



Choosing My Future with Kidney Failure



Developed by the Medical Education Institute

My Kidney Care Team

Kidneys are complex—and so is the care you need to feel your best. In fact, you will have a whole team to help you on dialysis. **You** are the most vital member of your own team, and the only one who knows how you feel. Other members are:

Team Member	How They Can Help
Family and friends	They can learn with you and help you see that you are still YOU.
Nephrologist	Your kidney doctor will prescribe treatments based on your blood tests and your goals for life. Be sure to share your goals!
Other Doctors	A primary care doctor may take care of your general health needs. You may see specialists for other issues.
Clinic Nurses	Nurses teach you and care for you. They assess your health and share what they learn with your doctor. Ask about your treatment and tell your nurse about symptoms.
Home Training Nurses	A home nurse can teach you how to do your home dialysis treatments. When you and your nurse are confident that you will succeed, you can go home. You will have a phone number to call for questions or help at any time of the day or night.
Registered Dietitian (RD)	Your RD will ask you what foods you like best, and help you fit them into your meal plans. What you can eat will depend on your blood tests.
Social Worker	Your clinic social worker can talk with you about your feelings and goals. Ask about rides and how to travel.
Technicians (techs)	A tech may do your treatments, with a nurse supervising. Your tech can teach you how the machine works.

Key Contacts:	Phone Numbers:
My Clinic is: _____	() _____
My Nephrologist is: _____	() _____
My Home Training Nurse is: _____	() _____
My Dietitian is: _____	() _____
My Social Worker is: _____	() _____
My Supply Company is: _____	() _____

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Disclaimer

This booklet is a guide for people who have chronic kidney disease or kidney failure. Use of this booklet does not replace the need to talk with your own doctor and healthcare team about your care and your options.

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My Future with Kidney Disease

You *can* have a good future with kidney disease if you **stay positive, learn, and take action to care for your health**. You can make choices that will let you keep doing things you love. Taking charge of your health can help make you less afraid.

Kidneys that stop working affect your mind and your emotions—not just your body. Even if you knew that you might hear this news one day, it can still be scary. It is 100% *normal* to have strong feelings, like:

- **Fear** – for your loved ones, your job, your home.
- **Grief** – for loss of the life you thought you would have.
- **Anger** – at yourself, at your doctor, at God.
- **Depression** – it may seem as if nothing you do matters.

While you may feel as if the life you knew is over, it's not!

With *any* chronic disease, you have a job: to self-manage. Your care team are experts in dialysis. But, YOU are the only one who can:

- Eat your food.
- Drink (or limit) your fluids.
- Stay active or exercise.
- Get all of the dialysis you need.
- Go to your doctor appointments.
- Take medicines the way your doctor prescribes them.
- Watch for symptoms and tell the rest of your care team.

You will need to learn a lot to do this new job—and it will be worth it. **You can do this.**

Learn Kidney Words in Our Glossary

Kidney disease brings you a whole new language. Learn it! Scan the code with your smartphone camera or go to <https://lifeoptions.org/glossary/>



Seek—and Give—Support

“Lean on me, when you’re not strong. And I’ll be your friend. I’ll help you carry on. For, it won’t be long ‘til I’m gonna need somebody to lean on.” - Lean On Me, Bill Withers

We *all* need to lean on people in life! When things are going well in your life, it can be easy to find others to spend time with. But now, you may not know how you will feel from one day to the next. You may need to cancel plans at the last minute—often. Friends may stop inviting you when you keep saying no. Having support helps *all* of us to feel better and maybe even live longer. So, how do you get the support you need?

Be More Than Your Illness

You are much more than just your kidney disease: **you are still you.** Show that you care. Listen to what loved ones are going through, and be happy for them when things go well. Encourage them when times are hard. If you can’t see them in person, you can still call, text, video chat, or email and stay part of their lives.

Learn What You Need

Think about what you need to feel supported. This can change over time, so what do you need *now*? You might want to hang out and watch TV. Share meals. Have someone throw in a load of laundry for you or run an errand. Or, you may just need to have someone listen and not try to fix things. **Make a list** that you can add to as things occur to you.

Try to have one or more people in your life who know your health history and can help you in an emergency. They can call others who are close to you and advocate for you with your care team. NOTE: You will need to sign a HIPAA release form if you want doctors or nurses to give your helpers information about your health.



Share What Would Help

People often say vague things like, “*Let me know what I can do to help.*” Some friends or family may fade out of your life; others may step up in ways you did not expect. **Ask those who offer to help to do one thing from your list.** For example, a friend who loves grocery shopping might not mind picking you up a couple of things. Your friend can feel good about helping you, and you can get some of what you need.

Add to Your Network

Reach out to meet new people. Use a higher energy time of day to do something you enjoy and will look forward to. If you like to read, find a book club. If you love to garden or fish or crochet, you



might teach others how. Join a faith community or fight for a cause you care about. It can be easy to forget that there's a world out there that needs what only *you* can do. Volunteer if you can—helping others helps you, too. If you go online, there are Facebook support groups for those with kidney failure. You can learn a lot and talk to others who know what you are going through.

Show Gratitude for Support You Receive

We all like to feel that what we do for someone else is *appreciated*—not just *expected*. You can show gratitude in a number of ways. Say thank you and tell people what their help means to you. Offer a hug. Sew on a button for a friend who can't thread a needle. Send on an article you know someone would enjoy, or do a chore he doesn't like. Buy her lunch. You get the idea.

Could I Be Depressed?

Depression is common in those who do—and don't—have kidney failure. If you've had some of these feelings most of the time for 2 weeks or more, you may be depressed:

Feelings	Signs
<ul style="list-style-type: none">• Sad, anxious, empty• Hopeless• Helpless• Low energy, fatigue• Irritable• Guilty, worthless	<ul style="list-style-type: none">• Loss of interest in things you enjoy• Trouble with thinking or decisions• Moving or talking slowly—or feeling restless• Sleeping too much—or not enough• Eating too much—or not enough• Thoughts of death or ending your life

Depression is a dark and hopeless place. Getting help for depression can bring light and hope back into your life. If you feel like this, there is help! You can:

- Spend time in nature.
- Get a plant or a pet to care for.
- Volunteer to help others.
- Talk to your doctor about safe exercise.
- Try an antidepressant.
- See a counselor.
- Switch treatments if the one you use does not fit your life.



