Quality Insights Renal Network 5

BUSTED In-Center Hemodialysis

Myth vs. Reality

Many people have fears and misinformation about dialysis treatment. This booklet shares common misconceptions about in-center hemodialysis. If your concern is not listed, ask your treatment team or contact the Network for more information by calling (804) 320-0004.

Myth: Dialysis is a cure for kidney disease.

Reality: Dialysis is not a cure for kidney disease. It only replaces the function of the kidneys enough to maintain life. A kidney transplant is the best treatment option.

Myth: Dialysis is painful.

Reality: There is very little pain associated with dialysis. Access cannulation can sometimes hurt a little. It is similar to getting blood drawn or having an IV placed. A numbing cream can be used to reduce needle stick discomfort.

Occasional cramping can occur. Cramping is often associated with excess weight gain. The best way to avoid cramping is to keep weight gain to a minimum. Tell your care team (doctor, nurse, social worker, technician and dietitian) immediately so they can take action. Join your care plan meetings to address ongoing issues.

Myth: I may have to begin dialysis, but I don't know what to do.

Reality: Speak with your kidney doctor about attending a kidney class where information is given about the different types of dialysis, diet and permanent access.



Myth: You lose your independence on dialysis. Clinic staff control everything.

Reality: You can become more engaged with dialysis by taking the initiative to learn more about the process. With proper training, more involvement in the dialysis procedure itself is possible. This allows you to have control in many aspects of your treatment.

Some patients even self-cannulate (insert their own needles)! The more you learn, the more confident you will become. As a result, you will feel more independent.

Communicate with your care team to help them effectively manage your treatment. You can request additional resources on dialysis from your social worker.

Myth: Patients on dialysis have no life.

Reality: Patients on dialysis can still work, travel (including cruises), spend time with family, swim, exercise, and do almost anything they did prior to dialysis. Home dialysis options can also offer more freedom and flexibility. Talk to your care team about your interest in home dialysis. Most of the time, after starting dialysis, patients feel better and have more energy to do the things they love.

Myth: Being on dialysis means I have failed and become a burden to my family.

Reality: Some patients struggle with the adjustment to end-stage renal disease (ESRD) and the need for dialysis. It is important to communicate with your care team because they can offer you support as you adjust.

Depression is very common in patients with ESRD, but it is TREATABLE. Talk with your social worker who can provide you with supportive counseling and resources for additional assistance if needed. Some patients may require a small dose of an



anti-depressant to help them with their mood and/or sleep as they adjust to dialysis.

Remember, you are not alone!

Myth: I want to keep my catheter because I see other patients having problems with their permanent access sites.

Reality: Routine and continued use of a temporary catheter can increase the risk of serious infection and reduce dialysis effectiveness.

A permanent access is surgically created and can last for many years. As a result, it will provide highly effective toxin and fluid removal from your blood. Special access centers are staffed by interventional kidney doctors and vascular surgeons. They are readily available to keep your permanent access in proper working order.

Myth: A dialysis access in the upper part of the arm can cause eventual limb loss (amputation).

Reality: This is extremely rare. Proper care of the access and prompt medical management help to keep a healthy working access. Ask your care team how you can properly assess your dialysis access.

Myth: Going to the access center means I am in trouble.

Reality: This is not true. Access centers have specialists dedicated to keeping your access working properly. Regular maintenance check-ups are required for a healthy access to function properly. Think of it as a "tune-up," not a disaster. Your access center will coordinate these check-ups and communicate them with your dialysis center.



Myth: Before I started dialysis, I was told to limit protein in my diet. Now I am told to eat more. It is confusing!

Reality: Some pre-dialysis patients are instructed to eat a low-protein diet to reduce strain on the kidneys, thereby extending adequate function for as long as possible. When your kidney function is no longer adequate to maintain life, you transition to dialysis. During dialysis, protein in your blood sticks to the filter fibers and cannot be returned to your body. Dialysis patients must eat a high-protein diet to replace the protein lost during treatments. Your dietitian can help you make this dietary adjustment.

Myth: I am spending too much time on dialysis.

Reality: You cannot have too much dialysis. Kidneys work 24 hours, 7 days a week, which is a total of 168 hours per week. A dialysis session lasting 3 to 4 hours is only 9 to 12 total hours per week.

It is very important to get adequate fluid and toxin removal. This is why it is vital to attend every scheduled treatment and stay for your full prescribed time. If you are having trouble doing this because you are having pain or other symptoms, speak to your doctor.

Myth: You are taking away my blood!

Reality: At any given time during your treatment, only a small amount of blood is out of your body. The blood is continually taken out, dialyzed, and returned to your body. At the end of your treatment, any blood still in circulation is returned to you during the rinse-back procedure. Small vials of blood are also taken from your body a couple of times each month for laboratory testing.



Myth: By starting dialysis I am automatically included on the transplant list.

Reality: This is not true. Transplant is a process and it is NOT automatic. A medical assessment is required. Express your interest in getting a transplant to your social worker or kidney doctor.

Did you know you can also self-refer? Many patients will take the lead and contact transplant centers themselves to be more proactive with the process. Your social worker has the resources and contact information to help you apply for placement on the list.

Myth: Once I am placed on the transplant list, I will be notified very quickly that a kidney is available for me.

Reality: This is not true. There is usually a wait time associated with all transplants, including those from living donors. Multiple tests must be done before a transplant can occur. Ask your transplant coordinator for details.

Myth: I can only be listed with one transplant center.

Reality: You can be listed with more than one transplant center. Transplant programs set their own criteria for acceptance of patients and organs. Getting listed in more than one program could increase your chance for getting a kidney more quickly. This will be a long relationship, so you should select a program(s) that best meets your needs.

In-center hemodialysis is one of many options available to you as a patient. You should understand all your choices for treatment and decide which choice fits best with your lifestyle. Ask your team for more information about nocturnal dialysis, home dialysis options and transplant.



Notes





Patients and care partners have reviewed this booklet from their perspective to help you better understand your in-center dialysis treatment option. Special thanks to Quality Insights Renal Network 5's Patient Advisory Committee (PAC) for developing the idea for this document and identifying the myths.

What is the Patient Advisory Committee?

The Patient Advisory Committee (PAC) is made up of dialysis patients, transplant patients and care partners from across Network 5, which includes Maryland, Virginia, West Virginia and Washington, DC. The role of the PAC is to help the Network identify common patient concerns, problems and educational needs that relate to the mission and philosophy of Quality Insights. Quality Insights works with dialysis and transplant providers to improve care given to patients. The ultimate goal is to improve patient quality of life.

If you would like to learn more about becoming involved, contact the Patient Services Director at (804) 320-0004, or email us at <u>girn5@nw5.esrd.net</u>.



300 Arboretum Place, Suite 310, Richmond, VA 23236 Phone: 804-320-0004 Toll-Free: 866-651-6272 Fax: 804-320-5918 Website: <u>www.qirn5.org</u>

This material was prepared by Quality Insights Renal Network 5 under contract with the Centers for Medicare & Medicaid Services (CMS). The contents do not necessarily reflect CMS policy. Publication No. ESRD5-120419