Vocational Rehabilitation
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Intro
The Vocational Rehabilitation (VR) Toolkit

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 VR referrals as appropriate.

Evidence of interdisciplinary assessment, education, assistance with barriers, and referral is documented in an individualized plan that reflects each patient’s preferences.

The goal of the VR quality improvement activity is to support gainful employment of ESRD patients. Specifically, the goal is to increase the percentage of project facility patients, ages 18 through 54, who are referred to and receiving VR services.

- Increase VR referrals by ten percent
- Increase patients receiving VR services by five percent
- Screen 100% of patients ages 18-54 for VR eligibility and interest
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VR Resource List

State VR Offices
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.

For more information on the California Vocational Rehabilitation Program visit:
http://www.dor.ca.gov/Home/JobSeekerConsumer

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

**Working While Disabled: How We Can Help**
Booklet explains the basics of working while on SSDI or SSI

**Working with Chronic Kidney Disease**
Booklet for people with kidney disease that reviews how to keep a job, prepare for and find a new job, plus laws and resources

**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
Eisenstein Rehabilitation (VR) Toolkit

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VR 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 and support home dialysis options and refer patients to other clinics for options you don’t 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. The *Family & Medical Leave Act* (FMLA) and *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 are have less financial stress, are less depressed, have a 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
  - ☐ Plan interventions to achieve patient’s rehabilitation goals

☐ 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
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Tips for Partnering with Local VR Offices

• **Contact and build a relationship with VR counselors.** Share materials, such as the manual “Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease.” You can use the “Find Help” directory for local VR offices, ENs, 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.

• **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).
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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. \(^2\)

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(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.  

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.  

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._ 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. VR counselors may not know that the diagnosis of “end-stage renal disease” is government-speak for “kidney failure.”

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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. In a recent study, 36 percent of dialysis patients ages 20 to 64 said they are able to work 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
GOOD NEWS!

DID YOU KNOW...

Dialysis patients can work and keep their Social Security check?

What are the benefits for your patients?

✔ Increased independence
✔ Higher self-esteem, less depression
✔ Social opportunities
✔ Fewer barriers to health care
✔ More likely to get a transplant
✔ Higher 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.\(^1\) Better physical functioning predicts fewer and shorter hospital stays – and a longer life.\(^2\)

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
- HealthInsight ESRD Network 18 - VR links and tools for download at www.esrdnetwork18.org or patients can call 888-268-1539.

**ESRD Network 18**

**Guide to Working with Your Local VR Office or EN**

**What is 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 a 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 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 and how your treatment plan and dialysis type and schedule can fit your work goals.
- Review these resources for work:
  - Working While Disabled: How We Can Help
  - Working with Chronic Kidney Disease
  - The Work Site
  - Choosing an Employment Network for You
  - Finding an EN and Assigning Your Ticket Worksheet
- Contact VR or an EN in your area and ask how to apply. You do not need a referral – you can contact them directly.

**To find your local office please visit:**

http://www.dor.ca.gov/Home/FindAnOffice or call 1-800-952-5544
What can I expect at a VR 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.
• VR 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 VR, and may need in a job to fit with your health and treatment. Having a plan for the work you prefer can make VR want to 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 VR 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 VR 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 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 has topics to ask.

To file a grievance, please contact HealthInsight ESRD Network 18 using our contact information below:
700 N. Brand Blvd., Suite 405, Glendale, CA 91203, 888-268-1539, www.esrdnetwork18.org
ESRD Network 18

VR 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 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.

People living in cities and suburbs may not know where there are open jobs to fit their skills. Living in a rural area, you may know how many open jobs there are, where they are and what skills you'd need. Whereas people in urban areas can avoid telling an employer they are on dialysis, but if you live in a rural area, everyone may know you're on dialysis. If you do in-center dialysis, you may need to ask for a dialysis time or work schedule that fit together, or you may want to think about a home dialysis option. More companies allow people to work at home, you may want to ask your employer if you are able to.