Choose a Treatment that is Right for You

There are three main types of treatment if your kidneys fail: Transplant, Dialysis, and Comfort Care. Some have more than one option. You have choices. The key is to choose a treatment that will fit how YOU want to live and what is most important to you.

"Dialysis and transplant are treatments—not cures. They let us extend our lives. Both offer a chance to live as normal and as productive a life as our attitudes allow."
Carol Z.

Why do I feel LUCKY to have kidney failure? My mom died from pancreatic cancer after 6 months of terrible suffering. She didn't get any options to keep living. My only brother died of a massive heart attack on his way to work at age 52. He didn't get any options to keep living. We have options."

Stephen B.



Kidney Transplant

For a **transplant**, a surgeon will put a healthy kidney into your belly. One new kidney will grow and do most of the work of two. You must pass many health tests to be approved for a transplant. And, you will need to take drugs to suppress your immune system so it will not fight off (*reject*) the new kidney.

Do you have type 1 diabetes?* **If so, ask your doctor about a kidney and pancreas transplant (KP).** When this works, you do not need insulin or dialysis. You may get a transplant faster if you need two organs. When both come from the same donor, you may need fewer meds than if you had two donors. *Some centers do KPs for people with type 2 diabetes who use insulin.¹

"For me, transplant was the answer and I've been blessed with so very few problems from my two transplants over the past 24 years that I wouldn't even bother listing them."

John L.

"I never left the hospital with my first transplant. A second one lasted 23 months. The 3rd never fully worked and I stayed on and off dialysis for a year until it quit. The last one never worked and was taken out because it caused fevers and pain. But, I am still here!"

Elaine V.

A transplant is not a cure. You will still have kidney disease. But, while a transplant works well, your life may be more like it was before your kidneys failed.

Transplant and Your Lifestyle

- **You may feel well and have more energy.**
- **Transplant is work-friendly for most jobs.**
- **Travel is easy, with no dialysis to worry about.**
- **You can eat and drink more like you normally would.** (A low salt, healthy diet is advised. Raw seafood is not.)
- **You may sleep well at night.**
- **Women who have had transplants can have healthy babies.**

Transplant Cautions

- **You will have a big surgery—and all surgery has risks.**
- **It can take months to recover from a transplant.** You will need help at home at first.
- **Your immune system must be suppressed to protect the new kidney.** You can catch other illnesses.
- **Very rarely, a kidney will not work at all.** And, a transplant can fail at any time.

Transplant Medicines

A new kidney may feel as if it is now part of you. Your body does not agree. The new kidney is “foreign,” so your immune system can reject it even years down the road. The closer the match of a new kidney is to your own blood and tissues, the fewer meds you may need. Like all meds, transplant drugs can cause side effects:

- **In the short term,** some people have stomach upset, diarrhea, mood swings, or strange dreams. They may have weight gain, swollen gums, or a puffy “moon” face. Hair may grow where it is not wanted. These problems, if you have them, tend to get better once your body gets used to the meds or your doses are reduced after a few weeks.
- **In the long term,** transplant meds raise the risks of cancer and diabetes. The cancer risk is mostly for skin cancer. Stay out of the sun and use sunscreen to help lower this risk. Each transplant center uses its own mix of meds. Talk to your center about the meds you would take and their side effects.

Most transplants work well for 5 to 10 years or so—and some last for decades.² As the meds get better, more kidneys may last longer. There are no guarantees. If a transplant fails, you can still do dialysis, either for good or until you get another kidney. Some people have had as many as four transplants.

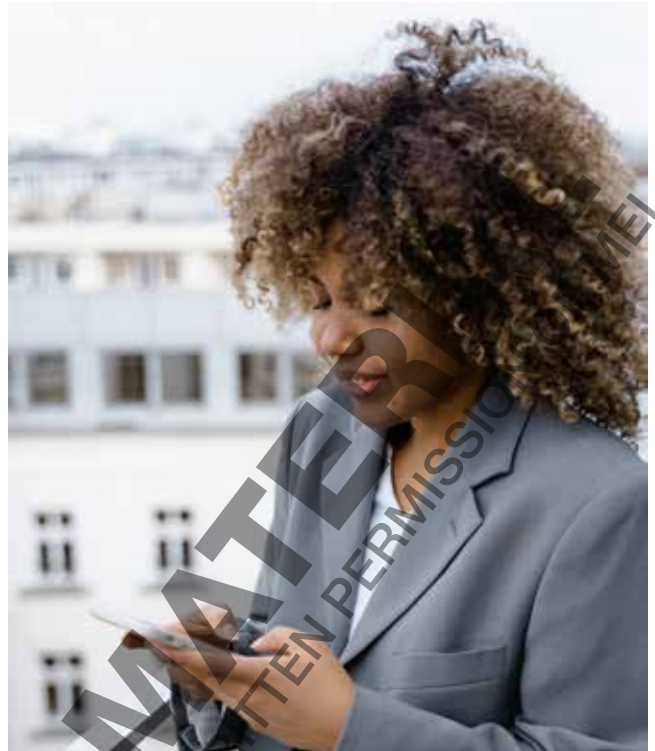


Where Kidneys Come From

Kidneys come from two types of donors:

Deceased donors. Some kidneys come from people whose families donate their organs after brain death. It can be a great comfort when something good comes out of the tragic loss of a loved one.

Living donors. A healthy living person can donate a kidney. Most living donors are relatives. But, neighbors, friends, and even strangers can donate. If someone is willing to donate, but is not a blood or tissue match for you, you may be able to trade donors. In a **paired donation**, your donor gives a kidney to someone else who needs one. Then his or her donor gives a kidney to you. All of the transplants may be done on the same day so no one backs out. Some “chains” of paired kidney donation have helped dozens of people. Living donor kidneys tend to last longer than deceased donor kidneys.



