

Questions or Concerns about a Permanent Access?

Let's Talk!



esrd.ipro.org

Why is it important for me to have a fistula or graft?

Your access for dialysis is your lifeline. Let your healthcare team help you make the access choice that is the best for you. For most people the best choice will be a fistula or graft.

It's normal to have concerns about your access, and it's important to talk about those concerns, especially with your kidney care team.



I'm worried about having surgery. What can I do?

Talking with your surgeon is the best way to help overcome your concerns. To help you get the most out of that conversation, before you see the surgeon, think about making a list of questions that you can use to guide your conversation. This will allow you to make sure all your concerns are answered and you have a clear understanding of what to expect. **Below is a list of questions that many patients find helpful to ask about the surgery to create a permanent access.**

- How long will I be at the hospital or surgery center when I have my surgery?
- Will I be asleep during the surgery?
- Will I have to stay in the hospital overnight?
- Should I take all my medicines before I come in for surgery?
- Should someone come with me to the hospital or surgery center?
- Can I drive myself home after the surgery?
- Will I be given pain medication to take home with me?
- Will my arm look different?
- How long will the incision be?
- When will I be able to use my arm?
- Are there any limits to using my arm?
- What should I not do?
- Is it okay to lift heavy things?
- Is it okay to wear tight clothing?



Before you leave the appointment with your surgeon, make sure all of your questions have been answered.

What if my surgeon visit is on my dialysis day?

If your visit is scheduled on your dialysis day, you need to go to both appointments. Your dialysis care team can help you work this out.

I am concerned about how my fistula or graft will look after surgery. Some of my worries are that:

- People might ask me what it is.
- I might feel embarrassed by how it looks.
- I could have scars or my veins may bulge.
- I might feel sad when I look at it.

Getting used to something different on your body is hard. Your healthcare team can help answer your questions and, if you like, can put you in touch with patients who can talk about their experiences. Talking with someone who has gone through the same thing can help you figure out how to cope with this change.

Here are some ideas on how to manage changes you are experiencing:

- ✓ Ask your surgeon what the access will look like.
- ✓ Talk with your social worker about ways to cope with how you are feeling.
- ✓ Consider your access a “badge of honor” or “lifeline.”
- ✓ Remind yourself that dialysis is life-saving, and you can live longer with a permanent access.
- ✓ Remind yourself that the change in appearance is necessary but does not change who you are.
- ✓ Consider clothing that will provide cover like flowing sleeves.

Talking with your kidney care team is important. They can also put you in touch with someone else who has a fistula or a graft.

When people ask you questions about your access, be open to sharing your story. Tell them how your vascular access helps you better manage your kidney disease.



How will I know if my access is OK after it is placed?

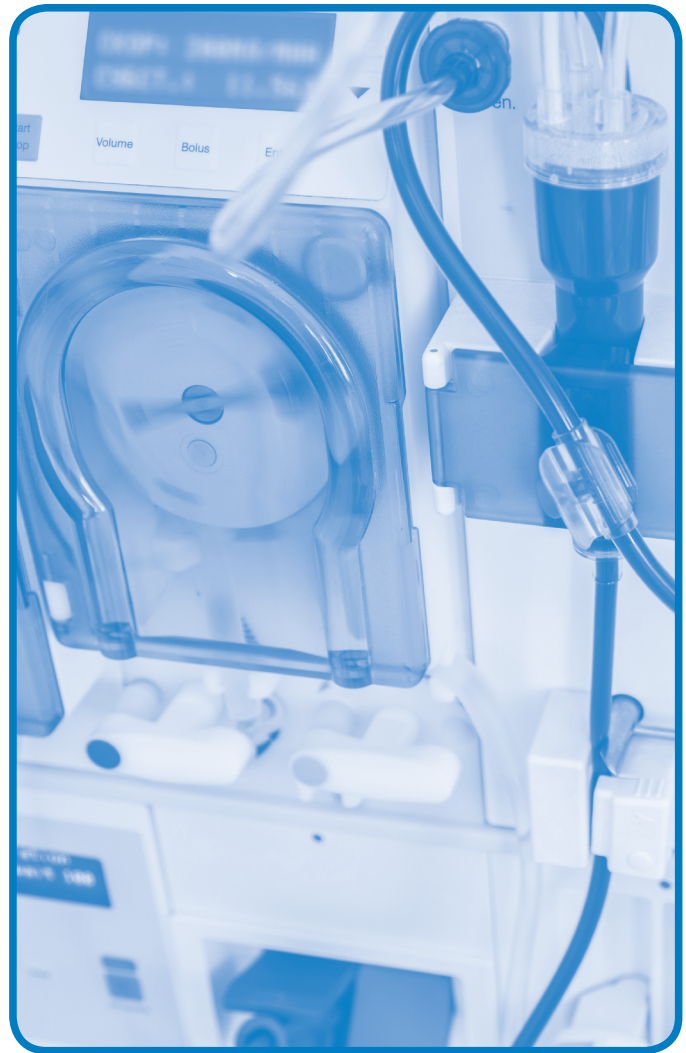
Your dialysis care team can explain what to expect as your fistula is growing or your graft is healing. The team can show you ways to check that your fistula or graft is OK.

