

Empowering Choices:

Your guide to making an informed home dialysis decision.

INTRODUCTION: HOW TO USE THIS TOOL

When managing your kidney failure diagnosis, it is important to remember that you are the leader of your health care team. Kidney failure, or end-stage renal disease, is the fifth and last stage of kidney disease. Once you are diagnosed with kidney failure, your kidneys have stopped working well enough for you to survive without dialysis or a kidney transplant. This tool, developed by the American Kidney Fund, can help you, your loved ones and doctors make health care decisions together. Using this decision aid tool will help you learn more about home dialysis and provide you with the information you need to



In Loving Memory of Nieltje Gedney

The American Kidney Fund dedicates this resource to Nieltje Gedney, a passionate home dialysis advocate who believed in empowering people with kidney disease to take control of their health.

WHY IS IT IMPORTANT TO MAKE YOUR DECISION?

Dialysis is not a one-size-fits-all treatment and there are different options that may best suit your lifestyle. Although you can choose to have dialysis in a center, home dialysis can help put you in charge of your treatments. Home dialysis can also give you more flexibility in scheduling treatments and allow you to spend more time with family and friends or doing other things you love to do.

Research shows there are disparities within home dialysis usage. Many Black and Hispanic/Latino people are not told that home dialysis could be an option for them¹. Being presented with all of the options means you'll be able to make an informed decision about your treatment.



Use the space below to write any notes or questions you have about your experience living with kidney failure.

better understand your options and choose the best dialysis treatment for you – all based on the lifestyle factors that are most important to you. You can also use this decision aid if you are already on in-center dialysis and interested in switching to a home treatment and would like to learn more about your options. After you have completed the activities in this tool, share the results with your health care team at your next doctor's appointment or dialysis visit, along with any questions or concerns, so that you can decide on your treatment together.

You are also more likely to:



Understand the pros and cons of each dialysis option



Be prepared to talk to your doctor about the available options



Have a better understanding of kidney failure



Follow through on your decision

YOUR DIALYSIS TREATMENT OPTIONS

Dialysis cleans your blood when your kidneys are unable to and removes extra waste and water. Although it can improve your symptoms, dialysis is not a cure for kidney failure, it only does about 10 to 15% of the work of healthy kidneys. Other treatment options for kidney failure include transplant and palliative care. A transplant will place a healthy kidney inside your body to do the work your own kidneys can no longer do. An alternative option is palliative care, which is specialized medical care focused on providing relief from the symptoms and stress of kidney failure, with the goal to improve your quality of life. The choice of dialysis as your treatment for kidney failure can change how you manage your condition on a day-to-day basis. You can choose to have your treatment at a dialysis center or at home. There are several types of dialysis, and each can offer different levels of flexibility in your treatment schedule. The two main forms of dialysis are **hemodialysis** and **peritoneal** dialysis.



Periotoneal cavity (inside of your belly) Catheter Catheter Drain line and drain bag

HEMODIALYSIS:

A dialysis machine and a special filter, or a **dialyzer**, removes, cleans, and returns blood to your body. This is a three-to-four-hour process and is done three times a week if completed at a dialysis center. Hemodialysis also requires surgery to create your **vascular access**, which is where the dialysis machine will connect to your bloodstream. Treatment can be done at a dialysis center or at home (home dialysis). A home dialysis machine is a smaller version of the in-center hemodialysis machine that does the same job.

PERITONEAL DIALYSIS:

A soft plastic tube (**catheter**) is placed in your belly by surgery. A cleaning liquid (**dialysate**) is put into your belly through the tube to filter your blood. Dialysate will stay in your belly for about four to six hours as it cleans your blood (**dwell time**). After it is finished cleaning, the dialysate leaves your body through the catheter and will be refilled with fresh dialysate (**exchange**). Peritoneal dialysis can be done at home, as well as during the day or night.





Hemodialysis

HOME HEMODIALYSIS

There are three types of hemodialysis that can be done at home:

1. Conventional home dialysis (standard home

dialysis) is done three times a week or every other day for up to three to five hours. You can choose treatment days and times that best fit your lifestyle. However, it's very important to follow your doctor's instructions for your treatment schedule. Once you are trained, you will need to visit your dialysis center at least once a month to meet with your care team, check your labs and discuss your **treatment logs**.

€ A trea your d

A treatment log is a detailed record of your dialysis treatments.