Things to Think About with Both Kinds of Donor

DECEASED DONOR	LIVING DONOR
HOW TO GET ONE	
<p>The United Network for Organ Sharing (UNOS) runs the U.S. program that oversees who gets kidneys from deceased donors. You must go to a transplant center and have many tests done to be on the list. Getting on the list is not automatic. But, when you get on the list, you get credit for the time you wait.</p>	<p>You must go to a transplant center and have tests. You will need to tell people you know about your kidneys. When you do, one or more may offer to be tested. Or not. Not wanting to be tested may be due to fear of pain or surgery. Or, they may not be able to lose the month it takes to recover.³ Someone can love you and not offer you a kidney.</p>
HOW LONG IT TAKES	
<p>Once on the list, your wait may be just days or weeks, but most people wait years. The wait time depends on your blood type. You can be listed at more than one transplant center, as long as they are in different states and you can get there quickly if they call you.</p>	<p>A living kidney transplant can go quite quickly after all of the tests are done. And, you can schedule the transplant at a time that works for you and your donor. If you don't have people who can or will donate, it can take time to find a donor. Some people have found donors through Facebook, billboards, and other creative ways.</p>
RISKS	
<p>You may not know much about a deceased donor and his or her health history. A donor may have a virus you could catch, or a hidden cancer.</p>	<p>Most donors do well. In the short term, all surgery has some risk. In the long term, there is a small risk of kidney failure. In 52 studies of over 100,000 donors, fewer than 1 in 1,000 went on to have kidney failure.⁴</p>

What to Expect After a Transplant

Right after a transplant, you will be in intensive care. You may stay in the hospital for a week or two. It can take time for a new kidney to “wake up” and work. If the kidney works, you will not need dialysis. You may need biopsy tests to see how the kidney is doing. You will take the new medicines, and your care team may need to change the doses, based on your test results.

Once home, you will need to go to the transplant center often for blood tests to check on your kidney. A healthy lifestyle can help you keep your new kidney. It is vital to not smoke—those who smoke after a transplant are much more likely to have it fail. Eat a healthy, balanced diet, drink lots of fluids, and stay active. Wash your hands and use hand sanitizer to avoid colds and other infections. If you want to have a baby, your doctors may suggest that you wait one year to try.

Seven Ways to Do Dialysis

There are two main types of dialysis: peritoneal dialysis (PD) and hemodialysis (HD). And, there are two ways to do PD and five ways to do HD. **So, there are seven ways to do dialysis all together.**

Good dialysis does more than just keep you alive. It eases your symptoms. It lets you *live*, and have a good quality of life. You can switch treatments at any time and choose a better fit for you. For example, if what matters to you is to:

- **Work or go to school**, you need to feel well and control your schedule.
- **Travel**, you may want a treatment you can take with you.
- **Eat what you love**, you may want fewer limits on your diet.
- **Have a baby**, you will need your blood to be as clean as it can be.
- **Care for children or others**, you will need to have a lot of energy.

- **To get a kidney transplant**, you need to stay as healthy as possible.
- **To live as long as you can**, you need more hours and days of treatment.



My Kidney Life Plan.org A program of the NIDDK

Kidney disease can affect every part of your life.

Your kidney treatment is your choice. Use this FREE web tool to help choose the right option for you.

Go to My Kidney Life Plan.org to learn how each option may impact your life.

PD Standard HD Daily HD Nocturnal HD Transplant Comfort Care

The banner features a background of yellow daisies and butterflies. It includes a QR code in the bottom right corner.

This free tool, at www.mykidneylifeplan.org, can help you see what may suit *your life* best. Share the 1-page summary with your doctor, and talk about what you want.

When to Start Dialysis

For many years in the U.S., doctors thought that dialysis should start at stage 5 chronic kidney disease (CKD). Now, a number of large studies have found that it does not help to start that soon.^{5,6,7} In fact, starting early may even be harmful.^{8,9,10} **Numbers alone are not enough, but kidney function of 6–9% may be the best “window.”**¹¹ If you have symptoms that bother you a lot, you may want to start a bit sooner. Your eGFR can be a useful guide for when to get an access or transplant work up. Scan the code to learn about CKD stages and your eGFR.



How Dialysis Works

Healthy kidneys keep a *constant balance* in your body. To do this, they:

- Filter each drop of your blood to remove water and wastes
- Help control your water, salt, and blood pressure levels
- Make hormones for strong bones and to form red blood cells
- Keep your blood at the right pH (acid/base) level



Dialysis cannot keep a constant balance, because you don't do it all the time. But, some types of treatment clean your blood far more than others.

All dialysis shares three things in common:

- 1. A membrane.** A filter with pores (holes) keeps in large cells, like protein and red blood cells. Smaller wastes and water can fit through the pores. Dialysis is a bit like a tea bag.
- 2. A way to access your blood to clean it.** A plastic tube may be used (for PD) or a surgeon can link an artery and a vein (for HD).
- 3. Dialysate (cleansing fluid).** Your blood is on one side of the membrane. Dialysate, a prescribed blend of water and salts, is on the other side. Wastes and water pass through the pores into the fluid, which is thrown away.

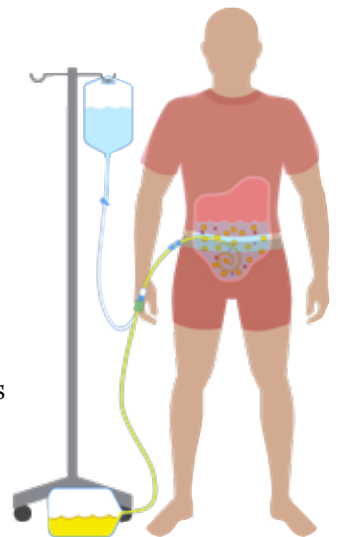
Two Ways to Do Peritoneal Dialysis (PD)

If you choose PD, a nurse will teach you how to do it at home. The inner lining of your belly is used as a membrane to clean your blood. You fill your belly with sterile dialysate using a tube placed by a surgeon. During a *dwell* (wait) time, wastes and water flow into the fluid, which you then drain out. This is called an *exchange*, and takes 20 minutes or so. There are two ways to do PD exchanges:

- 1. Automated PD (APD)** uses a cyclor machine to do exchanges at night while you sleep. You may also need to do one exchange during the day, by hand.
- 2. Continuous ambulatory (walking around) PD (CAPD)** means that you do all of your exchanges by hand. Most people do one around breakfast, lunch, dinner, and bedtime.



