

# Gainful Employment for People with End Stage Renal Disease (ESRD)

## *Quality Improvement Activity Toolkit*



**Midwest  
Kidney Network**

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# INTRODUCTION

The conditions for coverage for end-stage renal disease (ESRD) facilities require dialysis clinics:

- Evaluate each patient for referral to vocational and physical rehabilitation services.
- Assist the patient in achieving and sustaining an appropriate level of productive activity, as desired by the patient, including the educational needs of pediatric patients.
- Make rehabilitation and vocational rehabilitation (VR) referrals as appropriate.
- Ensure evidence of interdisciplinary assessment, education, assistance with barriers, and referral is documented in an individualized plan that reflects each patient's preferences.

Resources in this toolkit are designed to assist facilities to successfully assist patients in meeting their vocational rehabilitative goals. Resources are divided into two sections and include those that will be helpful to the professional, and those that will be helpful to patients. Materials in this toolkit can be copied and distributed freely as needed.



**SECTION 1: PROFESSIONAL RESOURCES**

## RESOURCE LIST

### State Department of Vocational Rehabilitation Offices

Michigan
<p><b>Michigan Rehabilitation Services</b> (800) 605-6722 <a href="https://www.michigan.gov/leo/0,5863,7-336-94422_97702---,00.html">https://www.michigan.gov/leo/0,5863,7-336-94422_97702---,00.html</a></p>
Minnesota
<p><b>Minnesota Division of Rehabilitation Services</b> (651) 259-7366 (800) 328-9095 <a href="https://mn.gov/deed/job-seekers/disabilities/">https://mn.gov/deed/job-seekers/disabilities/</a> <b>Benefits Counselors:</b> <a href="https://www.goodwilleasterseals.org/services/work-incentives-connection">https://www.goodwilleasterseals.org/services/work-incentives-connection</a></p>
North Dakota
<p><b>Division of Vocational Rehabilitation State of North Dakota</b> (800) 755-2745 <a href="https://www.hhs.nd.gov/vr">https://www.hhs.nd.gov/vr</a></p>
South Dakota
<p><b>South Dakota Division of Rehabilitation Services</b> (800) 265-9684 <a href="https://dhs.sd.gov/rehabservices/vr.aspx">https://dhs.sd.gov/rehabservices/vr.aspx</a></p>
Wisconsin
<p><b>Wisconsin Rehabilitation</b> (800) 442-3477 <a href="https://dwd.wisconsin.gov/dvr/">https://dwd.wisconsin.gov/dvr/</a> <b>Benefits Counselors:</b> Employment Resources, Inc. <a href="http://www.eri-wi.org">www.eri-wi.org</a> IndependenceFirst <a href="http://www.independencefirst.org">www.independencefirst.org</a></p>

Under the Workforce Innovations and Opportunity Act (WIOA), as of 2016, state VR agencies now collaborate with those with disabilities to develop an individual plan for

employment (IPE), provide employment, education, training and/or support for clients. The rehabilitation agencies also prepare them to find and keep a job with competitive wages (at least minimum wage), where those with and without disabilities interact doing their jobs and have the same advancement chances.

## **Provider Resources**

### **[Building Quality of Life: A Practical Guide to Renal Rehabilitation](#)**

A guide to help dialysis facilities incorporate rehabilitation into facility dialysis activities

### **[Council of Nephrology Social Workers \(CNSW\) Insurance Toolkit](#)**

Insurance information related to transplant, Veteran's Administration (VA) benefits, Consolidated Omnibus Budget Reconciliation Act (COBRA), coordination of benefits, and Medicare Part D, plus a list of helpful terms related to commercial insurance and ESRD and the Affordable Care Act (ACA)

### **[Cornell University: Institute on Employment and Disability \(EDI\)](#)**

A leading resource on employment and disability information for businesses, lawmakers, federal and state agencies, educational institutions, unions, and service providers

### **[Disability Evaluation under Social Security](#)**

A guide for physicians and health professionals that explains Social Security's disability programs, how each works, and what a health professional can provide to help ensure sound and prompt determinations and decisions on disability claims; includes in the listing of impairments genitourinary impairments (Section 6.00 for adults; Section 106.00 for children)

### **[Red Book](#)**

A summary guide to employment support for individuals on Social Security Disability Insurance (SSDI) and Supplemental Social Security Income (SSI) programs

### **[Unit Self-Assessment Tool for Renal Rehabilitation \(USAT\)](#)**

A 100-item, self-scored checklist that provides a user-friendly, practical, framework to help renal professionals assess rehabilitation programming in dialysis units

