

Vocational Rehabilitation for the ESRD Patient: Fulfilling the Promise



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Objectives

- State what we know about the current state of dialysis patient employment
- Explain how the interdisciplinary team can help improve patients' employment outcomes
- Describe how laws, work incentives, and rehabilitation providers can help
- List available resources

The Promise to Congress...

“60% of those on dialysis can return to work but require retraining, and most of the remaining 40% require no retraining whatsoever. These are people who can be active and productive, but only if they have the life-saving treatment they need so badly.”

Sen. Hartke Testimony, 1972



How Many Dialysis & Transplant Patients in the U.S. Work?

- Sadly, we don't know for sure
 - Information from patients is collected on CMS 2728 at treatment initiation
 - After that, data reported annually *by dialysis staff* on patients ages 18-54 but not by dialysis type
 - Data collected on transplant recipients but not reported in UNOS Annual Report
 - Patients working “off the books” may not be honest because of fear of benefit loss

Incident Patient Data from CMS 2728

All Ages (2014-2016)

	Full-Time		Part-time		Student	
	Prior	Current	Prior	Current	Prior	Current
0-4					10.8	7.2
5-9					58.5	56.4
10-13					67.5	65.7
14-17	6.1	5.0	1.6	1.8	66.0	64.9
18-21	16.3	10.5	10.2	7.7	26.9	24.4
22-24	25.3	17.6	11.5	9.6	8.3	7.6
25-29	31.6	22.0	8.4	6.5	2.2	1.7
30-34	33.0	23.4	6.8	5.5	0.7	0.7
35-39	34.2	24.4	5.8	4.8	0.3	0.3
40-44	33.5	23.9	4.7	4.1	0.2	0.3
45-49	31.0	22.3	4.2	3.5	0.1	0.1
50-54	26.9	19.0	3.7	3.0	0.1	0.1
55-59	21.6	14.9	3.3	2.8	0.0	0.1
60-64	15.4	10.3	2.7	2.4	0.0	0.1
65-69	6.5	4.2	2.2	1.9	0.0	0.1
70-74	3.3	1.9	1.6	1.5	0.0	0.1
75-79	1.9	0.9	1.0	0.9	0.0	0.1
80-84	1.2	0.5	0.6	0.6	0.0	0.1
85+	0.8	0.4	0.5	0.4	.	0.0

Reporting Vocational Status in CROWNWeb Annual Facility Survey (CMS-2477)

- For all dialysis patients ages 18 thru 54 living as of 12/31
 - Field 32: Number dialyzing at facility
 - Field 33: Number receiving public or private VR services
 - Talked with counselor, agreed to evaluation, requested medical records, assigned counselor
 - Had evaluation (e.g., interest, skills, aptitude, job readiness testing)
 - Had VR counseling, training/education at training center/school
 - Had VR help in job seeking, job retention, job accommodation
 - Field 34: Employed full- or part-time for taxable wages or self-employed paying taxes
 - Field 35: Attending formal education/training program full- or part-time

<http://www.esrdnetwork.org/sites/default/files/content/uploads/Dialysis-Facility-2744-Instructions.pdf>

<http://mycrownweb.org/help/glossary/>

Dialysis Patient Vocational Status Staff CROWNWeb Report, 2016



Table 16: Number of Dialysis Patients Aged 18–54 Years, Number and Percent Employed, Number and Percent Receiving Vocational Rehabilitation Services, Number and Percent Attending School, and Number and Percent of Facilities Offering Dialysis after Regular Business Hours, as of December 31, 2016