APD



CAPD

PD Option	Exchanges	Days	Site	Who Does the Treatment?
1. APD	Multiple	6–7 nights	Home	You, a care partner is optional
2. CAPD	4	Everyday	Home	You, a care partner is optional



PD and Your Lifestyle

- **PD is work-friendly.** With PD each day, your energy may be constant, which can help you keep a job. A manual mid-day PD exchange can be done in a clean room at work.
- **PD is travel-friendly.** You can take a cyclor for free on a plane. Or, put it in the trunk of a car or in an RV. Companies ship PD supplies at no charge in the continental U.S.
- **Your days may be free.** Most people use a cyclor at night. You may need a daytime exchange when your kidney function drops.
- **PD works gently and slowly.** This mimics how your kidneys used to work, which can help protect the function you have left. This function matters! Every little bit of urine you still make helps you live longer.¹²
- **There are no needles.** If you are afraid of needles, this is a big plus.
- **You can have pets**—but they need to stay out of the “clean” room you connect the PD tubing in. It may be best if pets don’t sleep with you at night if you use a cyclor.
- **Your diet and fluids may not have to change much.** How much depends on your blood tests.
- **You can reach to the bathroom or a loved one’s room on a cyclor.** Ask your care team how.

PD Cautions



- **PD supplies take up a lot of space in your home.** It can help to take the bags out of the boxes and store them in roll-out bins under a bed, in a sturdy dresser or file drawer, or on shelves.
- **Catheters can get blocked.** They may need to be moved or unblocked.
- **Some people have “drain pain” when they start to use a cyclor.** For most, this will go away. Or, some choose to do exchanges by hand.
- **You will lose 1–2 work days a month for a clinic visit and to get supplies.**
- **Having a PD catheter in your belly (or chest) can change how you feel about your body.** Some people have a hard time getting used to this, and it can affect their self-esteem.
- **PD fluid has sugar in it.** You may gain weight if you don’t limit other carbs. You may need more insulin if you have diabetes. Sugar can fuel infection, so you need to be extra careful.
- **Most clinics will not want you to take tub baths or use hot tubs.** They will not want you to swim in ponds, lakes, or public pools, due to the risk of infection. With a waterproof bandage, you may be able to swim in a private pool. With a chest (presteral) PD catheter, you can take baths, but many doctors don’t use these.
- **Over time, PD can stop working as well.** Have a plan for what treatment you want to do next.

Your PD Catheter

A PD catheter is a tube made of silicone or polyurethane. The tube is about the size of a soda straw, but soft and flexible. The tip should rest in your lower belly. You should not be able to feel it. A surgeon can place a catheter in half an hour or so, and you will go home the same day.

Most people do not have a lot of pain after a PD catheter is placed. Some go back to work the next day. Others have a few days where they need to take pain pills and wear sweatpants. Your PD training nurse will want to see your catheter and flush it with fluid. S/he will teach you how to care for it safely and avoid infection. If a PD catheter does not drain, shifts to the wrong spot, or hurts, it can be moved or you can get another one.

A PD catheter can be used right away, if you need urgent-start PD.^{13,14,15} You would lie down when fluid is put in your belly, to avoid putting pressure on the new catheter. And, less PD fluid is used at first. This is called *low-volume, recumbent-only* (LVRO) PD, and can be a safer choice than starting HD with a catheter. Or, you may not need to use a PD catheter right away. In this case, the surgeon may leave it under your skin. When it's time to start PD, a small cut will be made and the tube will be pulled out.



Five Ways to Do Hemodialysis (HD)

HD is done with a filter called a *dialyzer*. A clear plastic case is full of hair-thin, hollow fibers—the membrane. A pump on an HD machine pulls blood out of your access and brings it to the dialyzer through a tube. Your blood goes through the insides of the fibers. Dialysate bathes the outsides. Then, the pump



pushes your blood back to you through a second tube. With each pass through the dialyzer, some water and wastes flow through the pores into the dialysate, which is sent to a drain.

You can learn to do HD in the comfort of your own home, or at a clinic.

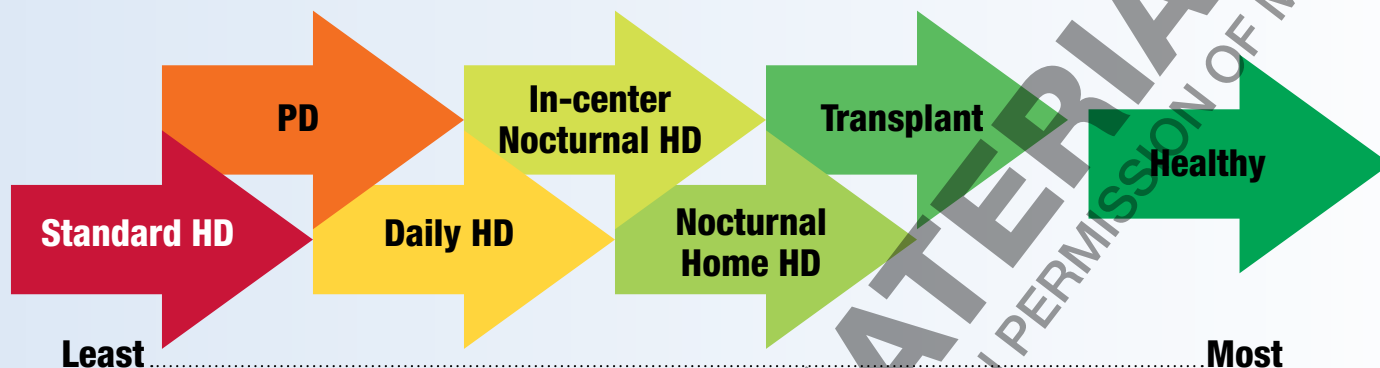
HD Option	Hours	Days	Site	Who Does the Treatment?
3. Standard home	4–5	3*	Home	You and a care partner
4. Daily home	3	5–6	Home	You, a care partner is optional
5. Nocturnal home	8	3–6	Home	You and a care partner
6. Nocturnal in-center	8	3	Clinic	Nurses, technicians, you†
7. Standard in-center	4	3	Clinic	Nurses, technicians, you†

* Or, every other day

† You can learn to do self-care in a dialysis clinic and help do your treatments.

More Dialysis FEELS More Like Having Healthy Kidneys

The arrows show you which options remove more water and wastes. If you choose a home form of HD, the clinic will get the machine for you. New home HD machines are easy to use. A nurse will teach you the steps and you will practice until you are *confident*.



With good dialysis, you can feel your best and live as well as you can. **If you do not feel well, talk with your doctor.** A change in your prescription—or your option—can make your life work better.