Most employers know little about dialysis and may think those on dialysis can't work or would need costly job changes. You may need to inform them and self-advocate to get an offer for an open job you know you can do well. Your doctor and health care team can help you educate an employer. Public or private 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 EN from the Choose Work site.

Every state has public VR agencies that provide in-person counseling. Some VR counselors believe finding a ride to their office shows you’re 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 don't have your own transportation, you may need to ask family or friends, people from your school or church, or you may need to post a ‘ride needed’ notice in a public place. If you ask someone to drive you, you may need to pay for the ride. If money is tight, you could 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, ongoing work support/work retention services, or 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's a library in your area, it may have internet access. You can find an EN using the ‘Choose Work Find Help’ site linked above. Insert your ZIP code or city and state, check the ‘Employment Network’ box, and choose the ‘virtual’ option on the left side of the page. The program may switch to ‘in person and virtual.’ To keep from having to go through many pages, choose to see all listings (the default is 20/page). The list has contact information, website, who the EN serves, and what services it offers. In February 2018, a database search found 19 ENs that provide services ‘virtually.’ Those working with 900 or more clients include:

- **AAATakeCharge** is ‘consumer-directed’ and pays work-related expenses if working and earning enough
- **AAATakeCharge Milestone LLC** is ‘consumer-directed’ and pays work-related expenses if working or in school or training enough
- **Employment Options, Inc.** offers work at home options
- **National Telecommuting Institute, Inc.** has links to Land a Job and NTI@Home
NOTE: Work-related expenses might include transportation to work, a computer or phone used for work, child care or a home dialysis partner that lets you work, drugs to control your condition, and many more.

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. The ODEP site has information and resources to help overcome barriers to working for yourself so you can consider this option with your counselor from VR or an EN. There is more than one way to get a job.

To file a grievance, please contact HealthInsight ESRD Network 18 using our contact information below:
700 N. Brand Blvd., Suite 405, Glendale, CA 91203, 888-268-1539, www.esrdnetwork18.org
ESRD Network 18
Transplant Candidates & Those with New Transplants 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 and think about.

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

The SSA ‘Blue Book’ lists conditions that could prevent someone from working. On the list are HD, PD, and the first year after transplant. The Blue Book lists other health problems you may have too. If you’re getting SSI and/or SSDI only because you’re on dialysis, you may not get SSI or SSDI long-term after your transplant. 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’re not still disabled, your SSI and/or SSDI check will stop whether you’re 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 work at jobs that don’t require as 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 work health insurance can last much longer.

What If You can't do Your Usual Job?
If you believe you can't do the work you did before, or you hated your old job, contact your state VR or SSA-approved EN. You can find them here. Ask what services they offer. Kidney failure is a listed condition in the Blue Book, so if you’re 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’ll 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 this through.

SSA Work Incentives/Employment Supports can Help:
People ages 18 - 64 who get SSI and/or SSDI are eligible for SSA employment supports under the TTW. We know this brief fact sheet can’t answer all your questions. We suggest you read more about these programs which can help you work in the Red Book online. Some that are especially important to know about if you’re looking at getting 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’ll get SSDI no matter how much you earn but you must report your earnings and still be disabled. Earnings under $850 per month don’t use any trial work months. Your TWP continues until you’ve 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 $1080 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, if you lose your SSDI due to work income, your free Medicare Part A, premium Part B and Part 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. **NOTE:** If you’re on dialysis, you can keep Medicare regardless of your work income if you pay the premium.

### What if you have other health problems that keep you 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](#), 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. **NOTE:** As long as you get SSI and/or SSDI after transplant, you can use the above programs to ease back into work.

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*To file a grievance, please contact HealthInsight ESRD Network 18 using our contact information below:*

700 N. Brand Blvd., Suite 405, Glendale, CA 91203, 888-268-1539, [www.esrdnetwork18.org](http://www.esrdnetwork18.org)
ESRD Network 18
VR Success Stories

The stories below were shared by four of Network 18’s Patient Advisory Committee (PAC) members.

