



Vocational Rehabilitation

**Fact Sheet for Rehabilitation Counselors to Help
Dialysis & Transplant Patients Work**



ESRD Network 18 Fact Sheet for Rehabilitation Counselors to Help Dialysis & Transplant Patients Work

What is Kidney Failure & How is it Treated?

Kidney failure is diagnosed when kidney function drops to 15 percent or less. People who want to live must have dialysis or a kidney transplant. Almost anyone is eligible for dialysis, but not everyone is a candidate for a transplant. Those who do not have a living donor may have to wait years for a transplant because there aren't enough deceased donor kidneys for those who need them.

Dialysis is a medical treatment that removes wastes from the body. There are two types of dialysis:

- HD removes wastes from the patient's blood by accessing their vessels with large needles or a central line that then connects to an HD machine. The machine pumps blood through a plastic filter ("dialyzer") multiple times during a dialysis treatment. Patients can do HD in a clinic or at home. In 2015, 30 percent of dialysis clinics offered dialysis treatments after 5 p.m.¹ Patients who are trained to do HD at home can schedule treatments to fit with their work schedule.
- PD removes wastes using the tissue lining the abdomen as the filter. PD patients drain a special fluid into their peritoneal cavity (where abdominal organs are) through a thin tube (catheter). They leave the fluid inside to dwell for a time and then drain the fluid, with wastes and extra water out. They can do this manually four or more times a day or with the machine for eight or more hours while they sleep.

A kidney transplant is a type of treatment for kidney failure; it is not a cure. It requires major surgery to place a healthy kidney into the lower abdomen of a person who has 20 percent kidney function or less. In most cases, diseased kidneys are left in place. Those wanting a transplant must be in good physical and emotional health. People who are working are more likely to get a transplant. A kidney transplant

Possible Work Limitations

People on any dialysis may have symptoms such as fatigue, low energy, and poor endurance, and they may have memory issues and depression. How and where dialysis is performed, medications, activities, and counseling may control symptoms. However, dialysis patients may need extra breaks and time off for doctor appointments or illness.

Patients on standard three times a week HD treatments may need to rest for a while immediately after dialysis. Working patients on HD in a clinic may need a flexible work schedule for dialysis days or may only be able to work on non-dialysis days. Patients who have HD at home may have shorter treatments more often or overnight HD and recover faster after dialysis. They may not need a flexible work schedule. However, they will need time off for home HD clinic visits and doctor visits. HD patients are not supposed to lift anything heavy while they're under care for dialysis while they are healing and can't let anything rest on that arm or leg. Dialysis access surgically combines an artery and vein to make a vessel large enough for needles to be inserted. Toxin-filled blood travels from one needle in the body through the lines to the HD machine and dialyzer and clean blood returns through the other needle in the access. The latest data reports that HD patients were hospitalized on average 11 days a year.²

¹ Centers for Medicare & Medicaid Services. End Stage Renal Disease Network Organization Program 2015 Summary Annual Report. Baltimore, MD: CMS; 2017. <https://www.esrdncc.org/contentassets/187eeba04ded4b7da4880050bdff04c7/2015esrdnccsmmryannlrprfnl508.pdf> (Accessed January 31, 2018)

² United States Renal Data System. 2017 USRDS annual data report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2017. https://www.usrds.org/2017/view/v2_04.aspx (Accessed January 31, 2018)



Patients on PD may have the same symptoms as other dialysis patients, but don't need time to recover after a PD treatment because it removes toxins more like natural kidneys. Like home HD patients, some PD patients need to have a fluid exchange during their workday. All they need to do this are their supplies and a clean, private place. Doctors may limit how much a PD patient can lift to avoid a hernia. PD patients need time off for home PD clinic visits and doctor visits. The latest data reports that on average PD patients were hospitalized 12 days per year.²

Patients stay in the hospital a few days after transplant and will have frequent follow-up visits that decrease over time to a couple a year. Stable transplant patients can return to usual activities within a few weeks. Transplant patients take drugs that suppress their immune system and need to avoid crowds or wear a mask. The side effects of the drugs make patients sun sensitive, and at risk for skin cancer, so they are advised to wear sunscreen and a hat if they expect to be in the sun. The most recent data reports that on average, transplant patients are in the hospital for about five days a year.²

ESRD & Insurance

Most patients qualify for Medicare if they're on dialysis and pay the Part B premium. Those with transplants who don't have another disability only keep Medicare 36 months after they get a transplant. Although it costs less in the years after transplant surgery, anti-rejection drugs cost on upward of \$2,500 a month. Transplant patients need a health plan to pay for these medications when Medicare ends. Without the anti-rejection medication, the body will reject the kidney, and the patient will have to restart HD or PD.

