors United—www.homedialyzors.org

Home Dialyzors United, a non-profit patient organization, is the only dialysis patient organization dedicated to the home dialysis community.

Alliance for Home Dialysis—www.homedialysisaliance.org

The Alliance for Home Dialysis promotes activities and policies that will facilitate treatment choice in dialysis care, while identifying and addressing systematic barriers that limit access for patients and their families to the many benefits of home dialysis therapy.

Renal-Related Organizations

American Association of Kidney Patients—www.aakp.org

American Kidney Fund—www.kidneyfund.org

End Stage Renal Disease National Coordinating Center—www.ESRDNCC.org

National Kidney Foundation—www.kidney.org

Kidney Patient News—www.kidneypatientnews.org

A special thank you to the Patient and Family SMEs of the NPFE-LAN. Their expertise, compassion, and dedication to making an impact for all dialysis patients is reflected in this educational piece. From March–September 2018, this group of individuals, located across the country, met by conference call monthly to discuss, enhance, and create this toolkit. Without their partnership and engagement, this resource would not exist as it does. We truly appreciate their input.

—ESRD NCC

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