### **[Your Ticket to Work \(TTW\)](#)**

An educational and resource website containing information about the various aspects of the TTW program

## **Patient Resources**

### [Ask JAN \(Job Accommodation Network\)](#)

Free, expert, and confidential guidance on workplace accommodations and disability employment issues which helps improve the employability of people with disabilities and shows employers how people with disabilities add value to the workplace

### [CareerOneStop](#)

The site offers free tools to help job seekers (including those with [disabilities](#)), students, businesses, and career advisors; sponsored by the Department of Labor (DOL)

### [Choose Work](#)

Maximus, a Social Security contractor for the TTW program, runs this website to provide information and work incentive seminar events (WISE) webinars, dispels myths, shares success stories, and has a helpline (866-968-7842 or 866-833-2967 TTY)

### [Dialysis Facility Compare](#)

A Social Security website that lists dialysis facilities by area and allows patients to identify facilities that operate evening shifts or offer home treatment options

### [Home Dialysis Central](#)

Provides information about home treatment modalities to suit individual schedule needs and enhance the quality of life

### [Insurance Options for People on Dialysis or with a Kidney Transplant](#)

A National Kidney Foundation resource for patients

### [My Life, My Dialysis Choice](#)

Tool to help people with kidney disease choose a dialysis treatment that fits their lifestyle and values

### [The Work Site](#)

Social Security explains TTW and provides contact information for the following partner agencies: Work Incentive Planning Assistance (WIPA) agencies, VR agencies, employment networks (EN), and protection and advocacy agencies

## Helpful Resources You Can Print Out and Share with Patients

### [Working While Disabled: How We Can Help](#)

SSA booklet explains the basics of working while on SSDI or SSI

### [Working with Chronic Kidney Disease](#)

NKF booklet for people with kidney disease that reviews how to keep a job, prepare for and find a new job, plus laws and resources

### [Employment: A Kidney Patient's Guide to Working and Paying for Treatment](#)

Life Options Rehabilitation Program booklet (108 page document) for people with kidney disease that reviews how to keep a job, prepare for and find a new job, school options, and understand disability programs

### [Choosing an Employment Network for You](#)

Ticket to Work fact sheet about Employment Networks

### [Finding an EN and Assigning Your Ticket Worksheet](#)

Ticket to Work tool to help patients keep track of information specific to their employment goals, and includes a glossary of terms

### [Returning to Work While on Dialysis National Kidney Foundation](#)

<https://www.kidney.org/newsletter/dialysis-returning-to-work>



## GAINFUL EMPLOYMENT BEST PRACTICES CHECKLIST

### Facility Operations

- Develop a comprehensive plan to promote VR (see [Building Quality of Life: A Practical Guide to Renal Rehabilitation](#) – employment module).
- Review your facility's policies and practices to determine if they are work-friendly: Do you prioritize schedules for in-center dialysis, home training, and home dialysis clinics for people who work or attend school?
  - Do you and your staff encourage, support home dialysis options, and refer patients to other clinics for options you do not offer?
  - Does your facility offer in-center dialysis treatments early in the morning, after 5 p.m. or overnight, and weekends?
  - Does your facility allow patients to use laptops and/or cell phones during dialysis?
  - Do doctors consult with the social worker before signing disability forms?
- Include rehabilitation themes in corporate websites, newsletters, and educational materials.
- Keep brochures and other materials on rehabilitation in public areas.
- Distribute information on rehabilitation resources to all patients.
- Encourage staff to attend rehabilitation seminars.
- Use the data from the Network annual facility survey to set vocational facility goals and assess activities (see employment section in the [Unit Self-Assessment Manual for Renal Rehabilitation](#)).
- Collaborate with rehabilitation and vocational personnel in the community and educate them about dialysis patients' vocational needs.
- Educate employers, and advocate for patients' jobs and needed workplace accommodations (job changes) as requested/needed.
- Include rehabilitation in patient assessments and plan of care forms.
- Collect and report patient rehabilitation status for patients ages 18 through 54 on the ESRD facility survey (CMS 2744) in CROWNWeb.
- Assess each patient's health-related quality of life (HRQOL).

## Patient Care

- **Upon admission**, meet with the patient and encourage working patients to continue to work. From day one, team members need to believe and let patients know they can work on dialysis. If patients have doubts, encourage them not to make any quick decisions, to take a leave of absence to get used to dialysis, and/or to ask for job accommodation. [Americans with Disabilities Act](#) (ADA) protect dialysis patients.
  