Network	Number of Dialysis Patients Aged 18–54 Years as of December 31, 2016	Number Employed*	Percent Employed*	Number Receiving Vocational Rehabilitation Services	Percent Receiving Vocational Rehabilitation Services	Number Attending School*	Percent Attending School*	Number of Dialysis Facilities After Regular Hours (5 PM)	Percent of Dialysis Facilities After Regular Hours (5 PM)
1	3,468	807	23%	25	1%	37	1%	59	30%
2	7,864	1,679	21%	44	1%	97	1%	113	40%
3	4,986	992	20%	19	0%	47	1%	70	32%
4	5,068	968	19%	17	0%	31	1%	50	15%
5	7,936	1,767	22%	16	0%	47	1%	74	18%
6	15,354	2,466	16%	73	0%	166	1%	36	5%
7	8,072	1,707	21%	62	1%	176	2%	65	15%
8	8,917	1,341	15%	15	0%	53	1%	25	6%
9	9,001	1,884	21%	46	1%	60	1%	89	15%
10	5,722	1,197	21%	7	0%	40	1%	35	11%
11	7,698	1,792	23%	99	1%	173	2%	280	55%
12	4,444	1,006	23%	10	0%	33	1%	33	10%
13	6,406	1,208	19%	134	2%	120	2%	26	8%
14	15,044	3,131	21%	137	1%	233	2%	68	11%
15	7,276	1,609	22%	16	0%	46	1%	91	25%
16	4,237	1,097	26%	57	1%	104	2%	111	52%
17	7,536	1,606	21%	14	0%	63	1%	68	24%
18	13,278	2,413	18%	61	0%	142	1%	386	100%
TOTAL	142,307	28,670	—	852	—	1,668	—	1679	—
% of Total	—	—	20%	—	1%	—	1%	—	24%

*Full- or part-time. NOTE: Items in this table are reported on the CMS-2744 Form in CROWNWeb. Due to the manner in which CROWNWeb calculates employment, vocational rehabilitation, and school on the CMS-2744 Form, the numbers reported in this table may vary slightly from actual totals.

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Occupations of Dialysis Patients Working for Wages

Dialysis Patients' Occupations	Percent
Clerical & sales workers or technicians	23.7%
Semi-skilled workers, machine operators	19.1%
Administrators, small business owners, semi-professionals	19.1%
Business managers, lesser professionals	15.4%
Executives of large businesses, major professionals	8.8%
Skilled manual workers	8.2%
Unskilled workers	8.7%

Comprehensive Dialysis Study, 2009 USRDS Annual Data Report, page 316-317.

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“Able to Work” & QIP Measures from ACTIVE-ADIPPOSE Study

- 528 eligible patients ages 18-64 on HD at least 3 months
- Asked if able to work for pay FT/PT or working FT/PT for pay (taxable wages) & screened with Center for Epidemiologic Studies-Depression scale
- Demographic, 5 QIP metrics
- 35.8% reported they were able to work
- Significant differences - able to work vs. not to work:
 - Able - younger, more with a high school education, fewer with diabetes
 - Unable – had HD catheter, had depression score ≥ 18 (clinically depressed)

Working Benefits Patients

- Greater independence & self-esteem
- More opportunities to socialize
- Less depression
- Higher income
- Better health plans
- Easier to follow the treatment plan
- Better chance of transplant & longer graft survival

Working Patients Benefit Facilities/Staff

- Fewer emergencies saving staff time, supplies
- Fewer & shorter hospital stays
- Longer survival
- More satisfied staff
- Less staff turnover, lower training costs
- If well informed, more patients may choose lower cost home dialysis options
- Higher revenues from employer health plans

Employers Benefit from Hiring/Retaining Dialysis Patients

- Saves money for recruitment & training
- Provides government tax credits/deductions
 - For workplace accommodations, if needed
 - For hiring SSI recipients, those currently or previously served by VR, Employment Network or veterans rehab
- Compliance with anti-discrimination laws

You Can Help Your Patients Work...

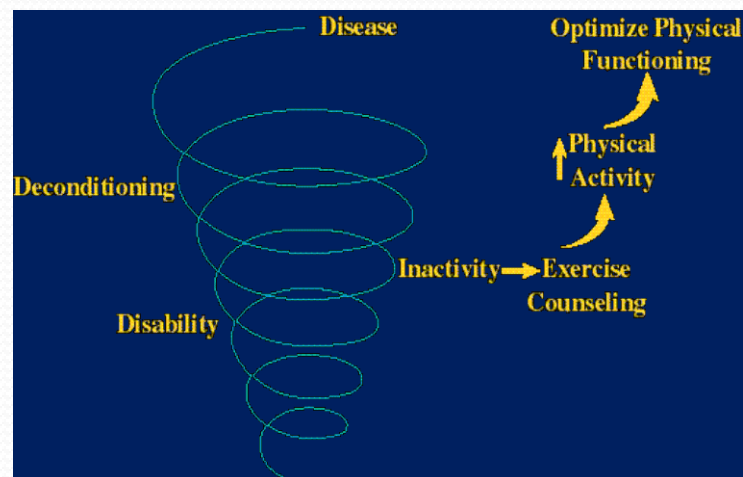


...But How?