VASCULAR ACCESS

All home hemodialysis methods require that you have surgery to create a **vascular access**. This access point is where the dialysis machine will connect to your bloodstream. The most common types of vascular access for hemodialysis are **artery vein (AV) fistula** and **artery vein (AV) graft**. An AV fistula is a connection between your artery and vein that is created during surgery and creates a large blood vessel that has a lot of blood flowing through it. An AV fistula is usually located in your arm between your wrist and elbow. An AV graft is a soft, rubbery tube that is usually implanted in your arm.

- 2. Short daily home dialysis is done almost every day for about two hours. Your doctor should discuss the amount of treatment needed. You can schedule your treatment at any time that is convenient. Since you are doing dialysis more often, less fluid needs to be removed each time. This can help you feel better between treatments.
- 3. Nocturnal home dialysis is done at night while you're sleeping. Each treatment session is 6 to 8 hours and can be done every other night, depending on what your doctor recommends. This may be an option if you have work, school, or other commitments during the day.

e If you need to immediately start dialysis, catheters are often used as a temporary access. A **catheter** is a tube placed into your vein, typically in your neck or upper chest. A catheter may be attached to a device called a port that is placed under your skin. The port can help cause less wear and tear on your veins.

An AV fistula is considered the "gold standard"² of vascular access because:

- It is less likely to become infected compared to other types of vascular access
- It can last longer than AV grafts and catheters because it has a lower chance of becoming blocked due to blood clotting

SELF-CANNULATION

Self-cannulation or placing your own needles into your vascular access point at the start of each treatment, is a requirement for home hemodialysis. Self-cannulation may be intimidating, but it can provide you with more control over your treatments, be less painful and may allow your vascular access to last longer. This skill is taught during the required training to dialyze at home, which can range from three to six weeks.

Training for Home Hemodialysis

Your care team will teach you how to:

- Use your dialysis machine
- Recognize and report problems
- Follow your kidney-friendly food and fluid plan, and more

ß

"Self-cannulation may seem like an obstacle but try practicing holding the needles correctly during your home dialysis training. When you're ready to try it on your own, a nurse will be available in the dialysis clinic to help you guide the needle into the fistula."

- Nieltje G., Home dialysis advocate

THE ROLE OF A CARE PARTNER

Some clinics may require you to have a **care partner** to qualify for home hemodialysis. A care partner can be a family member, friend, neighbor, or anyone you trust and can rely upon to assist you during your treatments. Your care partner will also need to attend your home dialysis training and be present during treatments for support, as well as act in the event of a medical emergency. Other responsibilities

may include helping you set up your home dialysis equipment, keeping you motivated during treatment and helping you stay as healthy as possible. Almost anyone can qualify to be a care partner if they receive proper training. Your care partner isn't required to have prior medical training to be able to support your healthcare needs.

What about In-Center Dialysis?

You can also choose to receive hemodialysis at a dialysis center. In-center dialysis can be a part of a hospital, or at a standalone dialysis center. This form of treatment requires you to travel to a dialysis center at least three times a week for three to four hours. Trained staff are available to perform all aspects of your treatment.

Peritoneal Dialysis

Another method of treatment you can choose is peritoneal dialysis, which is almost always done at home. There are two kinds of peritoneal dialysis:

1. Continuous Ambulatory Peritoneal Dialysis

(CAPD) doesn't use a machine for treatment and can be done during the day, but it must be done daily. It works by using gravity to help you do exchanges by hand. Most people do four exchanges a day. Before you go to bed, fill your belly with the cleaning liquid, dialysate, and let it stay overnight. In the morning, you'll start your exchanges again. It takes about 30 to 40 minutes to drain and refill your belly with the dialysate for each of the four exchanges. You can do CAPD anywhere that is clean and dry.

2. Continuous Cycler-Assisted Peritoneal Dialysis (CCPD) uses a machine called a cycler to do your exchanges. CCPD is usually done at night while you are sleeping, but it must be done every night. The cycler usually does three to five exchanges each night and takes about nine hours. In the morning, the machine will fill your belly with dialysate that will stay in your belly throughout the day and until you go to bed and start your treatment again.

CAPD and CCPD requires you to have surgery to place the catheter through the wall of your belly. This is a brief procedure that does not require an overnight stay at the hospital. Once your catheter is placed, you'll receive peritoneal dialysis training. During training, you'll learn how to care for your catheter, use your cycler (if you choose CAPD), how to do an exchange and more. Training usually takes one to two weeks and may be hosted in a dialysis center or hospital. In most cases, peritoneal dialysis can be done on your own. If you would like to have a care partner, they will also need to attend the peritoneal dialysis training.