- Educate patients about the benefits of employment (see [Keeping Your Job When You Need Dialysis](#)):
  - SSDI pays about 35 percent of what the average patient earns at work; less for those making a higher income.
  - People on dialysis who work, have less financial stress, are less depressed, have higher physical functioning, less pain, and better general health and energy.
  - People who work have fewer and shorter hospital stays – and live longer.
  - People who work are more likely to get and keep transplants.
  
- Discuss each patient’s personal rehabilitation goals, including but not limited to:
  - Employment/School
  - Hobbies
  - Physical activities
  - Social activities
  - Volunteering activities
  
- Educate yourself and patients about employment support listed below for SSDI and SSI recipients (see the Social Security Administration (SSA) [Red Book](#) for explanations).
  - SSI/SSDI: Subsidy and special conditions
  - SSI/SSDI: Unsuccessful work attempt
  - SSI/SSDI: Impairment-related work expenses (IRWE)
  - SSI/SSDI: Plans to Achieve Self-Support (PASS)
  - SSI/SSDI: Ticket to Work (TTW)
  - SSI/SSDI: Continued payment under VR or similar program (Section 301)

- SSI/SSDI: Expedited reinstatement
  - SSDI only: Trial work period (TWP)
  - SSDI only: Substantial Gainful Activity (SGA)
  - SSDI only: Extended period of eligibility (EPE)
  - SSDI only: Unincurred business expenses (self-employment)
  - SSDI only: Continuation of Medicare for persons with disabilities who work
  - SSDI only: Medicaid buy-in (AK, OR, WA) for SSDI recipients
  - SSI only: Earned income exclusions
  - SSI only: Student earned income exclusions
  - SSI only: Property Essential to Self-Support (PESS)
  - SSI only: Payments for people who work – Section 1619(a)
  - SSI only: Reinstating SSI eligibility without a new application
  - SSI only: Medicaid while working – Section 1619(b) and state thresholds
  - Blind only: Substantial Gainful Activity (SGA) (higher)
  - Blind only: Blind work expenses
- Tell every working-age patient the care team believes they can work and will support their efforts.
- Before each plan of care meeting***, ask patients:
- How satisfied are you with your current level of physical, social, and vocational activity?
  - How has your school, job or work status changed since the last time we talked?
  - If you went back to work, what would you like to do and what you need to get that job?
  - If you went back to school, what would you like to study and where? What would it take to do that?
  - What are your personal goals for returning to activities you enjoyed before you started dialysis?
  - What can our facility do better to support those goals?

- Have you considered home dialysis or transplant that may work better with your goals?

***During each plan of care meeting***, with the patient and rest of the interdisciplinary team:

- Use health-related quality of life (HRQOL) survey results (responses and scores) for care planning

In each ***quality assessment and performance improvement (QAPI) meeting*** with the team:

- Compare facility rehabilitation outcomes from the prior year, set improvement goals for the year and brainstorm interventions

## TIPS FOR PARTNERING WITH LOCAL VR OFFICES

**Contact and build a relationship with VR counselors.** Share materials that are user friendly for patients. You can use the “[Find Help](#)” directory for local VR offices, Employment Networks (EN), workforce ENs, Work Incentives Planning and Assistance (WIPA) projects, and Protection and Advocacy for Beneficiaries of Social Security (PABSS).

**Tell VR counselors** these things so they can help people on dialysis get and keep jobs:

- **ESRD** means end stage *of the kidney* (kidney failure) not of the person. Those who do dialysis or have a transplant can live for decades.
- Those with kidney failure may:
  - Do **hemodialysis (HD)** in a clinic or at home three or more times a week to remove toxins in the blood. Clinic or home HD can be scheduled to fit the work schedule.
  - Do **peritoneal dialysis (PD)** at home four or more times a day by hand or while sleeping using a machine to remove toxins in the blood. If needed during the workday PD can be done in any clean, private place. PD is work-friendly.
  - Have a **transplant** to replace the failed kidney. Transplant is a treatment, not a cure. People with transplant need jobs with health insurance to cover costly drugs.
- **People on dialysis and with transplants can work.** If a job change is needed, it is often no or low cost (e.g., flex-time, time off for doctor/clinic visits, extra breaks or labor-saving equipment). They can be productive workers. Work helps patients stay healthier physically, mentally, socially and financially, have higher self-esteem, and an enhanced sense of well-being. The Social Security [Listing of Impairments](#) (“Blue Book”) lists dialysis and the first-year post-transplant as being “severe enough to prevent any individual from doing any gainful activity.” Any of those conditions qualify the person medically for disability benefits.
- **Your dialysis clinic is committed to helping people work by adjusting treatment schedules and medical appointments**

**Meet face to face with your local VR counselors** at the dialysis clinic or in their office. Some dialysis clinics hold “VR Days” so VR counselors and/or Social Security work incentive coordinators (see “[Find Help](#)” directory) can visit with patients at the clinic to answer questions about Social Security benefits and work incentives.

