

HOW HEMODIALYSIS PATIENTS **Can Take Charge of Their Care**

A GUIDE FOR PATIENTS AND CARE PARTNERS





Having a diagnosis of end stage renal disease or chronic kidney disease can leave you experiencing many emotions. You may feel a sense of despair knowing that your condition is chronic or worsening. You may feel isolated and that no one understands what you're going through. You may also feel overwhelmed at your prognosis and treatment options.

Simple things like knowing your dialysis options, how to care for your access and receiving or providing support can improve your physical and mental health, which can help limit complications.



This guide will provide you with the tools to help you take charge of your care.

Get Familiar with Your Access

In order to receive dialysis, you're going to need an access. Your access allows the blood from your body to be cleaned and filtered.

Your access has three primary forms: **a fistula, graft or catheter.**

FISTULA

A fistula surgically connects your vein to an artery. This results in increased blood flow to that vein, which allows the vein walls to strengthen. Needles are then inserted in the fistula for hemodialysis. Fistulas are the preferred access because of their low complication rates.

GRAFT

A graft is a synthetic tube that's connected to your blood vessels. Like the fistula, needles are inserted into it for hemodialysis, but unlike the fistula the risk for complications is higher because it is made of synthetic materials.

CATHETER

A catheter, or a central venous catheter, is a tube-like device that's inserted into a vein in your neck or groin. A portion of the tube remains outside your body, while the other travels under your skin into a vein. The tubes are then connected to the dialysis machine when you receive treatment. Because parts of the tube remain outside the body, the risk for infection and other complications is high. This type of access is primarily used as a temporary access until you can receive a graft or fistula.

The phrase "your lifeline for a lifetime" might be familiar to you. That's because a vascular access allows your blood to flow into and out of the dialysis machine. But only a few sites on your body can be used for an access. So, once you have an access established — whether it's a fistula or graft, it's essential to care for it properly.

The One-Minute Check

It only takes a minute to keep your access working as it should and avoid infection. Early detection of issues allows you to get prompt treatment, which will extend the life of your access. [Here's how to do a "one-minute check" of your access.](#)

It Only Takes a Minute To Save Your Lifeline

The skin over your access is all one color and looks like the skin around it.

GO



Look

There is redness, swelling or drainage. There are skin bulges with shiny, bleeding, or peeling skin.

STOP

When you place your access next to your ear, you hear a sound. And it sounds the same as the last time you checked it.

GO



Listen

You place your access next to your ear and hear no sound. Or it sounds different than it did last time you checked it.

STOP

Thrill: a vibration or buzz in the full length of the access.

Pulse: slight beating like a heart-beat. Fingers placed lightly on the access should move slightly.

GO



Feel

Pulsatile: The beat is stronger than a normal pulse. Fingers placed lightly on the access will rise and fall with each beat.

STOP

If you notice any of the red signs, contact your dialysis care team immediately at the numbers provided.

Contact: _____

During business hours: _____

After business hours: _____

In addition to performing the one-minute check, you will want to make sure you:

- ☐ Don't use your access arm for heavy lifting or carrying purses
- ☐ Ensure your access arm isn't constricted by heavy clothing, which can act as a tourniquet to your vascular access

Know Your Dialysis Options

Dialysis helps filter your blood and do the work your kidneys no longer can. There are four options for hemodialysis:



IN-CENTER HEMODIALYSIS

These sessions typically happen three times per week in a dialysis facility.



HOME HEMODIALYSIS

These sessions happen in your home and you serve as a dialysis technician, inserting needles and operating the machine.



NOCTURNAL HEMODIALYSIS

As the name suggests, these sessions are done at night while you sleep. They can take place at home or in a center.



SHORT DAILY HOME HEMODIALYSIS

These sessions are about half the length of a regular hemodialysis session and occur five to seven days a week.

Is Home Hemodialysis Right for Me?

Home hemodialysis requires you to be in charge of all phases of dialysis. If you want to do home hemodialysis, you'll need to undergo training at a dialysis center and learn to insert needles. To be successful, you have to be willing to learn and do home hemodialysis for at least a year and have a center and care team willing to train you and follow your care, according to [**the National Kidney Foundation**](#).

If you're considering home hemodialysis, [**but aren't sure if it's the right choice for you**](#), Homedialysis.org recommends thinking about the things you like or want to do—like travel or work—and consider what you don't want—like spending hours at a center or keeping a machine and dialysis supplies in your home.

Additionally, the National Institutes of Health suggests considering these additional [**pros and cons of home versus in-center hemodialysis**](#).

Wondering which treatment option is right for you? This tool from the Medical Education Institute (MEI) can help you find one that meets your needs.

[**Use the Tool**](#)



Consider Learning Self-Cannulation

Whether you've chosen in-center or home hemodialysis, learning how to self-cannulate can increase your confidence and establish a greater sense of control. However, many patients feel uneasy about the process.

Self-Cannulation: Easing Fears

Your self-cannulation fears are not unique. Sixty-three percent of patients who had not yet undergone dialysis reported they could self-cannulate on their own or with help, but after receiving their first treatment in the hospital, 53 percent of patients said they didn't think they could do the procedure. Why? In addition to a fear of needles, patients cited fear of infection, excessive bleeding, pain and watching the needle be inserted.