Many other resources are available to help you check your access. Ask your dialysis care team or your ESRD Network to give you educational materials. Go to www.esrdncc.org to find your Network.

What will happen when the needles are put in and taken out?

Many patients have questions about the needles when they start using their access. Ask your care team if you have any concerns. Here are some of the questions you may want to ask them:

- Do the needles hurt when they go in?
- If they hurt, is there something that can be done for the pain?
- What can I do to get used to the needles?
- Will I have any problems with my needles during my treatment?
- How can we make sure the needles stay in during my dialysis treatment?
- Am I going to put the needles in, or will the dialysis care team do that?
- Can I learn how to put in my own needles?
- What will happen when the needles are taken out?
- What should I do if my fistula or graft starts to bleed when I am not at the dialysis clinic?



Here are some things that can make a difference when the needles are used.

There are a number of self-help strategies that you can also use to deal with your concerns:

- ✓ Consider taking control and being trained to put in your own needles.
- ✓ Teach yourself relaxation and distraction techniques.
- ✓ Practice deep breathing.
- ✓ Choose "not to look" during the "stick."
- ✓ Ask the clinic to have only their experts do the first few sticks.



Could complications happen when the dialysis care team uses my permanent access?

There are complications that can happen with any type of access that is used for dialysis. Be assured that your dialysis care team is trained to monitor and make sure you are safe during and after your treatment. The team will also teach you some important tips on how to take care of your access. Below is a list of things your care team can teach you to do that will help to make sure your access is OK:

- Your dialysis care team will teach you how to monitor your access every day to make sure it is working the way it should.
- The team will also explain what to do if you find a problem when you are checking it.
- The team will teach you how to apply clean bandages and pressure if your access starts to bleed when you are not at your dialysis clinic.



It is important to feel understood in your concerns. Talking with a care team member or peer mentor can help you overcome any challenges. The more involved you get, the more you can work through your concerns.

Remember, you're in control of your life, and your access is your lifeline for a lifetime! If you address your concerns about getting a fistula or graft, you will improve your overall health and wellbeing.



For more information, or to file a grievance, please contact us:

IPRO End-Stage Renal Disease Network of the South Atlantic
909 Aviation Parkway, Suite 300 Morrisville, NC 27560

Patient Toll-Free: (800) 524-7139 • Main: (919) 463-4500 • Fax: (919) 388-9637
E-mail: info@nw6.esrd.net • Web: esrd.ipro.org



Developed by IPRO ESRD Network of the South Atlantic while under contract with Centers for Medicare & Medicaid Services. Contract HHSM-500-2016-00006C.

Resource content adapted from the National Patient and Family Engagement (N-PFE) Learning and Action Network (LAN), under the ESRD National Coordinating Center (ESRD NCC) vascular access toolkit.