Nancy: A Little History and a Lot of Hope
Nancy is a registered nurse and has lived with kidney disease since 1959. Before starting dialysis in 1966, Nancy had to undergo a screening by the Admissions and Policy Committee (also called the ‘Life and Death Committee’) in Seattle, WA. All patients were reviewed for dialysis in those days before Medicare paid for treatments. The committee looked for people who could recover and go on to work or be contributing members of society. Returning patients to their prior level of functioning is the reason Medicare began to pay for dialysis.

Dr. Belding Scribner testified to Congress at that time that, unless a patient was rehabilitated, the treatment was inadequate. He emphasized that most patients who received funding would be on home dialysis or transplanted, and would be taxpayers.

“We had a vocational counselor at my kidney center, and I received assistance with my education and career, first as a school teacher, and later as a nurse. Throughout my adulthood, I continued to work and support my children. I retired from my nursing career in 2011, but still substitute teach, and nurse per diem. I never really liked the term ‘Life and Death Committee’! I always considered it a ‘Life Committee.’ They chose me to live – and with that privilege, there was a responsibility to realize my full potential. All I ever wanted was a normal, decent life with my children and the opportunity to give back to society at least as much as I have been given. I continue to strive toward that end.”

Esther: Nurses do it with Care
I hadn’t figured out how it would happen, but I was thinking about going back to school to study chemistry before I learned I had kidney disease on my 32nd birthday. I was ready to move on to a career, but kidney disease hit acutely and I found myself bedridden with 50 pounds of extra fluid on my body. As soon as I got the fluid off, I began working on a plan to be self-sustaining and have some extra money to help my mother.

About a year later, one of my friends who worked for VR told me about it. I applied and went to an appointment with a VR counselor right away. I had a kidney transplant and took a job as a medical scribe while going to school full-time. I graduated with a nursing degree from OHSU about four years after going back to school.

Medicare continued to pay for my transplant medications beyond the usual three years because I had been active in VR before my transplant. VR paid for most of my education, all of my books, and all other expenses related to getting a job after graduation. Now I work as a home dialysis nurse and train patients and their families to do peritoneal dialysis.
Gary: My Journey with Vocational Rehabilitation

When I consider my journey with VR, I recall a time before I could have fathomed needing such a service. My father was a laborer and instilled in me a desire to work with my hands, become a jack of all trades and most importantly provide for my family. However, having more academic as opposed to physical attributes, I joined the Air Force.

In 1984, I began my career as an inventory management specialist, supply clerk for short. I was stationed at JBER in Anchorage, Alaska. I met my wife Yalanda in Alaska, and we had our first child Icy in 1988. I was reassigned to Japan in 1989, just before the birth of Garyll, my second child.

Due to Garyll’s medical problems, I left Japan and the Air Force in 1990, to start my civilian life in Alaska. I took a job making $7.50/hour as a warehouseman at a rigging shop, and advanced to shop supervisor then foreman – thanks to my father’s example of a good work ethic.

My work involved long hours and hard days. We had our third child Shampaye in 1996, and then became foster parents for four more children – Roland, Damonta, Michael and Jashala. In 2012, just three days after my 46th birthday my life took a new path. Hours after arriving at the hospital with what I suspected was stomach flu, I was told I had a heart attack, three strokes and my kidneys had failed. My life on peritoneal dialysis began a few months later. I joined HealthInsight ESRD Network’s PAC in 2013, to add my voice to the many other voices that have come together to better the lives of kidney patients.

I went back to work in May 2014, but soon discovered that I could not continue as a rigging specialist. In August 2014, I was introduced to VR by my dialysis social worker. My VR counselor made sure I had a laptop and printer and covered any college-related expenses, and I enrolled in a retail management program.