Clue: It Takes a Team

Provide High Quality Care

- Help patients understand more dialysis is better
- Encourage patients to report work-limiting symptoms
- Promote self-management & address learning needs
- Inform yourself & educate patients about home options & transplant
- Promote physical activity
- Discuss KDQOL-36 results in plan of care meetings & QAPI



Reprinted from *The American Journal of Kidney Diseases*, Vol. 24, No. 1, Suppl 1 (July) 1994:52-59.

Triage Patients: Working/In School

- Patients live up or down to our expectations:
 - *Expect & support* workers to continue to work
 - *Expect & support* students to stay in school
- Establish a program with working patients as mentors
- Recommend patients use FMLA vs. applying for disability
- Advise employers how to accommodate medical & workplace needs of dialysis patients

Triage Patients: Not Working, Willing, Able

- Share info on work incentive programs to overcome fear loss of cash & health benefits
- Clarify work goals
- Refer early for job training or volunteer activity
- Build self-esteem
- Encourage patients to self-promote
- Support job/school search efforts
- Advise patients to ask for accommodations if needed—but not to divulge health status if not needed
- Promote entrepreneurship as appropriate

<https://lifeoptions.org/assets/pdfs/qualoflife.pdf>

Establish Work-Friendly Policies

- Review policies & eliminate any that foster dependence
- Promote patient independence/self-management
- Prioritize social workers' time for rehab-related counseling/education so they can help patients meet their vocational goals
- Have staff routinely ask about work-limiting symptoms
- Remind MDs to not routinely sign disability forms to help patients work
- Triage working age patients to “Home First” & arrange training & clinic schedules around work/school hours
- Prioritize shifts for in-center patients who are workers/students (early AM or after 5 PM, in-center nocturnal)
- Provide an environment that lets patients work on dialysis, if desired

Address Depression as Barrier to Employment

- Screen eligible patients for depression
- Provide brief counseling as needed
- Instill hope & promote self-worth
- Help patients set achievable goals
- Encourage any reasonable activity
- Identify motivators as needed
- Use working patients as mentors for new patients
- Encourage families to empower patients to succeed



Work Toward *Patients'* Rehab Goals

- Assess each patient's rehab status & expectations for productive activity, work, education/job training, treatment (psychosocial assessment)
- Help patients set personal rehab goals & document in plan of care plan for education, training, referral
- Document follow-up on VR activities, barriers, progress & need for care coordination, communication with VR and/or current or potential employers

Hall, L et al. Vocational Rehabilitation: Is Your Facility on Track? *Nephrol News Issues* 23(13):22-27, 2009

Refer to Vocational Rehabilitation

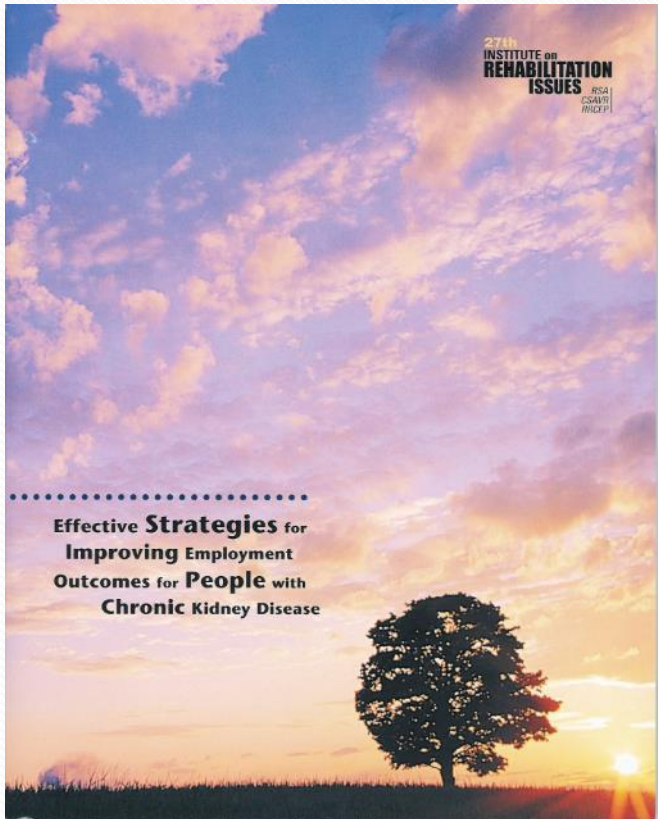
- Eligibility:
 - Physical or mental disability interferes with becoming employed
 - Wants to be employed
 - Needs help to find or keep a job
- VR must at least assess/refer all SSI/SSDI recipients
- Order of Selection if funding limited may wait list, for example:
 - Priority #1 have “most severe disability” (3+ functional limitations)
 - Priority #2 “severe disabilities” (1+ functional limitation)
 - Priority #3 disabled (0 functional limitation)
- Others that help SSI/SSDI recipients find/keep jobs:
 - Employment Networks (EN)
 - Workforce Employment Networks
 - Work Incentives Planning and Assistance Projects (WIPA)
 - Protection and Advocacy for Beneficiaries of Social Security (PABSS)