Home Hemodialysis (HD)

HD can be done in the comfort and privacy of your own home, once a nurse teaches you how. You won't go home until you are *confident* that you can succeed. And, you will have 24-hour nurse backup by phone. For home HD, you may need a partner. Medicare will not pay for one; most HD partners are family members or friends. In 2017, the FDA approved **solo home HD** during waking hours for capable adults who use a NxStage machine. So, you may not need a partner to do home HD.

Home HD and Your Lifestyle

Home HD can help you feel in more control and give you a more normal life:

- **You can do treatments on your schedule.** You will go to the clinic just once a month.

- **Home HD can be travel-friendly.** You can take a NxStage machine with you for travel. Or, set up treatments at a clinic.
- **You can eat and drink with fewer limits**—or you may have *no* limits with nocturnal HD.¹⁶
- **You may sleep better.** Home HD can help you sleep better at night than other options.^{17, 18, 19}
- **You may have more energy.** Daily home HD removes water 5 or 6 days a week. Nocturnal home HD removes it slowly, overnight. Gentle water removal boosts your energy.
- **Daily or nocturnal²⁰ home HD may allow for a more normal sex life.**
- **Nocturnal home HD is work-friendly.** You may feel well enough and have the energy to work,²¹ and treatments done at night do not take time out of the workday.
- **Nocturnal HD may make it possible to have a healthy baby.²²**
- **You may live longer.** Nocturnal HD helps people live about as long as with a transplant from a deceased donor. This is about three times longer than with standard HD or PD.^{23, 24}



Home HD Cautions

- **You *have* to do the treatments.** It may be tempting sometimes to skip them.
- **If you have a fistula or graft, you or your care partner will need to put in your needles.** If you can see and reach your access and use your hands, it's best if you do this. You are the *only one* who can feel both ends of the needles. And, it hurts much less when you do it. People can and do put in needles with their non-dominant hand, too.
- **When things go wrong at home, you will need to deal with them.** You will practice during training. Home HD is very safe—or the FDA would not have approved it. We suggest that you use a checklist at each treatment, just like an airline pilot would. It helps you avoid mistakes.
- **You lose 1–2 work days a month for a clinic visit and to get supplies.**
- **Home HD supplies take up space in your home—**about 1/3 of the space that PD needs.

Own Your Treatment—With or Without a Care Partner

- **It's your treatment.** *Do as much of it as you can.* Most do PD by themselves. Home HD can be done solo during the day if you are able. Don't make a partner do it all.
- **Put in your own needles** for home HD if you can see and feel well enough. This is the most stressful part of a treatment for you—and for a partner.
- **Ask for respite**—a treatment or two in the clinic—if your partner needs a break.

Show gratitude *often* to someone who helps you to feel better with home treatment. Have a date night. Hug during the standing blood pressure. Mainly, say thank you. Helping you with home dialysis means you are on a team to make both of your lives better.

Standard In-Center HD

You can also do HD in a clinic, where others get their treatments at the same time. You may have one or more choices of nearby clinics to work with.

- **Standard in-center HD** treatments tend to be 3–4 hours long, three times a week. Each treatment will be at the same time on Mon/Weds/Fri or Tue/Thu/Sat.
- **Nocturnal in-center HD** treatments tend to be from about 8 p.m. until about 4 a.m. on Mon/Weds/Fri.

Either way, there are four days a week with no treatments. So, zero water or wastes are removed.

In-Center HD and Your Lifestyle

- **You can travel.** The social worker can help you reserve a time slot at a clinic near where you want to go. The treatments on your trip will likely be standard ones.
- **You will spend time with others.** In the clinic, other people who are on in-center HD will be getting their treatments, too.
- **You will have diet and fluid limits.** Standard in-center HD is the least dialysis you can get. So, you must do some of the work with what you eat and drink. You may be able to have 32 oz. of liquid per day, plus your urine volume. The diet is complex, and you will have a dietitian to help you sort it out and find things you can eat and enjoy.
- **Nocturnal in-center treatments are more gentle than standard ones.** Since they are twice as long, they remove far more water and wastes, too. But, few clinics offer this.
- **Nocturnal in-center HD can make it easier to work.** Treatments done at night won't take time out of the work day, and you will have more energy.²⁵
- **People tend to live longer with more hours of HD.**^{26, 27, 28} Nocturnal in-center HD is twice as many hours as standard.

In-Center HD Cautions

- **Standard in-center HD can change your life the most.** You may not get to choose when your treatments are done. (You can ask.) You may feel less in control.
- **Standard in-center HD can affect your sleep²⁹ and your sex drive.** This option can also make it hard to have a baby or father a child.³⁰



- **Standard in-center HD is not work-friendly.** About one in four working people can keep a job once they start this treatment.²¹
- **Standard in-center HD can make you feel drained.** With just 12 hours a week to remove water, it tends to be done quickly, which is hard on you. You can help make the treatments easier on yourself. Avoid salt and follow your fluid limits—so you can remove less water.
- **In bad weather—or a pandemic—you still need to come to the clinic to get your treatments.**
- **Over time, your bones, joints, and nerves can be harmed by standard in-center HD.** The wastes in your blood that can cause the most damage take a lot of time to remove. Treatments of 3–4 hours at a time 3 days a week can remove only a small amount of these wastes.³¹

Why Do Some People Feel Worse After HD?

Recovery time is how long it takes to feel well after HD. With good HD, it is 2 hours—or less. People feel better *and* live longer when they recover in less than 12 hours.³² Why might it take a long time to recover?

Water. From day to day, how you feel on dialysis is almost all about how much and how gently water is removed. Body water is:

1. **Inside your cells** (about 67%)
2. **Between your cells**—a sort of soup your cells float in (about 24%)
3. **In your bloodstream** (about 7%)

When you swell or are short of breath, that water is inside or between your cells. *But, dialysis can only reach the water that is in your blood.* A treatment that



removes too much water—or does it too quickly—**stuns your organs.** Your blood pressure drops. Your brain and heart get less blood flow. They are starved of oxygen, which can cause:

- Painful muscle cramps
- A bad headache
- Stomach upset
- Dizziness, chest pain, heart damage—and even sudden death

Tell your doctor and care team if you still make a lot of urine. You may not need to take off much—or any—water. Cool dialysate can keep your blood pressure from dropping. Your doctor can adjust your treatment so you feel better. Or, you can switch to PD or a gentler HD option.