Thanks to VR, my lifelong dream of attending college is fulfilled and I have a new lease on life. VR is making it possible for me to return to the workforce and continue to be the man by father exemplified. I am currently listed for a kidney transplant and have a potential donor. An interesting twist to all of this – my daughter Shampaye attended college with me. She told me if I go to college, she could too.
Michael: Inspired by a Dialysis Social Worker

My name is Michael Mace. I had worked in the restaurant industry for about 20 years and was an assistant manager for Wendy's Restaurants in the Puget Sound area of Washington. I was diagnosed with Stage 5 ESRD in September 1997, after 23 years of being a Type 1 Diabetic. My nephrologist encouraged me to start the kidney transplant workup at that time. I started my kidney transplant application process in October 1997 and then went on dialysis Christmas week of 1997.

I met two social workers at the dialysis unit that encouraged me to finish my transplant workup and advised that I would make a great social worker given my experience working with the public. I made an appointment with Vocational Rehabilitation (VR). The VR counselor explained to me my options, provided me with resources, and sat down with me to set up a step-by-step plan to reach my goals to become a social worker. I finished my transplant workup in March 1998, and was listed for transplant in April 1998. I received my kidney transplant July 20, 1998.

In March 1999, I began my journey to follow through with the VR plan. I started my associate's degree program at Tacoma Community college, and graduated in 2003 with an AA degree and counseling certificate in Human Services. I then went on to obtain my Bachelor of Social Work degree and my Masters of Social Work degree at the University of Washington.

In March 2005, I obtained a social work job working part-time at a kidney dialysis center. In 2006, I went to full-time work as a nephrology social worker. I have been a nephrology social worker for 13 years now. It is with great appreciation for the VR counselors who assisted me to start my journey that I am able to be where I am today. I was able to keep my Medicare and SSDI while completing school and following my aspirations to become a social worker.

As a dialysis provider and a patient, I have been presented with opportunities to learn, grow, and discover my true potential. Following my purpose with focused effort has opened many opportunities to work with and for chronic kidney disease patients and the community to help and educate others on how to better manage CKD and improve their lives. My motto: Find and follow your purpose and thrive on.

Talk to your social worker about your lifestyle goals, and they can help you to get started.

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300 Pounds Lost, One Kidney Gained, and Financial Independence Recovered

Rob’s Story

Some would call Rob an “old soul.” He seems to have a kind of wisdom that many people don’t pick up before their Golden Years. Rob invests heavily in his relationships. He has cared for family, friends and neighbors in his community for years. Because Rob is a volunteer firefighter and Emergency Medical Technician (EMT), he has become a familiar and beloved figure in his hometown of Mountain, Wisconsin.

Mountain is a rural community located in Northeast Wisconsin. With fewer than 300 families, it’s not surprising that people take care of one another there. “When you think of other people, it makes life rich,” he says. “It feels good to connect with our neighbors and [be part of] our town.” As Rob travelled from prosperity to death’s door and back, he found that a strong connection to his community paid dividends when he most needed them.

Home-Grown Entrepreneur

A blizzard dumped two feet of snow on Mountain in 1987. Cars were stuck all over town, and there weren’t enough tow trucks. Rob was just 16 when he received a call from the sheriff’s department asking for help. He had bought himself a used tow truck, intending to earn some money. This was his chance to try it out for the first time. Soon, Rob was getting calls from four area sheriffs’ departments. It was the season that launched Rob’s towing & trucking business. His enterprise expanded quickly, and was incorporated as Big Rob’s Inc. (BRI) in 1998.

“We hired drivers, an office manager, a trucking manager, a dispatcher, two mechanics, two controllers and two attorneys,” he recalls. Rob was glad he could provide employment in his town, and BRI’s growth was a source of satisfaction.

Restless energy and a need to make ends meet fueled Rob’s drive to work several jobs at a time. “In a small community like [Mountain], people sometimes work 3 or 4 jobs to pay the bills,” he explains. Along with BRI and his work as a first responder, Rob became Director of Investigations for the local Gaming Commission. It was a period of prosperity, and he was satisfied with the activity in his 60-hour work week. But Rob’s ambitious spirit was no match for the health challenges he would have to face.