**Educate your staff** about VR resources and how key it is for people on dialysis to keep their appointments and follow the plan. Help staff see how key they are in asking patients about their goals, progress and encouraging them.

**Post VR materials** in public areas of the clinic.

**Educate dialysis & transplant patients** about the VR process

- Referral
- Orientation and receipt of the VR Handbook of Services
- Application
- Assignment to a counselor
- Eligibility
- Waiting list – priorities based on status, the order of selection and date of application
- If served, services based on counselor and client written plan
- If waitlisted, the requirement to refer and how private ENs can help

**Ask patients to keep you informed** of VR activities, barriers, progress and help-needs (e.g., rescheduling dialysis, communication with counselors, educating employers, coordination of care).

**Provide information and referral** to resources including Independent Living Centers and State Services for the Blind



## FACT SHEET FOR REHABILITATION COUNSELORS TO HELP DIALYSIS & TRANSPLANT PATIENTS WORK

### What is kidney failure and 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 are not 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, hemodialysis (HD) and peritoneal dialysis (PD):

1. 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. \* Patients who are trained to do HD at home can schedule treatments to fit with their work schedule.
2. PD removes wastes using the tissue that lines the abdomen as the filter. PD patients drain a special fluid into their peritoneal cavity (where abdominal organs are encased) through a thin tube (catheter). They leave the fluid inside to dwell for a time, and then drain out the fluid with wastes and excess water. 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.

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\* 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/187eeba04ded4b7da4880050bdf04c7/2015esrdnccsmmryannlrprtnl508.pdf>

## Possible Work Limitations

People on any dialysis may have symptoms such as fatigue, low energy, and poor endurance. They may also 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.

## Hemodialysis

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 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 are under care for dialysis and cannot let anything rest on their access arm or leg. Dialysis access surgery combines an artery and vein to make a vessel large enough for large-gauge 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 are hospitalized, on average, 11 days a year.<sup>†</sup>

## Peritoneal Dialysis

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.<sup>2</sup>

## Kidney Transplant

Patients stay in the hospital a few days after transplant and will have frequent follow-up visits that decrease over time to a couple per 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.<sup>2</sup>

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<sup>†</sup> 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](https://www.usrds.org/2017/view/v2_04.aspx) (Accessed January 31, 2018)



## ESRD & Insurance

Most patients qualify for Medicare if they are on dialysis and pay the Part B premium. Those with kidney transplants who do not 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 does not have health plan through an 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 is 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 Americans with Disabilities Act (ADA)

*Fiscus v. Walmart Stores Inc.*<sup>‡</sup> 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.<sup>§</sup> VR counselors may not know that the diagnosis of “end-stage renal disease” is government-speak for “kidney failure.”

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<sup>‡</sup> *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](https://digitalcommons.law.villanova.edu/cgi/viewcontent.cgi?article=1177&context=thirdcircuit_2004) (Accessed January 31, 2018)

<sup>§</sup> 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)

<sup>§</sup> 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.<sup>1</sup> In a recent study, 36 percent of dialysis patients ages 20 to 64 said they are able to work<sup>5</sup> 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 is 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) that 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 résumé 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 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 to assist patients back to work by:

- Treating work limiting symptoms
- 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

# DID YOU KNOW..?

## Dialysis Patients Can Work and Keep Their Social Security Check



**GOOD  
NEWS!**

### What are the benefits for your patients?

- ✓ Increased independence
- ✓ Can increase self-esteem
- ✓ Increased social opportunities
- ✓ Fewer barriers to health care
- ✓ Increased income
- ✓ Insurance coverage

The pursuit of personal rehabilitation goals can help dialysis patients stay healthier and feel better. In fact, research shows that people on dialysis who keep working feel better. They are more physically able, have less pain, and have better general health and energy.<sup>1</sup> Better physical functioning predicts fewer and shorter hospital stays – and a longer life.<sup>2</sup>

Talk with your patients about the benefits of maintaining an active lifestyle *before* they decide to go on disability. If you are not comfortable doing this, consult a local renal social worker.

