



RRR Renal Rehabilitation Report

Employment for People with Kidney Disease

A Review of the Benefits for Patients, Providers, and Payers

“Whatever treatment kidney patients choose, the important thing is to get out into the world and stay engaged in life,” says Beth Witten, MSW, ACSW, LSCSW, and emeritus member of the Life Options Rehabilitation Advisory Council (LORAC).

For many patients who are of working age, part of active engagement means being employed. And, the overall benefits seem clear. When patients are able to work, they help themselves and their families, they help their dialysis centers, and they help the healthcare system as a whole.

LIFE OPTIONS AND EMPLOYMENT

Life Options has long recognized the importance of employment for people with kidney disease. In *Bridging the Barriers*, its initial report to the renal community, the LORAC discussed the barriers to employment and suggested ways providers, organizations, and the government could work to overcome or eliminate these barriers.

In addition, the first Life Options research project was focused on employment. The study marked an important step forward in the overall understanding of work-related issues for people with kidney disease.

EMPLOYMENT RESEARCH

“The Life Options Employment Study helped to dispel many of the myths that had long surrounded employment for people on dialysis,” says Witten. “It also identified strategies to help healthcare professionals promote employment for their patients.”

Among the study’s findings, 24% of working age (18–62) in-center hemodialysis patients were working—and another 21% considered themselves “able and willing” to work. Working age patients with higher functional status were significantly more likely to be employed.¹ “The higher patients function—physically and mentally—the more likely they are to be employed. By targeting patients who

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Message from the LORAC Chair

The “5 E’s” of renal rehabilitation have always guided Life Options, and the employment “E” has always been an important part of life for working-age dialysis patients.

In the 10 years since findings from Life Options’ first research endeavor—the Employment Study—were published, the benefits of working for people with kidney disease have been well documented. Patients who work remain actively engaged in life and have higher self-esteem.

The renal community can encourage patients who are able to work to seek out jobs, and patients who are

employed to continue working. By accommodating dialysis around work schedules, appropriately treating anemia, and offering home treatment options, the renal community ensures great benefits not only for the patients, but for providers and payers as well. ♦

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Facilitating Patient Employment ESRD Networks Serve as Educators and Advocates

For people with kidney disease, rehabilitation means not only returning to better health, it means returning to productive and fulfilling lives. Employment for working age patients can play a major role in this process.

Vocational rehabilitation (VR) has long been a primary focus of renal rehabilitation programming and evaluation. "It is a marker that was instituted years ago by Medicare," explains Roberta Bachelder, MA, Patient Services Manager for ESRD Network 1. "At that time, VR was the most quantifiable outcome—it was something we could really get our arms around."

NETWORK BACKGROUND

In 1978, the ESRD Network system was created to help ensure the most efficient use of Medicare dollars allocated for dialysis and kidney transplantation. Since that time, the Networks have served as liaisons between

the federal government and ESRD service providers, with primary functions in the following areas:

- Maintaining current data regarding the ESRD program
- Monitoring clinical quality of care indicators
- Providing community education and outreach
- Helping to resolve patient complaints and grievances

Each of these functions is administered at the local level in 18 regions across the country. This structure helps provide a direct link between treatment providers and the Centers for Medicare and Medicaid Services (CMS).

THE ROLE OF NETWORKS

Today, employment remains a central focus among members of the renal community—from patients and providers to the ESRD Networks. But, there is work to be done.

"Many people, even in the renal community, are unclear about the role Networks play," says Bachelder. "In the most basic terms, we're here to help improve the quality of care and quality of life for people with kidney disease." Promoting all components of rehabilitation, including employment, is a big part of that mission.

DATA MANAGEMENT

The Networks play a vital role in collecting, managing, and sharing data, maintaining one of the most comprehensive disease-specific databases. With these data in hand, the Networks are able to provide information that helps inform federal policy and financial decisions, as well as research within the renal community.

To help track employment, each Network completes an annual VR survey, as mandated by Medicare. "We send a questionnaire to social workers in each clinic," explains Bachelder. "They are asked to report how many of their patients were referred to or are receiving Vocational Rehabilitation services, and how many are going to school or working full or part time."



Since 1993, Life Options has been making important contributions to kidney patient education and research. You can help ensure that our work continues, by making a tax-deductible donation to the Medical Education Institute, to support the Life Options Rehabilitation Program. Any amount is welcome. You can offer your tax-deductible financial support to Life Options in one of two ways:

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PROVIDING INFORMATION

When it comes to providing education, Networks most often work directly with unit staff. “We offer information and materials that support their efforts to assist patients,” explains Bachelder. “At Network 1, we send a large number of materials via mail, and we also provide a great deal of telephone assistance.”