Even if you have previously received hemodialysis in center or are struggling with the idea of self-cannulation, there are steps you can take to reduce fears and self-cannulate successfully.

These include:

- Watching someone else get their needles inserted
- Watching — even if it's just a glance at first — your own needles be inserted
- Holding your sites at the end of treatment
- Asking the staff if you can hold a needle in your hand to get used to how it feels
- Using a cream or gel to numb your access if you're concerned about pain
- Asking the staff to teach you how to insert the needles





Also, try the advice below to ease your fears.



Establishing control

Control can take three forms: mental, physical and lifestyle, according to study authors. Mental control, according to patients from the study, involves not allowing a fear of needles or cannulation to grow in your mind.

“When a needle goes in, it’s not the needle you’re scared of, it’s the thought of the needle going in that scares you. It’s the feelings we sort of make. It’s your mind playing tricks on you,” said one patient.

Patients also want the physical control of inserting the needles themselves and to have greater control over their lifestyles through home hemodialysis.

Building confidence

This involves creating and maintaining confidence through training and support from members of the dialysis care team. Many patients reported their nursing and care team provided them with the confidence they needed to begin home hemodialysis. Confidence can also come from patient education. One patient reported his confidence increased after he read literature on self-cannulation and taught himself to do the procedure.

Normalization

For many patients, the success of self-cannulation came after they accepted that the procedure was part of their identity and had become the norm for them.

Create a Support Team

Chronic kidney disease or end stage renal disease care requires a team effort. Your dialysis care team typically consists of several people who will oversee your care including:

- A nephrologist
- An advanced practice practitioner like a physician assistant or nurse practitioner
- A nephrology nurse
- A renal dietitian and social worker
- A patient care technician
- A vascular access coordinator

Your team will oversee your care while you are receiving dialysis treatments in center, but it's equally important to have a friend or family member be aware of your health and current treatments. They can advocate for you if you are unable to do so.



Questions to Ask Before You Start In-Center Hemodialysis

Consider asking your care team these questions before beginning treatment at a center:

- How do I choose a dialysis center or facility? _____

- What is the process for first treatments? _____

- How many stations are there and how many shifts? _____

- Can I eat or drink while being treated? _____
- What precautions are taken to ensure infection control? _____

- How often will I see the nephrologist? _____
- Do you offer support groups for patients or families? _____
- Who will be cannulating? _____
- Do you encourage and teach self-cannulation? _____
- Are patients taught how the dialysis machines work? _____

- Am I able to modify my schedule, if needed? _____

- Do you offer home hemodialysis? _____

- How will my vascular access be checked for proper function? _____

Questions to Ask Your Support Team about Home Hemodialysis

Though you'll receive extensive training on home hemodialysis from your in-center care team, there are some things you still might be wondering about. Consider asking your care team these questions about home hemodialysis:

- Is the cannulation process different at home than in-center? Will I need to adjust the position of my arm or reach angle to cannulate my access? Will how I hold the needle, tape the needle and remove the needle be different? _____

- What equipment do I need to start home hemodialysis? _____

- Do I need a dedicated room for dialysis? What electronic, plumbing, internet and phone connections do I need? _____

- What storage space will I need? _____
- How clean will I have to keep my dialysis area to ensure my success? _____

- How often do I need to return to the center for additional training or a refresher once I go home? _____
- Is respite care available if my care partner or I need a break? _____
- Is a nurse available to help me set up at home for my first treatment? _____
- Would I need to come back to the center for any medications? Can I be taught to give my medications at home? What about my anemia management and bone disease management? _____

- Who do I call if I have questions? _____
- How can I make sure my dialysis prescription is right? _____

Join a Support Group

Living with chronic kidney disease not only takes a physical toll, it can take an emotional one as well. It can be difficult, whether you've been living with the disease for a while or are a newly diagnosed patient, to process your emotions. Not only that, but attempting to express your concerns during a short office visit with your care team can leave you feeling frustrated as well.

Social support from peers with chronic kidney disease can help. [Studies have shown](#) that social support, like that received in support groups, improves survival rates and quality of life for those on dialysis. Why is peer support so effective? It gives you something you can't receive at a clinician's office — shared life experiences.

"Research shows that people often cope better when they interact with peers with whom they identify and share common experiences," according to [the National Kidney Foundation](#) (NKF). "In this way, feelings are validated, social isolation and stigma are reduced, hope for the future and optimism grows, and experiences are normalized,"

It has also been shown that the mentee — or person providing the help—receives improved health benefits from providing social support.

Find the Support that's Right for You

Attend a support group, gather more information, speak to someone on the phone or form your own support group using the information below.

The NKF helpline:
1.855.653.2273

Become a mentor or find out more about support services in your area on the [NKF Peer site](#).

Find information about support groups in your area, by visiting the [American Association of Kidney Patients' listing](#).

If you're interested in forming your own support group, the [Renal Network has a helpful guide](#).

Get support for home hemodialysis by visiting [Home Dialyzors United](#) and [Home Dialysis Central](#)

Learn about the myths and realities of home hemodialysis with this [booklet](#) from the ESRD NCC.



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