***Your intervention can have an impact on the social functioning of patients!***

#### More Information

- SSA - [Working While Disabled](http://www.ssa.gov/pubs/en-05-10095.pdf) (www.ssa.gov/pubs/en-05-10095.pdf)

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<sup>1</sup>Blake C, Codd MB, Cassidy A, O'Meara YM. Physical function, employment and quality of life in end stage renal disease. J Nephrol; 13 (2): 142-9, 2000.

<sup>2</sup> Lowrie EG, Curtin RB, LePain N, Schatell D. Medical outcomes study short form-36: a consistent and powerful predictor of morbidity and mortality in dialysis patients. Am J Kidney Dis. 2003 Jun 41 (6): 1286-92



## SECTION 2: PATIENT RESOURCES



## **GUIDE TO WORKING WITH YOUR LOCAL DEPARTMENT OF VOCATIONAL REHABILITATION SERVICES (DORS) OFFICE OR EMPLOYMENT NETWORK (EN)**

### **What is vocational rehabilitation (VR)?**

Having chronic kidney disease has changed your life, but there are things you can do to reduce its impact on your lifestyle and income. Work with your dialysis team to feel well enough to gain employment. You should be able to do most of the job tasks you did before you started dialysis. If an employer requires hard labor, you may even be able to do that job with an assist device or labor-saving equipment. VR can:

- Evaluate your strengths, resources, priorities, concerns, abilities, capabilities, and career interests
- Help you get education or training you need to get a good job
- Help you get the special equipment you need to do that job
- Provide changes to your home so you can work
- Help you keep a job after you get one

### **Am I eligible for services from VR or EN?**

Social Security's Listing of Impairments says dialysis and a new transplant may limit workability. If you want a job and get disability checks from Social Security, the Ticket to Work (TTW) program can help you get services through your state VR or a private EN.

## What steps should I take next?

Ask your dialysis social worker today about VR. Your social worker can help you identify local agencies and resources, and help you make a plan. Other questions you should ask your treatment team:

- How can my treatment plan be modified to fit my work goals?
- What schedule options are available to better accommodate my work goals?
- Would other types of dialysis treatment work better with my work goals?

Contact VR or an EN in your area and ask how to apply. You do not need a referral – you can contact them directly.

## What can I expect at a Department of Rehabilitation Services (DORS) office?

Some have group orientations to describe services and provide a handbook. If you're interested, the next step is to fill out an application. DORS will contact you and assign a counselor.

When you meet with the counselor, be prepared to educate him/her about your kidney disease and treatment, how it limits you from finding employment, what help you need from them, and what you may need in a job to fit with your health and treatment. Having a plan for the work you prefer helps DORS work with you.

Keep in regular contact with your counselor and be persistent. The counselor will decide if you are eligible based on such factors as:

- If you receive Social Security disability benefits
- How motivated you are to work
- Your medical records and doctor's release to work (make sure your doctor knows you want to work and limits you have, if any)

If state DORS has limited funds, it must serve those with the most severe disabilities first (under "order of selection"), and may provide services and equipment to help those at risk of job loss keep their jobs. Others may have to wait for services. If the wait is long, you can ask DORS to refer you to someone else to help you work.

When active, you and your counselor will write an individualized plan for employment that states what you need to prepare, find and get a job, and keep it. Tell your dialysis team how your work with VR or the EN is going. Ask for their help if you need it to keep getting services to reach your work goals. When VR closes your case, you may seek help from an EN to keep your job.

## What can an Employment Network (EN) do for me?

ENs can provide counseling about benefits and work incentives, career planning, job search and placement, and ongoing employment support. There are different types of ENs and each one can choose what geographic area to cover, which disabilities to serve and what services to provide. If you want to work with an EN, be sure you know all about that program. The [Finding an EN and Assigning Your Ticket Worksheet](https://choosework.ssa.gov/Assets/docs-materials/BeneficiaryWsht-form6-05-2015_508.pdf) ([https://choosework.ssa.gov/Assets/docs-materials/BeneficiaryWsht-form6-05-2015\\_508.pdf](https://choosework.ssa.gov/Assets/docs-materials/BeneficiaryWsht-form6-05-2015_508.pdf)) has topics to ask.





## VOCATIONAL REHABILITATION FOR PEOPLE ON DIALYSIS LIVING IN RURAL AREAS

Having chronic kidney disease has changed your life, but there are things you can do to reduce its impact on you. If you get SSI or SSDI and are 18 - 64, the Ticket to Work (TTW) program may be for you. It offers incentives for those who want to work. There are sources of help even if you live in a rural area.