HD Access: Getting Your Blood to and from the Dialyzer

There are three types of access for HD, as you can see in the chart on the next page. If your veins are healthy enough, get a fistula or a graft.

Care for Your HD Lifeline

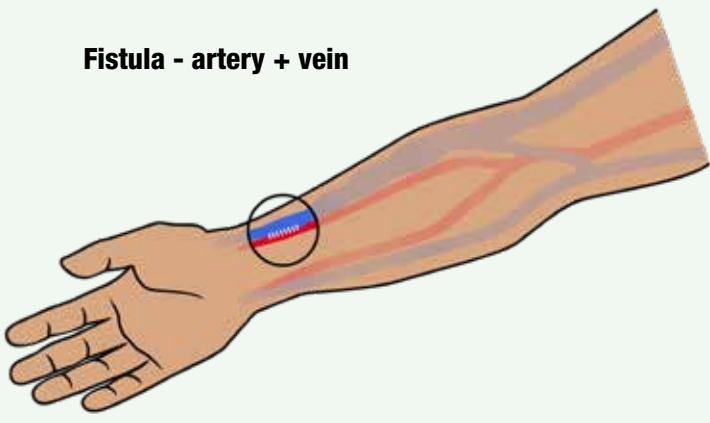
Your access is your HD lifeline. Always tell your care team or surgeon if you have a fever. You may need to go to the emergency room.

- **Look** at your access each day for signs of infection. These include warmth, redness, pain, pus, or swelling. Tell your care team if you have these.
- **Feel** a fistula or graft each day to be sure it has a pulse, called a *thrill*. If the pulse stops, quick action could save your access. Call your surgeon or clinic right away.

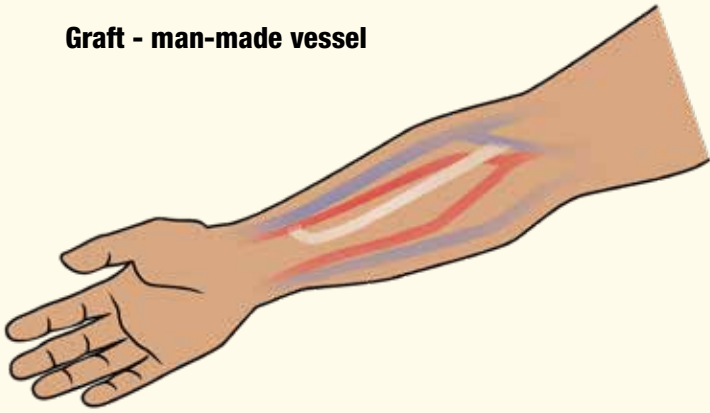
- **Protect** your access. Never squeeze your access arm. See that staff wash their hands before they touch it. Don't let anyone draw blood, start an IV, or take your blood pressure on your access arm. Keep scissors away from a catheter. If an access starts to bleed a lot, put pressure on it and call 911.

All HD accesses will need maintenance. You may need to go see your surgeon. Or, you may be seen in an interventional radiology center. With care, an HD access can last for years.

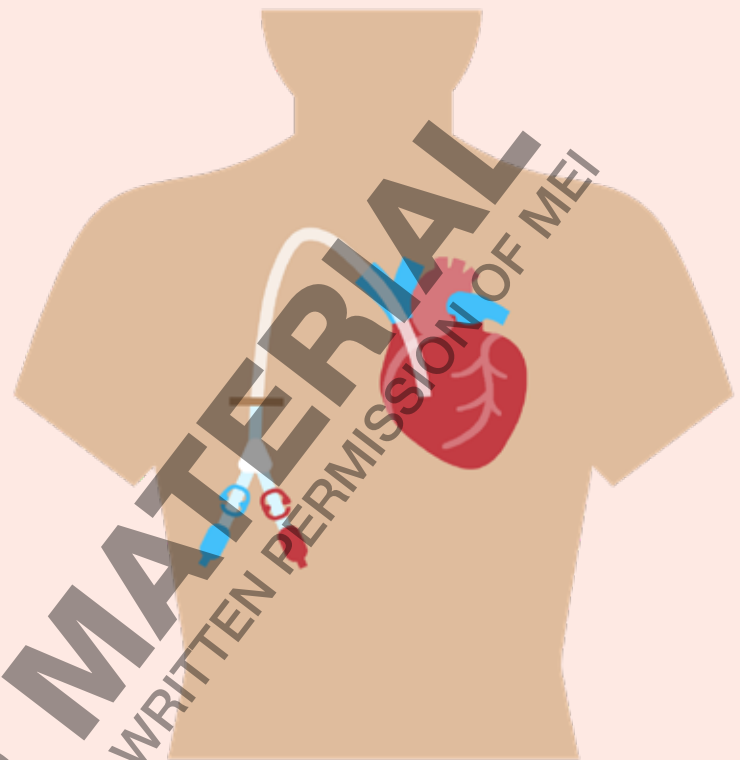
Fistula - artery + vein



Graft - man-made vessel



HD Catheter - goes into your heart



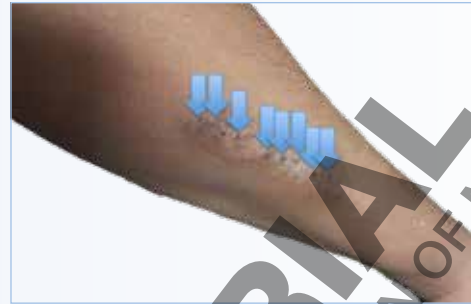
Type of HD Access	Pros and Cons
<p>Fistula – A surgeon links an artery to a vein under the skin of your arm. Ask about an endovascular fistula. No surgery is used to make one.</p>	<ul style="list-style-type: none"> • Best choice: it is under your skin and made of your own vessels. • Least likely access to get blood clots or blood infections. • Some fistulas last for decades, with good care. • A fistula uses two needles at each HD treatment. • It may take more than one try to get a working fistula. • A fistula can “steal” blood from your hand, which can hurt.
<p>Graft – A surgeon uses a man-made vessel to connect an artery to a vein.</p>	<ul style="list-style-type: none"> • Second best: a graft is foreign tissue under your skin. • A graft uses two needles at each HD treatment. • Grafts are more prone to clots or infections than fistulas. • Grafts may need de-clotting and/or procedures to open them up every few months. • A graft can last for a few years, then must be fixed or replaced.
<p>Catheter – A surgeon tunnels a plastic tube under the skin of your chest. The tube goes into a large vein in your heart or groin.</p>	<ul style="list-style-type: none"> • A catheter does not use needles. • Catheters can be painful and hard to sleep on. • You must keep a catheter dry to take a shower. • You may get less treatment and not feel as well. • Catheters have a high risk of blood infection and death.³³