According to Bachelder, a Network’s core educational materials often include publications from a variety of sources. “We depend heavily on resource referrals, and right now there are a lot of great resources out there,” she says. “We often use materials from Life Options, the National Kidney Foundation, the American Association of Kidney Patients, the American Kidney Fund, and the federal government.” Most Networks also have VR contact information for regional states posted on their websites.

The Life Options *Unit Self-Assessment Tool* (USAT) for Renal Rehabilitation is an example. “When the USAT was first unveiled, we sent it to all the clinics in our region with a cover memo urging them to give it a try,” says Bachelder. “Though we can’t mandate its use, we wanted to make our clinics aware that it was available.”

The Internet is also a good source of information. “I use the Internet all the time,” says Bachelder. “For example, if someone calls in need of an inspirational patient story to help with a return to work, I’ll direct them to the Life Options *Keys to a Long Life* materials or Life Options Kidney School (www.kidneyschool.org).”

In the end, Bachelder says the bottom line is simple. “We constantly look at what’s new, what’s out there, what’s free, what’s on-line,” she says. “That’s our job.”

DISCRIMINATION

In addition to their role as educators, the Networks serve a vital function as patient advocates. This work sometimes involves employer and workplace issues.

“We occasionally receive complaints about disability-based workplace discrimination,” says Bachelder. “When that happens, our role as stated in the Medicare guidelines is to educate and advocate, and we do so by working directly with patients.”

Though this work happens on an individual, case-by-case basis, Bachelder says most instances are resolved by referring



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back to the Americans with Disabilities Act (ADA) or the Equal Employment Opportunity Commission (EEOC).

THE IMPORTANCE OF NETWORKS

Employment remains a complex and important issue in rehabilitation for people with kidney disease. Through their roles in data collection, education, and advocacy, the ESRD Networks play a vital role in promoting employment success.

Bachelder reminds patients and staff to contact their local Network if employment questions or issues arise. “Each clinic is required by Medicare to post their Network’s telephone number in the waiting room or another public area,” she says. Network information may also be obtained on-line, at www.esrdnetworks.org. ♦

Employment for People with Kidney Disease

A Review of the Benefits for Patients, Providers, and Payers (continued from page S1)

are unemployed now but willing and able to work, we can nearly double the employment rate. We can do this by addressing depression, promoting fitness, and helping patients set realistic goals and encouraging them to work toward meeting those goals,” says Witten.

The Employment Study showed that healthcare professionals’ attitudes play a major role as well: patients who felt their caregivers believed they could work were more likely to do so. “People tend to live up—or down—to our expectations,” explains Witten. “If we believe it’s possible and we do what we can to help patients, we open a door that they may believe was closed to them by having kidney disease.”

Findings from the Employment Study helped form the basis of several Life Options educational materials, including *Building Quality of Life: A Practical Guide to Renal Rehabilitation*, and *Employment: A Kidney Patient’s Guide to Working and Paying for Treatment*. (For more information, see *Resource Update: Revised Life Options Employment Book Now Available*, on page S8.)

EFFECTS OF KIDNEY DISEASE AND TREATMENT ON EMPLOYMENT

In 2000, about 67% of the general population over age 16 worked full or part-time.² Six months before kidney failure, only 37% of patients 18 to 55 were working full or part-time. At the start of treatment this had dropped to only 23%.³ (See chart below.)

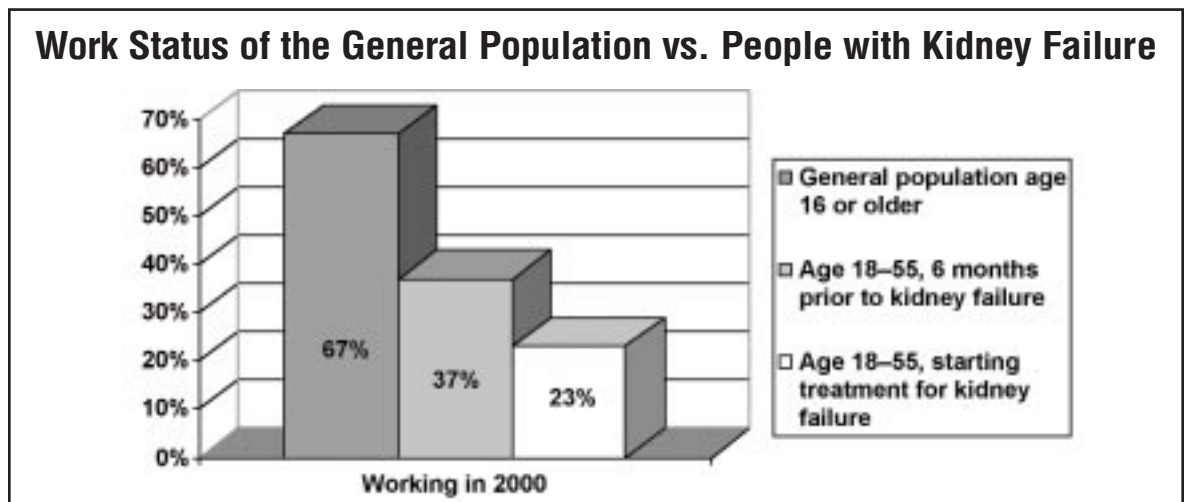
It is unknown exactly how many patients who were working when their treatment started still continue working afterwards. After the Medical Evidence Report (CMS-2728) form is completed at the start of treatment, patients are never routinely asked their employment status again. Dialysis social workers annually report to Networks how many patients they believe are working and in school and how many have been referred to vocational rehabilitation (VR). In 2000, social workers reported that 24% of dialysis patients were working or in school and another 12% were referred to VR.⁴