VR's Individualized Plan for Employment Could Include

- Vocational counseling & guidance
- Job placement assistance
- College/vocational training
- Supported employment services
- Skills training
- Job coaching/tutoring
- Transportation
- Interpreter services
- Services to transition-age youth
- Accommodations
- Assistive technology and rehabilitation technology services
- Referral services
- Support, advocacy, & follow-up ≥90 days after job placement

Educate VR Counselors about ESRD

http://iriforum.org/download/27IRI_kidney_desease.pdf



Manual Table of Contents:

- What Is Kidney Disease & Its Treatment
- Referral
- Vocational Service, Planning & Delivery
- Job Development, Job Placement, Job Retention
- Where Can I Go for More Help
- Directory of Resources for People with Kidney Disease
- Toolkit

Collaborate with Rehab Counselor(s)

- Build relationship locally
- Invite Work Incentive Coordinators to CNSW meetings
- Encourage VR counselor(s) to visit your clinic
- Hold “VR Lobby Days” for staff and patients
- Provide in-service for staff & MD about VR services
- Post photos of workers & students (with their ok)
- Advocate for policies that promote work

Hall, L et al. Vocational Rehabilitation: Is Your Facility on Track? *Nephrol News Issues* 23(13):22-27, 2009

NJ, PR, VI Work Incentive Coordinators - <https://www.ssa.gov/ny/win-coordinators.htm>

Help Patients Use Such Work Incentives As...

(2020 Figures)

- 9-month SSDI trial work period (TWP) in rolling 60 mo. period
(1 month used if earn >\$910)
- SSDI Substantial gainful activity after TWP (\$1,260/month; if legally blind \$2,110/month)
- Impairment-Related Work Expenses (IRWE)
- Continued payment under VR
- Continuation of Medicare
- Expedited reinstatement
- SSI earned income exclusion
- SSI Student exclusion (\$1,900/mo or \$7,670/yr)
- 1619(a) – sliding scale reduction of SSI cash as work income increases
- 1619(b) – Medicaid while working (threshold test)
- Plan for Achieving Self-Support (PASS)
- Reinstatement SSI & Medicaid without re-application

Find full descriptions of these and more at <https://www.ssa.gov/redbook/>

Article & chart at <https://www.homedialysis.org/news-and-research/blog/270-working-on-home-dialysis-what-dialysis-staff-should-know>

Tell Patients About Laws That Protect Workers with Disabilities



- Equal Employment Opportunity Commission enforces:
 - Rehabilitation Act
 - Americans with Disabilities Act
 - *Fiscus v Walmart* (ESRD case)
 - Other anti-discrimination laws



- Department of Labor enforces:
 - Family & Medical Leave Act
 - Other wage & labor laws

Advocate with Employers

- Help patient identify & request needed job accommodations
- Help patients be responsible employees
- Dispel employer myths about ESRD & dialysis

SAMPLE PHYSICIAN LETTER TO EMPLOYER (HEMODIALYSIS)



Dear _____,

As the physician coordinating the dialysis care of _____, one of your employees, I'm writing to you about individuals with kidney failure and their ability to work.