Take Charge of HD Needles

Cannulation means putting in needles. Needles are less scary when you control them:

- **Numbing cream, gel, or spray** can ease pain and needle fear. Some creams need a prescription. Your clinic must give this to you for free if your doctor prescribes it.
- **Learn your pattern.** Needles should go *all* the way up and down your access, like knots on a **Rope Ladder**. Or, with the **Buttonhole technique**, needles go in the exact *same* two spots over and over—like pierced earring holes. Do *not* let the needles go into the same two small areas (area cannulation). This can cause weak spots on your access that form big bumps (*aneurysms*)—that could burst.³⁴
- **Learn to put in your own needles.** You are the only one who can feel the inside of your access. Needles hurt less when you focus on getting them in, too.

Rope Ladder




Buttonhole



Avoid – Area Cannulation



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Learn more about vascular access from www.KidneySchool.org



What to Expect from a Dialysis Clinic

Dialysis clinics are not all the same. Some give better care than others. Your health plan may have clinics near you to choose from. Medicare has a website that lets you compare them. (www.medicare.gov/care-compare, and choose “dialysis facilities”). When you are at the clinic, look around. You will find clues that can help you tell if it provides high quality care. This table shows you some of them.

Signs of High-Quality Care	Signs of Concern
<input type="checkbox"/> The surfaces of the clinic look clean.	<input type="checkbox"/> You see dirt, trash, or blood.
<input type="checkbox"/> The clinic smells clean.	<input type="checkbox"/> The clinic smells bad.
<input type="checkbox"/> The bathrooms are clean.	<input type="checkbox"/> The bathrooms are not clean.
<input type="checkbox"/> You see a social worker and dietitian.	<input type="checkbox"/> What social worker and dietitian?
<input type="checkbox"/> Staff wash their hands and put on fresh gloves often.	<input type="checkbox"/> You often see staff forget to wash their hands or put on fresh gloves.
<input type="checkbox"/> Staff treat you with respect.	<input type="checkbox"/> Staff laugh at you or yell at you.
<input type="checkbox"/> Staff treat each other with respect.	<input type="checkbox"/> Staff argue or yell at each other.
<input type="checkbox"/> Staff ask what matters to you.	<input type="checkbox"/> Staff don't ask you anything.
<input type="checkbox"/> Staff answer your questions.	<input type="checkbox"/> Staff ignore your questions.
<input type="checkbox"/> Staff encourage you to learn and take an active role in your care.	<input type="checkbox"/> Staff turn the machine away from you and will not let you take part.
<input type="checkbox"/> Someone is on the floor at all times.	<input type="checkbox"/> Everyone goes on break together.
<input type="checkbox"/> An access nurse puts needles into new fistulas.	<input type="checkbox"/> Anyone can put needles into new fistulas.
<input type="checkbox"/> Access infection rates are low (ask!).	<input type="checkbox"/> Access infection rates are high.

Besides this list, **listen to your gut**. Do you look forward to seeing your fellow warriors? Or, do you dread each treatment? Can your clinic train you for the option you want?



Getting to the Clinic

If your clinic is far from home or you don't—or can't—drive, it can be a real challenge to get there three times a week. Medicare does not pay for rides unless you have an emergency. Medicaid or other health plans may pay for rides—in some states. These tips may help:

- **Talk to the social worker.** S/he should know if your clinic offers or pays for rides. Most do not—but some have contracts with transport companies. S/he will know about other ways to find rides for you.
- **Use paratransit.** Your town may have a ride service for seniors and those with disabilities. The name of the service varies by where you live.
- **Ask a friend to drive you.** Since most people have busy lives, you may not be able to rely on a friend three times every week. Perhaps three friends could each help you one day a week. You might offer to trade favors for their help, and pay for gas.
- **Ride a train, bus, or subway.** If there is a direct route, a train, bus, or subway can be low cost and fairly fast. If you need to transfer, it takes longer and is harder on you.
- **Take a taxi.** The cost may make this a better once-in-a-while option.
- **Carpool with someone on your shift.** You may have to go a bit out of your way to pick someone up and drop them off when it's your turn to drive. But, you only have to drive half as often. You both save on gasoline, too.
- **Use Uber or Lyft.** Both may be cheaper than taxis. You can order a car from an app on a smart phone. It takes just a few minutes for a ride to arrive, so this can be a good last-minute option if something else falls through.
- **Look for a free car.** It is a long shot, but this website lists eight charities that give cars to people with low incomes who qualify. Even if a car is free, though, gasoline, insurance, and upkeep are not. <http://www.lowincomefinancialhelp.com/free-car-assistance-how-and-where-to-apply/>
- **Choose a home treatment.** Once you are done with training, you only have to go to the clinic once a month to meet with your care team.

Comfort Care – No Dialysis or Transplant

Dialysis does not always help people live longer. For those who were 80 years old or more *and* were frail or had other illnesses, dialysis did not extend life.³⁵ For some, the best way to treat kidney failure may be to just treat the symptoms. We call this *comfort care*. It may also be called *Active Medical Management*.

Choosing comfort care may make sense if:

- There is a lot of pain (such as from cancer) that can't be helped.
- More than one severe chronic disease is present at the same time.
- Quality of life is poor, with little hope that it will get better.
- Someone does not know what is going on or fights the treatment (as with dementia).

Comfort care is not “doing nothing.”

It is an active course of treatment, with:

- **Palliative care.** From the word “to cloak,” palliative care offers help to cope with a chronic disease and boost quality of life. It does not shorten life or lengthen it. The patient will have clinic visits. In fact, a whole team of healthcare staff will seek ways to relieve pain, symptoms (like shortness of breath or sleep problems), and stress. Physical therapy, massage, medicines, diet, and other techniques may be used. Counseling and spiritual aid are offered.
- **Hospice care.** Hospice *includes* palliative care, and starts when a doctor says someone has 6 months or less to live. Hospice staff will help a dying person and his or her family. Medicare will pay for hospice care. They will check on the patient and coordinate care. Services can be provided at home, in a hospital, a skilled nursing facility, or an inpatient hospice center.