According to Witten, “People with chronic kidney disease (CKD) begin complaining of weakness and lack of energy when kidney function is 50%.⁵ Without encouragement from healthcare providers, CKD patients may quit their jobs needlessly and may have trouble later finding a new job once their health is stable.

To reverse this trend, we must treat anemia and other symptoms that impact work ability early in CKD, offer home dialysis and transplant, accommodate work and school schedules, and advise patients who ask about working or disability to take medical leave rather than quitting work when starting treatment or when health setbacks occur.”

BENEFITS TO PATIENTS

Over the years, the benefits of employment for people with kidney disease have been well-documented, both within and outside of the Life Options program. Employment can





help maintain patients' confidence, standard of living, and health insurance coverage. It may even help them live longer.

"When patients work, they are generally more independent," explains Witten. "They feel better about themselves, are less depressed, and they have more opportunities to meet people and interact socially. They also have more income to pay their bills and pursue activities they enjoy."

Various studies have confirmed these observations. Employed patients have reported higher self-esteem and quality of life than unemployed patients, and they have scored higher on measures of medical, psychological, and social adaptation,⁶ all of which help predict survival.^{7,8}

CKD education, home therapies, and transplant help patients keep their jobs. Twice as many blue collar workers kept their jobs after receiving CKD education compared with those that did not receive education.⁹ Of those who received CKD education and were working when starting home hemodialysis or CAPD, 74% kept their jobs.¹⁰ Patients who are transplanted preemptively or within the first year of dialysis are more likely to work full-time and to keep their transplants at least 5 years.¹¹

Working patients may also adhere better to their treatment regimens.⁶ "Patients who feel their jobs are important to them will do whatever it takes to keep working, including taking better care of themselves," explains Witten.

BENEFITS TO PROVIDERS AND PAYERS

The advantages of employment extend well beyond patients. Facilities with more employed patients may have more money to spend on quality care. "Most providers say that Medicare does not reimburse enough to cover the cost of providing dialysis care. Working patients are more likely to have commercial insurance. Commercial insurance compensates facilities at a higher rate than Medicare, and this can result in extra revenue for facilities. Commercial insurance also helps patients pay costs of treatments and medications not covered by Medicare so they can be more adherent," says Witten.

Studies have also shown that active patients experience fewer treatment stresses.⁶ Patients who are vocationally active—work, attend school, or complete household tasks—

have significantly better relationships with dialysis staff and other patients.⁶

"Working patients are typically more self-sufficient and can do more for themselves," explains Witten. "Clinics where patients function at a higher level have happier staff and experience less turnover." Ann Stivers, administrator at the Dialysis Center of Lincoln, reports that including rehabilitation as a routine part of the treatment plan has reduced their staff absenteeism and turnover and improved job satisfaction.¹²

BENEFITS TO PAYERS

The cost savings that result from patient employment may be felt on an even wider scale. "People at higher levels of physical and mental health functioning are less likely to be hospitalized," explains Witten. "Aside from the obvious benefits, this also results in cost savings for payers."

Witten says that employed patients are also more likely to choose less costly treatments, such as home dialysis and transplant—something that may benefit patients on more than one level. "When payers are spending less for disability benefits, it helps preserve the Social Security trust fund," she says.

ACTIVE ENGAGEMENT

While the benefits of employment seem clear, it is also true that not every person with kidney disease can—or even should—work. The full spectrum of kidney disease includes patients of varying ages and functional abilities. In the end, benefits are realized when all patients are able to find meaning and purpose, whether it is through employment, schooling, volunteer work, or hobbies.