### Working and Doing Dialysis

There are pros and cons to living in a rural area when it comes to employment. You may know how many open jobs there are, where they are, and what skills you need. However, if you live in a rural area, everyone may know that you are on dialysis, including potential employers.

If you do in-center dialysis, you may need to ask for a dialysis time or work schedule that fit together. More companies allow people to work at home. Ask your employer if that could be an option for you. Consider changing your treatment type to a home dialysis option. Home dialysis has many benefits including:

- More flexibility to do the treatment around your work schedule.
- Better treatment, which makes you feel better and have more energy.

Most employers know little about dialysis and may think those on dialysis cannot work or would need costly job changes. Here are some options for handling this:

- Your doctor and health care team can help you educate an employer
- Public or private vocational rehabilitation (VR) counselors can help you find work AND educate employers, too. You can find a state VR counselor or a counselor from a Social Security-approved Employment Network (EN) from the [Choose Work](https://choosework.ssa.gov/findhelp/) site (<https://choosework.ssa.gov/findhelp/>)
- If you are currently working and finding it hard to do with your disability, VR can also help your employer make better accommodations for you
- Vocational Rehabilitation and Employment Networks (VR/EN) can help you retrain or increase your education to find a better job for your needs

- VR/EN can help you get work-related expense resources \*\*

Rural people on dialysis and others with disabilities may need to look for other ways of working. Some start a business. According to the Department of Labor's Office of Disability Employment Policy (ODEP), people in rural areas are twice as likely to be self-employed as others. Working for yourself allows you to make your own decisions, set your own schedule, save money on transportation if you work at home, and you may even keep SSI or SSDI if your income (and assets if on SSI) is within certain guidelines.

## Transportation Challenges

Every state has public VR agencies that provide in-person counseling. Some VR counselors believe finding a ride to their office shows you are motivated to get a job. However, a large barrier for those in rural areas is that the closest VR office may be a long way from where you live, and there may be no transportation services. If you do not have your own transportation, here are some alternatives:

- Ask family or friends, people from your school or church for a ride
- Post a 'ride needed' notice in a public place, such as the post office or store
- Offer to do an errand or chore in exchange for a ride
- Some state VR agencies can help pay for transportation

If getting to a VR office is too hard or costly, you might want to choose to work with a private Social Security-approved EN that offers 'virtual' counseling. Services often include career planning, job placement/job placement assistance, and ongoing work support/work retention services. An EN might even hire you!

Counselors may use FaceTime, Skype or another program to 'meet' and counsel you. They may have online training and tools on their website to help you. This option can work well if you have internet access yourself or if you can access the internet through a friend. If there is a library in your area, it may have internet access. You can find an EN using the [Choose Work](https://choosework.ssa.gov/findhelp/) site (<https://choosework.ssa.gov/findhelp/>). In February 2018, a database search found 19 ENs that provide services 'virtually.' Those working with 900 or more clients include:

- AAATakeCharge 'Consumer-directed' and pays work-related expenses if working and earning enough <https://www.aatakecharge.com/>
- [National Telecommuting Institute, Inc.](#) Has links to Land a Job and NTI@Home work-at-home options

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\*\* Work-related expenses might include transportation to work, a computer or phone used for work, childcare or a home dialysis partner that lets you work, drugs to control your condition, and many more.





## TRANSPLANT CANDIDATES AND RECIPIENTS: NOW IS THE TIME TO CHECK OUT VR

Do you have a new kidney transplant or are you hoping to get a transplant soon? Here are some key things you should know.

### Why work?

Staying active while you are on dialysis is one way to make the change to life after transplant easier. You may feel better after transplant and have more energy and focus. You will have more time. But, if you have been out of the workforce for a while, it can be hard to get back into the swing of it. Planning can help.

The Social Security Administration's '[Blue Book](https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm)' (<https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>) lists conditions that could prevent someone from working. On the list (Genitourinary Disorders) are hemodialysis, peritoneal dialysis, and the first year after transplant. The Blue Book lists other health problems you may also have. If you are getting Social Security Income (SSI) and/or Social Security Disability Income (SSDI) only because you are on dialysis, you may not get SSI or SSDI long-term after your transplant.

The Social Security Administration (SSA) can ask for health records or ask you to see a doctor to review your disability status as early as a year post-transplant—or it could be later than that. If SSA decides you are not still disabled, your SSI and/or SSDI check will stop whether you are working or not. So, it's important to make a plan to find a job that will replace that money before you lose it.