Decline

Rob had struggled with his weight since childhood. By 1999 he weighed 550lbs, and was finding it increasingly difficult to do the things he wanted to do.

“Everything was hard. People stared. Travel was complicated. I had to buy special clothes. But the most difficult part was the effect on my health. It was deteriorating and I couldn’t keep up with work.”

Rob was diagnosed with renal failure, and his company filed bankruptcy in 2000. “Things really started to fall apart,” he recalls. “I went into a depression when I had to tell the employees we were going out of business. All these families depended on [BRI]. I felt terrible.”

With the right support, Rob found his path to a better future. To learn more, call the Ticket to Work Help Line at 1-866-968-7842 (V) or 866-833-2967 (TTY), or visit socialsecurity.gov/work.
Rob began dialysis in 2005. He would need a new kidney and wondered whether his time was up. He was not ready to give up on life, but didn’t know whether his body was. For a kidney transplant to succeed, Rob needed to lower his blood pressure and manage other health conditions that could complicate recovery. Rob and his doctors decided that gastric bypass surgery offered him the best chance. He was approved for Social Security Disability Insurance (SSDI), and prepared for the medical challenges that lay ahead.

Dialysis, With a Side Order of College... To Go

Rob was hospitalized for much of 2006. His surgery was a success, and the results surpassed everyone’s expectations. “The doctors were astonished that the weight came off so quickly,” he recalls. “I lost both kidneys. But I also lost 300lbs, my high blood pressure, and sleep apnea!”

Dialysis treatment continued for 6 hours per day, 3 days a week, and Rob became restless. “I never in my life came to a stop… I had to keep moving forward,” he said. Rob decided to use his time on dialysis to earn a bachelor’s degree. With help from Wisconsin’s Department of Vocational Rehabilitation (VR), he purchased a laptop and enrolled at the University of Wisconsin Green Bay. Classes were online, and he worked on a degree in interdisciplinary studies while waiting for a kidney.

In November of 2008, Rob was thankful for many things. Neighbors held a fundraiser for medical bills, and the support was overwhelming. But nothing touched him like the generosity of his friend Pam Nelson. During the 15 years that they worked together as emergency responders, she watched him struggle with kidney disease. Pam decided to give Rob one of her kidneys. “She’s a special person,” he says. “She saved my life.” The transplant was a success, and Pam was recognized with a medal for her heroic gift.

Rob’s Ticket to Work

After Rob’s health improved and he had earned a bachelor’s degree, he felt ready to return to work. His VR counselor told him he was eligible to receive free employment support services through Social Security’s Ticket to Work program. Social Security disability beneficiaries age 18 through 64 qualify. A range of services that help people prepare for and find employment are available through VR agencies and authorized providers known as Employment Networks (ENs). ENs also offer support services that can help people stay employed or advance in their career. (see boxes: “Employment Networks” and “About Work Incentives”)

Employment Networks

ENs offer free services through Ticket to Work that can help you:

- Find answers to your questions about employment and benefits
- Prepare for the workforce
- Find a job and stay employed
- Advance in your current job
- Get job accommodations
- Stay in touch with Social Security
- Stay Organized

Visit socialsecurity.gov/work for tips on choosing the right EN. Use the “Find Help” tool to connect with providers who offer the services you need to start or advance your career.

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Rob received help with his résumé and job leads from Wisconsin’s state VR agency. In 2011, he was offered a job as a Field Agent Examiner for the Department of Transportation (DOT). He looked forward to returning to work, but was also apprehensive. “SSDI and Medicare are stable. The workforce is not. I was glad to find work, but didn’t want to lose my disability benefits,” he said.

An EN Joins ‘Team Rob’
When Rob’s VR services came to an end, his counselor referred him to an EN called Employment Resources, Inc. (ERI). ERI would continue where VR left off, providing services to help him succeed in the workforce. Providers (like ERI) that offer benefits counseling can help people understand what employment will mean for their benefits. Rob was grateful to find attentive professionals who answered his questions, explained the rules around Social Security benefits and employment, and made it easier to focus on achieving his employment goals. He came to the meeting with his benefits counselor carrying a heavy load of concern, and he left looking forward to his new job at DOT.