"Not everyone can or will work," says Witten. "But, whether you're a patient, a provider, or a payer, the ultimate goal is the same: to help patients live to their potential—to help keep them healthy, out of the hospital, and living a good life in spite of kidney disease."

THE FINAL ANALYSIS

The subject of employment for people with kidney disease is a complex one. Though much work has been done, challenges and barriers to employment remain.

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Employment in the Life Balance

Enjoying Work as Part of a Well-rounded Lifestyle

“Being employed keeps your mind active. If you keep your body and mind active, you can overcome just about anything.”
—Robert Davies



Nearly 2 years after starting dialysis, 37-year old Robert Davies has a fresh perspective on life. “I’ve learned to appreciate things,” he explains. “I’m enjoying my kids and my life. Now, I take the time to sit on the porch and watch the squirrels.”

But don’t get Davies wrong. He also works up to 50 hours a week as manager of systems engineering for a North Carolina mortgage insurance company—a job he’s held for more than 7 years. It’s a job he enjoys, and one he feels helps keep his life in balance.

DIAGNOSIS AND TREATMENT

Davies’ introduction to kidney disease came abruptly in January of 2002. “I had gone in for a routine physical because I wanted to resume exercising,” he recalls. “Up until that point, I hadn’t noticed any real symptoms.”

All that changed in an instant, however, when blood tests revealed Davies’ creatinine level was 14. He was immediately sent to the hospital and put under a nephrologist’s care. He began hemodialysis the next day.

While the specific cause of his kidney failure has never been determined, doctors suspect hypertension. “Right away, they asked me a lot of questions about my background and family history,” he explains. “I did recall having experienced some swelling and shortness of breath.”

A POSITIVE APPROACH

Even in the midst of this whirlwind of events, Davies began his adjustment to kidney disease with a positive attitude. “There was no time to dwell on things,” he says. “I don’t think I ever let myself sit around and mope.”

Instead, Davies looked to the Internet for information. “I wanted to learn as much as possible about what was happening to me,” he says.

He found several resources to help. “I came across the *dialysis_support* e-mail list, the Life Options website and Kidney School,” he says. “I found out there were a lot of things I could do—that if I stuck with the diet, exercised, and went to my treatments as scheduled, I could live a relatively normal life.”

Q&A

ASK THE EXPERTS: PARTNERING EFFECTIVELY WITH STATE VR AGENCIES

An Interview with Miriam Greene
Vocational Rehabilitation Specialist
ESRD Network of New York, Inc. (Network #2)

As part of a 3-year pilot program to help promote VR in the Network 2 service area, Miriam Greene provides information and assistance to dialysis center staff as well as to dialysis and transplant patients who are interested in exploring employment options. A certified vocational rehabilitation counselor, Greene offers:

- Assistance in developing vocational plans
- Information and referrals for training or other services
- Up-to-date information on benefits and work incentives
- Tips for job seeking via the Internet
- Information on laws that can protect disabled workers
- Information on where to file a complaint if a patient has encountered workplace discrimination

Of the more than 500 patients Greene has counseled as part of the Network 2 pilot, 46% have applied for job training, 17% have begun job training, 10% have retained their jobs, and 8% have found new jobs.

Q *What steps can healthcare providers take to ensure successful VR referrals?*

A Providers can set the foundation for success by creating an environment that supports employment. Beyond that, the first step is to identify patients with an interest in exploring employment. Staff can then begin clarifying specific issues related to each patient’s return to work.

Simply distributing contact information for the local VR office can help provide patients with the impetus to call or go in for an interview. Obtaining the appropriate VR medical forms and facilitating their completion also helps expedite the process for patients.

Q *Who makes a “good candidate” for VR?*

A There are many factors to consider, but motivation is the key. Patients who have done some thinking ahead of time are attractive candidates for VR.

Patience and flexibility are also helpful. Sometimes, the first option may not be the best fit. Of course, patients should speak up if they feel uncomfortable and ask if there are alternatives. It helps if they can be honest about their feelings—and open to new ideas.



STAYING EMPLOYED

For Davies, this “normal life” included keeping his job. “I looked into all the options,” he says. “I decided that, as long as I felt good, there was no reason I couldn’t continue to work.”

To that end, Davies began making arrangements. “I spoke with my employer by telephone while I was in the hospital,” he said. “We got everything worked out, and I was able to return to work the day after I was discharged from the hospital.”