WHY CONSIDER HOME DIALYSIS?

- You will have more freedom and the ability to dialyze at your own convenience
- You can have more flexibility with what you can eat and drink²
- You may have an easier time keeping employment
- You will experience fewer dialysis side effects
- Less travel time to a dialysis center, as well as reduced transportation costs
- Increased frequency of dialysis can lead to lower mortality rates and better quality of life
- May lead to improved heart health and lower risk for heart disease³

ARE THERE ANY DRAWBACKS TO DOING DIALYSIS AT HOME?

- To get the most out of your treatment, peritoneal dialysis must be done daily or nightly
- Peritonitis, an infection in your belly, is the most common problem that may occur when doing peritoneal dialysis
- The dialysate solution used during peritoneal dialysis contains sugar, which can lead to weight gain if not closely monitored by your care team
- Training for home hemodialysis will take a few weeks to complete
- Some dialysis clinics may require that you have a care partner to be eligible for home hemodialysis
- Learning how to insert your own needles into your vascular access is required to begin home hemodialysis treatments
- Dialyzing at home may lead to a slight increase in your electricity and water bills
- Peritoneal dialysis supplies can be heavy and require significant and clean storage space





Dialysis Decision Map

Use the decision map below to navigate your best option for treating kidney failure. Consider using this decision map to start a discussion with your care team to make a shared-decision on the best treatment for your health needs.





Thinking About Switching from In-Center Dialysis?

Transitioning from in-center treatment to dialyzing at home can give you more freedom, but you may be nervous about trying something new. In addition to using this tool, you can take some time to hear from home dialysis experts and advocates to gain a better understanding of what to know and ask your care team.



Your Dialysis Options

The chart below provides an overview of each form of dialysis. As you read through the options, begin to think about which treatment may best fit into your lifestyle.

	How does it work?	Vascular Access	Sessions and Timing	Training required
Continuous cycler-assisted peritoneal dialysis	Uses a cycler to do your exchanges. The cycler fills and empties the belly three to five times a night while sleeping.	Catheter in your belly (abdomen)	9 hours to complete 3 to 5 exchanges	1 to 2 weeks
Continuous ambulatory peritoneal dialysis	Uses gravity to help you do the exchanges by hand. Water with salt flows from an IV bag through the catheter into your belly. Dialysate and waste drain out of the body.	Catheter in your belly (abdomen)	30 to 40 minutes to drain and refill the solution for each 4 exchanges	1 to 2 weeks
Conventional home hemodialysis	Blood flows from your vascular access through a dialysis machine, which cleans your blood of extra waste and water, and sends the clean blood back into your body.	AV fistula, AV graft, or catheter	At least 3 times a week, with 3 to 5 hours each session	4 to 6 weeks
Daily home hemodialysis	Works similarly to conventional dialysis, but treatment is done for about two hours daily or every other day in home.	AV fistula, AV graft, or catheter	2 hours daily or almost every other day	4 to 6 weeks
Nocturnal home hemodialysis	A dialysis machine cleans your blood as you sleep through long and slow treatments.	AV fistula, AV graft, or catheter	6 to 8 hours at least 3 to 4 times a week	3 to 4 weeks
In-center dialysis	Uses a larger machine built for in-center to filter and return your blood to your body. All treatments are administered by dialysis staff.	AV fistula, AV graft, or catheter	At least 3 times a week, with 3 to 5 hours each session	No training required

MAKING YOUR DECISION

As you complete the section below, consider the activities that are important in your life at this time, your opinions about different home dialysis options and which treatments you think will best fit into your lifestyle. It may be helpful to also ask your nephrologist any questions you may have about home dialysis so you can understand all your options and be confident in your decision.

Check one box based on the importance of each activity or value.

	Not very important	Not important	Neutral	Important	Very Important
Option to continue working and/or go to school					
Flexibility in what you can eat or drink					
Traveling (locally, abroad)					
Having support from other individuals on dialysis					
Ability to serve as a caregiver (for a child, loved one, pet, etc.)					
Having a health care professional do my dialysis treatments					
Having support from other individuals on dialysis					
Improved quality life while on dialysis					
Option to compartmentalize your in-center dialysis treatment from your home life					

Use the space below to write additional activities and values that are important to you.