I have always regarded the ability to choose the time, the hour, the place and the manner of our death as the greatest privilege that dialysis gives us. And it is unique to us. So I'm grabbing the chance with both hands. I wish I had a third to embrace it even harder. I've had a great life, thoroughly enjoyed it, all 80 years of it. Even the last 10 years on dialysis. Now it's time to call quits, to take the Last Train home, to leave while the going's good.” Bob H.

People tend to live from about 6 months to 2 years or so if they do not start dialysis.^{36,37} So, you should have time to think about what a good death looks like to you. This means that you can plan for what you want, and talk with your loved ones. You can write a “bucket list” of things you want to do, and make some memories.

“What is the point of having a longer life when you can’t do and eat what you want? I will be exhausted and so will my family members. Regardless, my kidney disease will not be cured. As for dialysis, it is just trying to extend my life a little... If my life will only shorten a couple of years, I’d rather have that than going back and forth to the hospital.”³⁸

“Let me lead as close to the type of lifestyle as I would have if I didn’t have health issues going on. Just allowing me to do what I can as long as I can is a form of support for me. And, just having people around me that care and do whatever they can for me.”³⁹

Feeling Hopeless or Afraid is Not a Reason to Choose Comfort Care

It is very normal to be scared when you know that your kidneys are failing. It is also normal to worry about being a burden on your loved ones. You may worry that your life won’t be worth living if you have to use a machine to survive. You are not alone if you feel this way.

You are still YOU, whether your kidneys work or not. And, you matter. Don’t let depression make choices for you. Talk to someone, get treatment so you feel better, and make a choice when you are not as upset and afraid.

“I imagine that this is the beginning of the end. That from now on I will grow sleepier and sleepier day by day until I finally lapse into a coma. I still feel as relaxed about it as before... I would recommend it to anybody thinking of trying death for the first time.” Bob H.



Moving Forward with Comfort Care

If comfort care is what you want, **talk with your loved ones.** Be sure they know how you feel, and why, and what your wishes are. Expect that they will feel sad and may try to change your mind. It may help to have a counselor or chaplain help you talk with them. Most faiths view comfort care as letting natural death occur—not as suicide.

Kidney failure can be a good death. As toxins build up in your blood, you will start to feel sleepy. Water building up in your blood can make it hard to breathe. You may want to have treatments that remove water but not toxins, to make you comfortable. An *Advance Directive* is a way to say what you do and do not want for your healthcare in case you are not able to speak for yourself. All adults need to have one. A *Healthcare Power of Attorney* form lets you choose someone who can speak for you for healthcare decisions. To get these forms, go to a lawyer, look on the Internet, or ask your doctor’s office.

How to Talk About Kidney Disease and Dialysis

Most people don't know a lot about kidneys or dialysis. So, you may run into a lot of errors in what people think about your health—or hear a lot of bad advice that could harm you. Stay calm. You might not know a lot about an illness you don't have, either.

Ask people what they know, and then you can fill in the blanks for them. Once they know more, they may want to help, or even offer to be tested as a donor. Here are some common myths and some things you could say to help educate people.

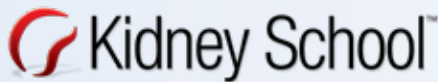
Myth	What You Could Say
<i>“Drink more water. It’s good for your kidneys.”</i>	Water is great when kidneys work. But, mine don’t, so water would just make me swell up like a balloon.
<i>“You look good! You must be getting better.”</i>	I do dialysis _____ times a week. And, I take medicines and have diet and fluid limits. Doing that helps me feel as well as I can with kidneys that don’t work.
<i>“A healthy diet would fix your kidneys.”</i>	Kidneys remove wastes. Since mine don’t work, I can’t eat some things, or wastes will build up in my blood.
<i>“I could catch kidney disease from you.”</i>	Kidney disease is not contagious. The two main causes in the U.S. are diabetes and high blood pressure. Mine was caused by _____.
<i>“You are lazy.”</i>	Since my kidneys don’t work, I have anemia. There is not enough oxygen in my blood. This causes severe fatigue. Just crossing a room is like walking through syrup.
<i>“You get to relax in a chair every week.”</i>	Dialysis is not relaxing. I often feel _____.
<i>“Dialysis is a death sentence.”</i>	Dialysis is a <i>life</i> sentence. It keeps me alive, along with my diet and medicines. A lot of other diseases don’t have treatments. But, it’s not a cure, and it can limit my life.
<i>“My mom had kidney disease, so I will, too.”</i>	There is a lot you can do to protect your kidneys. You don’t have to have kidney failure.

The more others know about kidney disease, the better they can protect their health and yours.

Where to Learn More

Medical Education Institute, Inc. (MEI)

The non-profit MEI, founded in 1992, helps people with chronic disease learn to manage and improve their health. To donate or to learn more, please visit www.mei.org. MEI programs include:



Free set of learning modules on 18 topics to help you manage your kidney disease.
www.KidneySchool.org



Learn about living well with chronic kidney disease.
www.LifeOptions.org



Read patient stories, learn about the home treatment lifestyle, get expert advice, and more!
www.HomeDialysis.org



This free tool lets you choose lifestyle values and matches them to the treatments with the best fit.
www.MyKidneyLifePlan.org



ONLINE AND PHONE SUPPORT

Facebook – Home Dialysis Central. www.facebook.com/groups/HomeDialysisCentral

NKF PEERS. (855) 653-7337. Phone support from fellow dialyzors.

RSN Hopeline (800) 579-1970. Toll-free phone support from fellow dialyzors.

OTHER WEBSITES

Home Dialyzors United www.homedialyzorsunited.org. Advocacy and support for home treatments.

American Association of Kidney Patients. www.aakp.org. Free membership group.

ESRD NCC <https://esrdncc.org>. Government sponsored kidney information.

Medicare www.medicare.gov. Learn all about how Medicare pays for dialysis.

National Kidney Foundation www.kidney.org. A to Z guide, local chapters.

Renal Support Network www.rsnhope.org. Podcasts, teen prom, and more.

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