COMMUNICATION AND SUPPORT

Davies says he is fortunate to have a supportive employer, who offered several options for working around his treatment schedule. “They even offered to let me work from home on my dialysis days,” he says. “But I haven’t taken them up on that offer.”

Instead, Davies dialyzes 4 hours each Tuesday, Thursday, and Saturday morning. He gets to work by 11:30 am on dialysis days and makes up the missed time during the early evening. By choice, he even goes to work early on his non-dialysis days. “I feel better working a full week,” he says. “That way, I’m not short-changing the company.”

Davies says his co-workers have been very understanding. “In the beginning, some people asked questions,” he says. “Most people aren’t sure what dialysis is, or how it impacts you. I’ve found that educating people helps a lot—explaining that I do have to go to treatment, and that there are things I can eat and things that I can’t. A lot of people are amazed that I’m still able to work.”

How does Davies juggle his treatment schedule with work and family responsibilities? For one, he credits a solid network of support, which begins with his wife and three children, ages 16, 12, and 10. “My nephrologist has also been wonderful,” he says. “He’s such a caring person—he goes above and beyond to make sure you understand the illness and treatment.”

LOOKING AHEAD

Davies says, for those who are physically able to work, the benefits of employment are clear. “Being employed keeps your mind active,” he says. “If you keep your body and mind active, you can overcome just about anything.”

It’s a theory that has played out to perfection in Davies’ own life. “I’ve learned not to give up—that I can live a normal life,” he says. “I don’t let anything hold me back.” ♦

Q *How can social workers coach patients to succeed with VR?*

A Social workers can help patients clarify and evaluate their employment goals and options. They can also provide patients with simple tips: to present themselves in a positive light, to provide clear information about their past life experiences and future goals, and to keep appointments, return calls, and follow through on assignments. The social worker could also encourage the patient to seek out aptitude testing if offered by the VR agency.

Finally, social workers can coach patients on being assertive. For example, VR counselors often have very large caseloads. If some time has passed between contacts, a call or brief note on a patient’s own behalf can remind counselors that the patient is still there and is motivated to succeed.

Q *What can a patient do if VR does not produce the desired outcome?*

A Sometimes this is simply a miscommunication. Perhaps the paperwork hasn’t been completed, the patient has an unrealistic goal, or the counselor has misconceptions about a patient’s ability to work. Most often these issues can be cleared up, and the social worker can help.

If it’s not a simple misunderstanding, there are options. Patients can ask to speak with a supervisor, or ask for a new counselor. If this doesn’t help, they can enlist a patient advocate. All states have client assistance programs, outside agencies that advocate and negotiate for clients with VR.

If all else fails, patients may ask for a “fair hearing”—a process that is guaranteed in every state. In the end, the most important thing is for patients not to give up, to seek other options, and to find ways to compromise.

Q *What resources can help VR counselors better understand employment issues relative to kidney disease?*

A A portion of every VR training manual is devoted to rehabilitation for people with chronic kidney disease. Beyond that, several helpful resources are available.

The Rehabilitation Services Administration (RSA) funded development of *Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease*, which is published on-line at www.rcep6.org/IRI27.pdf. Other materials are available from the National Kidney Foundation.

Of course, VR agencies can also call upon the Networks in their area to provide additional information, educational materials, and training. ♦

Employment for People with Kidney Disease A Review of the Benefits for Patients, Providers, and Payers

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When it comes to the benefits of employment, however, Witten says it all comes down to a simple equation. “Promoting patient employment can save money and staff time,” she explains. “More importantly, it helps keep patients healthier, happier, and feeling more productive.” ♦

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Resource Update: Revised Life Options Employment Booklet Now Available

Life Options recently completed an updated and expanded version of *Employment: A Guide to Work, Insurance, and Finance for People with Kidney Disease*. Supported by the Forum of End Stage Renal Disease Networks and partially funded by CMS through a subcontract with the ESRD Network Clearinghouse, the revised booklet addresses vocational and financial issues for patients at all stages of chronic kidney disease—from the diagnosis of chronic kidney disease to dialysis and transplant.

Topics covered in the new booklet include up-to-date information on employment and insurance options, services and benefits for people with kidney disease, and patient stories. Also included are tips on

resume writing and interviewing, information about the Ticket to Work and Work Incentives Improvement Act of 1999, and a variety of other resources not covered in previous editions.

This comprehensive guide was reviewed and edited by professionals in the renal field, and features case examples of people with kidney disease who are successfully employed and/or engaged in other rehabilitation activities.

The new and improved, 108-page Employment Book is now available in downloadable PDF format via the Life Options website, www.lifeoptions.org, and from the Forum of ESRD Networks website, www.esrdnetworks.org. ♦