Some people work on dialysis, especially those who are younger, have fewer health problems, more education, and jobs that do not require hard labor. People who work are more likely to get transplants, and their transplants last longer. Transplant drugs are costly, and Medicare can end three years post-transplant, while health insurance through work can last much longer.

## What if I can't do my usual job?

If you believe you cannot do the work you did before, or you hated your old job, contact your state vocational rehabilitation office (VR) or SSA-approved EN. You can find them at the [Choose Work](https://choosework.ssa.gov/findhelp/) site (<https://choosework.ssa.gov/findhelp/>). Ask what services they offer. Kidney failure is a listed condition in the Blue Book, so if you are getting SSI or SSDI and want to work, you should be eligible for services. State VR agencies offer the most services, but ENs can work with you in person or provide services online. A counselor can look at your work history, skills, values, and interests to see if they offer the services you need. The more you think about what job you want to do and what you need to do it, the better you will look to the counselor. You may need to educate him/her about your health, treatment, barriers to finding a job on your own, and services you need to overcome them. Your dialysis social worker may be able to help you think through this.

## SSA Work Incentives/Employment Supports can help:

People ages 18 - 64 that get SSI and/or SSDI are eligible for SSA employment supports under the Ticket to Work (TTW) program. Read more about programs that can help you work in the [Red Book](https://www.ssa.gov/redbook/) online (<https://www.ssa.gov/redbook/>). Some that are especially important to people considering a transplant or got one recently include:

- **Continued Payment under Vocational Rehabilitation or Similar Program (Section 301):** Allows you to keep your SSI or SSDI check if you started getting services from VR or an EN while still getting SSI and/or SSDI if your goal is to go off SSI and/or SSDI after you finish the plan. Those who keep SSDI while working with VR or an EN keep Medicare too, which extends beyond three years depending on the timeline for the plan.
- **Trial Work Period (TWP):** The TWP allows you to test your workability for at least nine months. You will get SSDI no matter how much you earn but you must report your earnings and remain disabled. Earnings under \$850 per month do not use any trial work months. Your TWP continues until you have used nine trial work months (not necessarily in a row) during a five-year period. After that, SSA looks at whether your earnings are above the SGA level, after deducting any IRWE. Both are described below.
- **Substantial Gainful Activity (SGA):** The SGA amount in 2018 is \$1180 for non-blind or \$1970 for legally blind. If after the TWP ends you continue earning more than the SGA, your SSDI checks will stop.
- **Impairment Related Work Expenses (IRWE):** SSA deducts the cost of certain items and services that you need to work from your gross wages before it decides if your work is SGA. Examples include prescribed drugs, medical devices, work-related transportation, home changes to work at home or to leave home for work, etc.

- **Continuation of Medicare & Medicare for Persons with Disabilities Who Work:** If you have a transplant and another disability, or if you lose your SSDI due to work income, Medicare Parts A, B and D continue for another seven years and nine months. Afterward, you can keep Medicare Part A and B by paying those premiums. Your state may pay your Part A premium if you qualify.<sup>††</sup>

### What if I have other health problems that keep me from working?

Now is the time to make sure all your health problems are noted on your chart. For example, if you have heart, lung, blood vessel or nerve problems, are legally blind, or you have any of the many other problems listed in the [Blue Book](https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm) (<https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>), make sure your health care team lists those problems in your chart. This way, if SSA reviews your disability status after transplant, it is easier to show that kidney failure was not your only disability.<sup>††</sup>

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<sup>††</sup> If you are on dialysis, you can keep Medicare regardless of your work income if you pay the premium.

<sup>††</sup> As long as you get SSI and/or SSDI after transplant, you can use the above programs to ease back into work.



## HOME DIALYSIS/TRANSPLANT: WORKING WHILE ON DIALYSIS

PATRICIA

Working while on dialysis presents challenges. I personally was worried about scheduling trainings and dialysis process. I didn't feel tip top. I felt a little like it was time to give up. However, my upbringing with my deceased World War II Veteran, captain of a ship, dad would never permit anything but "buck it up". Attitude is important. It also helped that I loved my job, which was a sit-down one too!

I was working for a major hospital system when it became apparent that my kidneys were failing. I continued to work despite having days when I felt nauseated and exhausted. Talking with patients distracted me from my own problem. When I was informed that my GFR was at '9' I was told that it was time to go on dialysis. The various modalities were presented with the physician's bias apparent-peritoneal dialysis to be undertaken at home was preferred. We agreed.