The benefits counselor at ERI told Rob about Social Security rules called Work Incentives. Work Incentives make it easier for adults with disabilities to enhance job skills and gain work experience. As an SSDI beneficiary, some of these rules were of particular interest to him. When Rob learned that SSDI recipients can receive cash benefits while they test their ability to work during a 9-month “Trial Work Period” (TWP), he became less concerned about returning to work. As soon as the TWP ends, a 36-month “Extended Period of Eligibility” (EPE) begins. During the EPE, SSDI cash benefits are suspended only in months when earnings go over the amount that Social Security calls “Substantial Gainful Activity” ($1,700 for adults with blindness, or $1,040 for adults with other disabilities).

Rob was particularly relieved when his benefits counselor informed him about a Work Incentive called “Continuation of Medicare Coverage”. According to this rule, SSDI recipients who work continue to receive Medicare benefits for at least 7 years and 9 months after completing the TWP. The Work Incentive that put Rob most at ease is known as “Expedited Reinstatement” (EXR). Rob learned that EXR may enable Social Security to re-start his benefits without a new application, if he has to stop work because of his disability within five years. He felt better about returning to work knowing he would have time to acquire new skills and settle into his job without fear of losing his benefits.

Most people who become employed with help from a state VR agency find that VR services end approximately 90 days after they start working. Many people like Rob need ongoing support to remain employed and increase earnings over time. To provide support services for employed Ticket program participants, VR agencies sometimes collaborate with ENs. This arrangement, known as “Partnership Plus,” gives participants continued access to individualized employment services if needed. You may decide to work with an EN of your choice to receive support that continues after you are on the job. Partnership Plus sets people up for success by providing support at each step to financial independence.

About Work Incentives
Many different Work Incentives are available to help people go to work. These rules can help you:

- Keep your Medicaid or Medicare coverage while working
- Prepare for work while receiving cash benefits
- Work while receiving some or all of your cash benefits
- Get back on benefits if you are unable to continue working

To find out how Work Incentives apply to you, consult a benefits counselor. To find one, use the “Find Help” tool at socialsecurity.gov/work. Or, call the Ticket to Work Help Line at the number below. Ask for help finding an EN that has a qualified benefits counselor on staff.

With the right support, Rob found his path to a better future. To learn more, call the Ticket to Work Help Line at 1-866-968-7842 (V) or 866-833-2967 (TTY), or visit socialsecurity.gov/work.
“Keeping track of my benefits and the rules I needed to follow was overwhelming,” he said. “ERI was there to answer all of my questions and they helped me with the Social Security correspondence that can be so intimidating. I’ve got a lot on my plate, and it helps to have them on my team!”

Another Filling Day

Motorist despair at the DMV is a familiar phenomenon. But those who land in Rob’s line will find a friendly and helpful reception when they reach the front. “I process drivers’ licenses…” he explains with enthusiasm. “My favorite part of the job is taking people out for their road tests. I meet a lot of interesting people this way, and also come across some welcome familiar faces!”

Rob has traded his SSDI cash benefit for a larger paycheck, and he’s not looking back. He says it feels like he has lived several lives and travelled 10,000 miles since the start of his health challenges. He’s content, and appreciates having days that are once again fulfilling.

“I love my job,” he says. “The people I work with are like family and I get to interact with the community again. When I was sick I had to give up a lot. The [Ticket] program helped me transition back to stability, and it feels great to have choices again. Ticket to Work and Work Incentives helped me recover them!”

Sources: In addition to direct interviews with Rob and staff at ERI, information for this article was paraphrased from a fox11online.com article titled “Thankful for a Special Friend,” published 11/27/08. Reference was also made to “Education on a Road to Recovery,” featured in UW-Green Bay’s Inside newsletter, January 2008 issue.

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