First, let me acquaint you with dialysis. Dialysis is a medical outpatient procedure performed usually three times per week to remove harmful toxins in the blood when a person's kidneys have failed and can no longer do that vital job on their own. Thus, kidney failure is treatable.

It is a myth that once a person starts dialysis he or she categorically cannot work. Certainly, one's age, general health, and other factors may determine physical limitations, but the range of those limitations is a vast one, indeed. Most patients will be restriction-free, and with the exception of heavy physical labor, capable of performing the specific job tasks they did before starting dialysis.

Regarding any concern you may have about the use of sick time, it may be necessary for the employee to take short-term medical leave during times of acute illness, possibly requiring a hospital stay. Those needs, however, are about as predictable as those of all your other employees. For the routine dialysis treatments each week, every attempt will be made to schedule them so as to avoid interfering with the work schedule. Another option, if necessary, may be to consider a modified work schedule, deemed a reasonable accommodation by the Americans with Disabilities Act, which does recognize kidney failure as a qualifying physical impairment.

In summary, my experience with people on dialysis is that the opportunity to continue working after starting dialysis provides the employee with economic stability, personal satisfaction, and an enhancement to the sense of well-being, as well as giving you, the employer, a willing, highly motivated, experienced member of your team.

Please don't hesitate to call if you have further questions about _____'s physical capabilities in relation to employment.

Sincerely,

_____, MD



Serving: Arizona, Colorado, Nevada, New Mexico, Utah & Wyoming as ESRD Network #15

SAMPLE PHYSICIAN LETTER TO EMPLOYER (PERITONEAL DIALYSIS)



Dear _____,

As the physician coordinating the peritoneal dialysis care of _____, one of your employees, I'm writing to you about individuals with kidney failure and their ability to work.

First, let me acquaint you with peritoneal dialysis. Peritoneal dialysis is a medical procedure performed several times daily to remove harmful toxins in the blood when a person's kidneys have failed and can no longer do that vital job on their own. This type of dialysis can be done by the patient in any clean, private environment—even at work. Thus, not only is kidney failure treatable, but this type of treatment, in particular, may be most compatible with the demands and schedule requirements of a job.

It is a myth that once a person starts dialysis he or she categorically cannot work. Certainly, one's age, general health, and other factors may determine physical limitations, but the range of those limitations is a vast one, indeed. Most patients will be restriction-free, and with the exception of heavy physical labor, capable of performing the specific job tasks they did before starting dialysis.

Regarding any concern you may have about the use of sick time, it may be necessary for the employee to take short-term medical leave during times of acute illness, possibly requiring a hospital stay. Those needs, however, are about as predictable as those of all your other employees. For the routine dialysis treatments each day, every attempt can be made to schedule them so as to avoid interfering with the workload. Another option, if necessary, may be to consider a modified work schedule, deemed a reasonable accommodation by the Americans with Disabilities Act, which does recognize kidney failure as a qualifying physical impairment.

In summary, my experience with people on dialysis is that the opportunity to continue working after starting dialysis provides the employee with economic stability, personal satisfaction, and an enhancement to the sense of well-being, as well as giving you, the employer, a willing, highly motivated, experienced member of your team.

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Sincerely,

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Help Patients Consider Self-Employment

- Self-employment rate is 50% higher among people with disabilities compared to non-disabled
- Self-employment is more common in states with widely dispersed population & in rural areas
- Who might be a good self-employment candidate:
 - Motivated self-starters
 - Good planners & organizers
 - Want/need flexible work hours/work at home
 - Have barriers to working for others

Some Employment Resources

- Social Security Work Site - <https://www.ssa.gov/work/>
- Ticket to Work site & list of service providers - <https://choosework.ssa.gov/>
<https://choosework.ssa.gov/findhelp/>
- Office of Disability Employment Policy (under Dept. of Labor) - <https://www.dol.gov/odep/>
- Job Accommodation Network (supported by Office of Disability Policy) - <https://askjan.org/>
- SCORE (mentoring program supported by U.S. Small Business Administration) - <https://www.score.org/>

The Key to Helping Your Patients Work Is in Your Hands...



You Can Do It!