How much do you think each dialysis option will most likely affect the activities and values that are important to you? Check one box for each treatment.

	Not at all likely	Not very likely	Somewhat likely	Very likely	Extremely likely
Conventional Home Dialysis					
Short Daily Home Dialysis					
Nocturnal Home Dialysis					
Continuous Ambulatory Peritoneal Dialysis (CAPD)					
Continuous Cycler-Assisted Peritoneal Dialysis (CCPD)					
In-Center Dialysis					

Which dialysis option do you think will most likely fit into your life currently?

dialysis may best fit my lifestyle at this time.



Asking your doctor questions about your in your decision. Use the space below to have about dialysis.

Here are some suggested questions to ask your doc

1. How can I get the most out of my treatment?

2. Will home dialysis allow me to take less medicine

3. Can I do home dialysis if I have other health probl

4. Does my clinic require me to have a care partner?

5. How often will I meet with my care team for chec

6. What should I do if I want to switch dialysis treat

7. How much storage will I need at home?

dialysis options will help you be more confident write down any questions or concerns you may
stor:
e?
lems?
2
•
kups?
ments?

NEXT STEPS

Choosing your method of dialysis is a personal and important decision. Even if you are unexpectedly diagnosed with kidney failure and need to start dialysis, you still have the option to choose your preferred dialysis modality, and it can be changed at any time. If your dialysis choice doesn't match your expectations, start a conversation with your health care team to explore other options.

Share the results of this decision aid with your health care team to discuss the next steps in starting a dialysis treatment or switching from in-center to a home option. If you're interested in doing dialysis at home and your doctor turns you down, consider asking for a second opinion. You can also speak with your social worker to discuss the reasons you were turned down, as well as work with your health care team to determine ways you can meet the requirements for home dialysis.

Become proactive and informed about your treatment decisions by sharing any questions, symptoms, or concerns with your health care team.

American Kidney Fund Resources

- <u>Kidney Failure (ESRD) Symptoms, causes</u> and treatment options
- Your CKD toolkit
- <u>Dialysis</u>
- Peritoneal Dialysis

Hemodialysis

- Home Hemodialysis
- Choosing a hemodialysis treatment plan
- <u>About vascular access</u>

Citations

¹<u>https://www.kidneyfund.org/health-equity-home-dialysis</u>

² https://www.kidneyfund.org/treatments/dialysis/about-vascular-access

³ https://www.ahajournals.org/doi/10.1161/CIR.000000000001088



 Interested in more information about insurance coverage and dialysis?
 Visit our webpage to learn more. For additional information on
 kidney disease and dialysis
 visit kidneyhealthforall.org.

GLOSSARY

Albumin-to-creatinine ratio (UACR)	A test to check UACR measure in a person's ui to figure out yo
Artery vein fistula (AVF)	A type of vascu your vein. This to flow through get access to y
Nocturnal Home Dialysis	A soft rubbery needles are ins
Care partner	A family memb upon to assist
Catheter	A tube for mov
Chronic kidney disease (CKD)	Lasting damag cause your kid blood. This car your health.
Continuous ambulatory peritoneal dialysis (CAPD)	A soft rubbery needles are ins
Continuous cycler-assisted peritoneal dialysis (CCPD)	The process of
Conventional home hemodialysis	A treatment yo This form of di schedule beca for you.
Diabetes	A disease that cannot make o body makes th
Dialysate	A cleaning liqu blood. This liqu
Dialysis	A treatment to remove waste
Dialyzer	The part in a he cleaned.
Dwell time	The amount of while it cleans





c for the signs of kidney disease or other health problems. es the amount of albumin (protein) and creatinine (waste) rine (I.e., your pee). Your doctor will compare these results bur UACR.

ular access to create a connection between your artery and is done surgically to make a large blood vessel for blood n it. During dialysis, needles are inserted in the AV fistula to your bloodstream.

tube that a surgeon implants into your arm. During dialysis, serted into a tube to get access to your bloodstream.

per, friend, neighbor, or anyone who you trust and can rely you during your home dialysis treatments.

ving fluids in and/or out of your body.

ge to your kidneys that can get worse over time. CKD may neys to lose their ability to filter waste and fluid out of your n cause waste to build up in your body and harm

tube that a surgeon implants into your arm. During dialysis, serted into a tube to get access to your bloodstream.

f using a machine, called a cycler, to do your exchanges.

bu do yourself at home or with the help of a care partner. ialysis may allow you to have a more flexible treatment suse you can do your treatments when it's convenient

causes your blood sugar to be too high because your body or use insulin the way it should. Insulin is a hormone your hat helps turn sugar from the food you eat into energy.

iid with sugar in it that pulls fluid and waste from your uid is used during peritoneal dialysis.

clean your blood when kidneys are unable to. It helps and extra fluids in your blood.

emodialysis machine where your blood gets filtered or

^f time dialysate stays in your belly, usually four to six hours, your blood.