Initially, my primary worry was working the training in with my husband's and my work schedule. The nurse assigned to me said that she definitely would work around this. All appointments were conveniently scheduled. Rosemary was wonderful-- cheerful, accessible, reachable, and detail oriented. It seemed to take us a long time to "get the hang of it" -meaning all of the procedures one must follow to insure that the cyclor machine functioned well and that no infection resulted from improper procedures. She tactfully told us that the brighter people are, the longer it takes! What a peach!

The solution bags arrived and in came the cyclor too. We stored the solution bags in the closet and I took over the guest bedroom. Still urinating with partially functioning kidneys, another worry was reaching the bathroom during the night. The solution? An extra-long catheter! My skin tore with every taped dressing and, admittedly, I didn't sleep well.

I worried unnecessarily about power failures because I would need to dialyze manually or end up half dialyzed when the machine cut out. I worried that I might be late for work. I worried that I would not be *able* to work and do what I enjoyed doing. I worried that I might let people down. None of this ever happened.

My husband, my family, friends, and co-workers were beyond supportive. I probably could not have done it without them. At the end of the workday, I faced the alternative between mounting a short stairway and taking the elevator. I opted for the latter but someone always kept me company. Thank God I had a sit-down job! In addition to his help with the machine, my husband patiently went shopping with me. It was important to me to camouflage the port so that others' attention was not drawn to this. In fact, when you got down to the truth...I didn't want anyone to even know that I was ill. Aside from those in the "inner circle", I told no one.

When my doctor learned of this, he strenuously insisted that it was important to tell *everyone*. He said that I never knew who might want to be a donor. Sure enough, people approached with their offers of the most special gift. Some people could not qualify to be donors due to their own health challenges. My boss expressed interest. One of my friends did not match me but was willing to give one to someone else if their donor would donate to me. She went through all of the testing. My brother who is five years my senior, and in great physical shape, was a willing match.

I hope that others will not see anticipated hurdles as high as I did. Know that they are lower than you think and are surmountable! I actually think that working and undergoing testing distracted. It'll be helpful if you like your job but hope for the future is the best asset and attitude.





## HOME DIALYSIS/TRANSPLANT: WORKING WHILE ON DIALYSIS

MAGGIE

Can you work while on Dialysis?

The short answer is yes, it's doable. It isn't always easy, but it is doable. I know, because I did. I lost kidney function while I was in my early 40s and, 25 years later, I am thinking about retiring soon. But there are some adjustments you may need to make and some things to think about.

First is Time. I was lucky. My job was 9 to 5 and I did in center dialysis in the evenings. But those were long days. I found it much easier when I switched to home dialysis. This gave me the flexibility I needed to dialyze on a schedule that worked best for me and to adjust it when I needed to. I would encourage you to consider home dialysis. At least give it a try.

The second issue is Energy. Dialysis does tend to reduce our energy and that can sometime make working difficult. Again, I was lucky. I had a desk job. But I know many, many people with more physically demanding jobs who still work on dialysis. But if your job is too strenuous you might want to consider switching to a less demanding one. If you don't have the skills needed for the switch, consider taking some classes or attending some job training seminars. Some good places to look for job training are local Community Colleges, local libraries, and your local County. They can all help you gain the skills you need and even help you with job placement.

If you already have a job you like, but you find that it has become difficult to keep up with it, talk to your boss. Sometime there are options that you haven't even considered. I know a physical therapist who found himself in that exact position. Treating patients all day had become too physically demanding, so he spoke to his boss about it. He ended up getting promoted to management and spends half his day at a desk and the other half treating the patients that he loves so much. You don't know if you don't ask.

The Bottom line is that it may not be easy. But it is often doable. Just look at your options and see what changes you can make in your life to make it happen. There will be some bad days, but there will be some incredibly good days too. But isn't it like that for everyone?



## IN-CENTER DIALYSIS/TRANSPLANT: WORKING WHILE ON DIALYSIS

MITZI

I was 32 years old when I was diagnosed with kidney disease. Because I was so young, I decided to continue working as long as I felt up to it. I always knew that if my health would get worse, or that I was no longer strong enough, I would have to discontinue. I always had the attitude that I would not let this disorder get the best of me. So I did my best to stay compliant with doctors' orders such as my diet and light exercise to stay as healthy as I could. So I was able to continue working while doing in-center hemodialysis for 5 years. I am now 2 years post-transplant. I will still continue to work as long as my health allows me to. Working keeps me socially available to meet new people. It keeps my mind busy. It keeps me from feeling sorry for myself because of having a health issue. So in closing, I suggest discussing this with your health team if anyone would like to continue or go back to their employment.