If a job covers someone for health insurance, the plan pays first for 30 months. The clock starts when the patient is eligible for Medicare whether she/he enrolls or not. If someone doesn't have health plan through their employer, Medicare pays first. If a patient who has Medicare as a primary payer gets a job with health insurance during the 30 months, the employer plan pays first only for what's left of the 30 months. After that point, the employer plan pays second. This is different from Medicare secondary payer rules for those with other disabilities besides ESRD who work.

ESRD & the ADA

*Fiscus v. Walmart Stores Inc.*³ set a legal precedent that those on dialysis have ADA protection because "a physical impairment that limits an individual's ability to cleanse and eliminate body waste does impair a major life activity." Employers with 15 or more employees cannot discriminate against people on dialysis. They need to provide workplace accommodations, but only if requested and only if providing that change is not too much of a burden to the employer. Most workplace changes that dialysis and transplant patients need cost little or nothing.

Eligibility for VR

The SSA has stated in the Listing of Impairments in *Disability Evaluation Under Social Security*, being on dialysis or having had a transplant within the last year can be too disabling to work. Patients are eligible for Social Security disability benefits and work incentive programs. The Rehabilitation Act at 34 CFR 361.42 requires agencies to work with people who seek employment, but have severe disabilities that are an impediment to work and need VR services.⁴ VR counselors may not know that the diagnosis of "end-stage renal disease" is government-speak for "kidney failure."

³ *Fiscus v. Wal Mart Stores Inc.*, 385 F3d 378 (3d Cir. 2004). https://digitalcommons.law.villanova.edu/cgi/viewcontent.cgi?article=1177&context=thirdcircuit_2004 (Accessed January 31, 2018)

⁴ 34 CFR 361.42 - Assessment for determining eligibility and priority for services. <https://www.law.cornell.edu/cfr/text/34/361.42> (Accessed January 31, 2018)

⁵ Kutner NG, Zhang R. Ability to Work among Patients with ESKD: Relevance of Quality Care Metrics. *Healthcare (Basel)*. 2017 Aug 7;5(3). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5618170/pdf/healthcare-05-00042.pdf> (Accessed January 30, 2018)



If a working-age person chooses to treat kidney failure with dialysis or transplant, she/he could live productively for decades. Those who are willing and able to work need to have the chance to be productive members of society.

A 2015 report stated that 18 percent of dialysis patients between the ages of 18 and 54 are working full or part-time. Only one percent were receiving VR service.¹ In a recent study, 36 percent of dialysis patients ages 20 to 64 said they are able to work⁵ and only 18 percent of patients ages 18 - 54 were working full or part-time. If VR counselors, dialysis staff, and patients work together, it's possible to double the number of working-age people who have jobs.

How Public or Private Rehabilitation Counselors can Help

Public and private rehabilitation counselors need to know that people on dialysis and with transplants can work and have employment. Candidates for a transplant need to prepare for life after transplant and loss of Medicare. Patients who are out of the workforce for a while may lack self-confidence and not value their strengths. Rehabilitation counselors can evaluate patients for such things as their interests, skills, aptitude and job readiness. They can counsel patients to:

- Know the type(s) of job(s) would suit them and help them set realistic goals
- Determine if they have the education or training needed and help them get it
- Know how to write a winning resume that highlights their strengths
- Give an interview that asks the right questions and promotes their knowledge and skills
- Assess what job accommodation they might need and how to ask for them.

How the Dialysis Staff can Help

The dialysis team includes a nephrologist, nurses, technicians, dietitians and social workers. They are responsible for helping patients achieve their goals for rehabilitation, which includes referring suitable patients to public or private VR services. Dialysis clinics can help VR counselors help patients work by:

- Treating work limiting symptoms
- Providing high-quality care
- Offering counseling to reduce depression and improve self-esteem
- Scheduling dialysis around VR appointments and job interviews (with notice)
- Prioritizing in-center dialysis schedules to fit with school, training or work
- Offering interested patients home dialysis or referring them to a clinic that provides it
- Encouraging patients to follow the steps in the employment plan
- Keeping in touch with the rehabilitation counselor to address questions or concerns
- Working with the rehabilitation counselor to help patients who get jobs to keep them