Estimated Glomerular Filtration Rate (eGFR)	A blood test that shows how well your kidneys are working.		
eGFR stage 1	eGFR is 90 or higher, meaning it is normal or high. An eGFR number of 90 or more means your kidneys are working well to filter waste from your blood.		
eGFR stage 2	eGFR is 60 to 89. An eGFR number between 60 and 89 means your kidneys' ability to filter waste from your blood may be mildly decreased.		
eGFR stage 3	 Stage 3a: eGFR is 45 to 59; Stage 3b: eGFR is 30 to 44. An eGFR number between 45 and 59 means your kidneys may have mild to moderate damage and do not work as well as they should to filter waste from your blood. An eGFR number between 30 and 44 means you may have moderate to severe kidney damage. Your kidneys still work to filter waste from your blood, but not as well as they should. 		
eGFR stage 4	eGFR is 15 to 29. An eGFR number between 15 and 29 means you may have severe kidney damage. Your kidneys still work, but they are close to failing (which means not working at all).		
eGFR stage 5	eGFR is less than 15. An eGFR number lower than 15 means you may have severe kidney damage. Your kidneys have failed and no longer work to filter waste from your blood, or they are very close to failing.		
Exchange	The process of draining used dialysate out of your belly and refilling it with fresh dialysate.		
Hemodialysis	A type of dialysis treatment for kidney failure, which uses a machine to clean your blood.		
High blood pressure	A condition that occurs when the force of your blood pushing against the walls of your blood vessels is too high. This is also known as hypertension and is one of the most common causes of kidney disease.		
Kidney failure	The final stage of chronic kidney disease. During this stage, your kidneys have stopped working well enough for you to survive without dialysis or a kidney transplant.		
Nephrologist	A doctor who specializes in the kidneys and kidney diseases.		
Nephrology nurse	A registered nurse who is trained to take care of kidney patients. You will see nephrology nurses in your doctor's office and in your dialysis center.		
Nephrology social worker	A licensed or certified professional that can help you and your family cope with kidney disease and all the changes that come with it, such as insurance, work and travel.		
Nocturnal home hemodialysis	This treatment schedule allows you and your care partner to do your treatments at home, while you sleep.		

Peritoneal dialysis	A type of dialys uses a fluid tha your blood.
Peritonitis	An infection in y happen when d
Short daily home hemodialysis	A type of hemo week or almost convenient for y
Self-cannulation	A technique tha access to start
Renal (kidney) registered dietitian nutritionist (RD or RDN)	A professional t nutrition to help and fluid plan.
Support system	A network of pe support. Some driving them to
Vascular access	The location wh Before you can surgeon. The m AV graft and a c

sis treatment for kidney failure that can be done at home. It at you put in your belly and is then removed to clean

your belly that is the most common problem that may doing peritoneal dialysis.

odialysis that is done for about two hours, every day of the st every day. It can be done at any time of the day that is you.

at allows you to place your own needles into your vascular t home hemodialysis treatment.

that has special education and training in food and p people with kidney disease follow a kidney-friendly food

eople who provide an individual with practical or emotional e examples can include cooking meals for someone and o an appointment.

here the dialysis machine connects to your bloodstream. In start dialysis, a vascular access will be created by a most common types of vascular access are the AV fistula, catheter.

SPONSORSHIP RECOGNITION

The development of this tool was made possible thanks to Kidney Health for All Presenting Sponsors AstraZeneca, Boehringer Ingelheim and Eli Lilly and Company, Travere Therapeutics, Inc., Vertex Pharmaceuticals, as well as Equity Sponsors Otsuka America Pharmaceutical, Inc., and Sanofi. Additional support is provided by Merck.





KIDNEY HEALTH FOR ALL™

KIDNEYFUND.ORG