

How to Use *In Control*

Each issue of *In Control* offers background, tips, and patient education material on one issue that is important to living well with kidney disease. The 2-in-1 format of *In Control* is designed to make it easy to find the information and share it with your patients.

For you, there are 4 pages of professional content (pages S1, S2, S7, and S8), along with practical tips for putting key concepts into practice.

For your patients, there are 4 pages (S3–S6) of easy-to-read information. There's also a quiz patients can use to test their knowledge.

We encourage you to make copies of *In Control*. Use it to supplement your own education materials, and call us at (800) 468-7777 if you want to reprint an article. Help your patients get “in control” of their kidney disease!

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CKD and Job Retention

“I am at the end stage of renal disease and I am on the transplant list. About a month ago my kidney doctor placed me on disability and as a result I got fired from my work. As soon as they fired me they stopped my medical insurance. I applied for SSDI but it takes a while before they approve it. Right now I have all these doctor’s appointments and no insurance while I am almost ready to go to dialysis. I am not married and live with my sister and brother-in-law at their home because I can’t afford even food...”

—Message posted on Life Options Bulletin Board, November 2004

Retaining a job can make a world of difference in the life of a person with chronic kidney disease (CKD). Unfortunately, little attention is focused on helping CKD patients keep their jobs—and currently, many working-age people with CKD stop working when their kidneys fail, or even sooner.

Cause for Concern

Among the 32% of patients ages 18–55 who started dialysis in 2002—the most recent year for data—just 23% had full- or part-time jobs.¹ In comparison, 64% of Americans in the same age group are working (U.S. Census data).

As a community, we don’t have to take low employment rates among CKD patients for granted. Rather, they should be a cause for our concern. Why? Because the impact of job loss on patients’ lives, as the posted message shows, can be devastating. And because

there is evidence to suggest that more people with CKD could be working. For example, in a Life Options study by Curtin et al., 21% of unemployed working-age dialysis patients said they were both able and willing to work.²

Benefits of Working

Efforts to help people with CKD keep their jobs can pay off in benefits for patients and dialysis clinics. Documented benefits of employment for CKD patients include:

- Higher functioning and well-being³ (which is linked to survival)⁴
- Improved mental state⁵ and self-esteem³
- Greater access to group health insurance³
- Opportunity for higher income⁶
- Increased likelihood of receiving a transplant⁷

When patients work, dialysis clinics benefit too: 72% of full-time working patients keep their employer group health plans (EGHPs).¹ On average, EGHPs pay three times as much as Medicare for dialysis—a difference to the clinic of more than \$36,000 per year, per working, insured patient for dialysis alone.

Timing and Options

The reasons for underemployment in people with CKD are complex, but data reported by the Medical Education Institute¹ provide insight into two critical factors:

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The Kaiser Approach in Southern California

The nation's largest health maintenance organization, Kaiser Permanente, commits significant resources to maintaining jobs among people with CKD. Using a multidisciplinary team, they begin outreach and education early—usually at stage 3 or 4 CKD, or about nine months before the start of dialysis.

Several published articles have reported on the success of the Kaiser approach. A group of working-age, blue-collar workers on in-center hemodialysis achieved an employment rate of 55%.¹ Among Kaiser patients who chose home dialysis (home hemo or peritoneal dialysis), the employment rate was even higher—fully 79%.²

Few dialysis clinics have the organizational structure needed to replicate the Kaiser case management program. However, the case management model does prove that employment rates can be improved substantially by offering:

- Early referral and intervention
- Comprehensive education
- Patient-centered scheduling (appointments, labs, treatment)
- Treatment modality options
- Multidisciplinary care
- Dedicated renal case managers
- Expectation of “ability rather than disability”

Here is an overview of the Kaiser CKD management program at Baldwin Park Medical Center, as described by Brenda Chemleski, RN, CNN.

Early Identification of CKD

All patient lab reports are reviewed using a specialized program. Patients with elevated creatinine levels or reduced GFRs are flagged as at risk for CKD. Subsequent labs are checked for signs of progression or change.

Involving Primary Care Physicians

Nephrologists present educational sessions about CKD to primary care physicians, and provide special tips

cards with important clinical, lab, and medication concerns of CKD patients. At appointments for high-risk patients, a CKD report is included with medical

records. Consultation and referral are requested as needed to transfer follow-up to the CKD team.

Providing CKD Education

All patients referred for CKD case management are invited to attend the appropriate classes: “Kidney” classes for anyone with CKD, and “Choices” classes for patients with CKD stages 4 and 5.

At Baldwin Park, a series of four classes—three hours each—for stage 4 CKD patients is scheduled monthly. Each session includes a group presentation plus individual meetings with the multidisciplinary team, including the physician, nurse, social worker, dietitian, and pharmacist. Meeting topics include:

1. Overview of kidney disease (individual case reviews)

2. GFR review and treatment choices (individual case progress report)
3. Advanced directives, medications, diet (individual case progress report)
4. Modality choice presentations, herbs, cholesterol, coping and self-management, employment (individual case report)

Tracking Lab Values

Renal team pharmacists watch lab values for all CKD patients, paying close attention to Hgb and iron to ensure optimal anemia management. GFR and creatinine levels are also followed closely and results trigger access creation.

Case Manager Followup

The renal case manager follows each patient through CKD education and dialysis; employment issues may be referred to an occupational case manager. Specialists—social worker, dietitian, pharmacist, nurse—are called in as needed. An annual report tracks quality measures, e.g., vascular access data, lab values, and employment rates.

Measurable Results

This comprehensive approach to job retention and rehabilitation has produced measurable results. Chemleski reports that “the rate of permanent disability at the start of ESRD in Kaiser Permanente Southern California (KPSC) patients has steadily decreased from about 11% in 2001 to about 8% in 2003. The death rate is 30% below the rate for non-Kaiser facilities in the same region—and hospital days for dialysis patients are significantly lower than the national average.”

(continued on page S4)

“The death rate is 30% below the rate for non-Kaiser facilities in the same region...”

What to Say to CKD Patients About Working

An interview with Annette James-Rogers, LCSW, Kaiser Permanente West Los Angeles, CA

Annette James-Rogers is a renal social worker at Kaiser Permanente’s West Los Angeles clinic. In her clinic, she is “first on the agenda” in the education classes for CKD patients. And she uses that spot to set the tone for her patients.

“About 97% of our patient population is blue-collar, and African-American,” she notes. “Since kidney disease does run in families and certain ethnic groups, many of them have heard something about kidney disease and dialysis—and most of it is negative.”

But, she has seen positive effects from the CKD education program. “I have seen these classes change people’s perceptions about kidney disease, disability, and what they can do, including work,” she explains.

Here are the key messages that Annette—and the entire CKD education team—find most effective for CKD patients:

- **Your kidneys are impaired, you aren’t** — kidney disease, by itself, is not a reason to curtail your activities, including work.
- **What you’ve heard on the street isn’t true** — there has been a lot of progress made in kidney care. What you’ve heard about the grim side of kidney failure and dialysis does not have to be true for you.
- **You have a role in your own care** — the training classes are about teaching you what *you* need to do. You are part of the kidney care team.
- **Stay physically active** — it’s not about “exercise,” it’s about staying active. There’s a method for every level of fitness...from a commercial health club to “Chair Dancing®”. No excuses!
- **Living on disability is limiting** — if you decide to take disability, you will probably have to cut back on spending, and that will limit your enjoyment of life.

Building Trust

“Most patients will respond to these messages once you’ve earned their trust,” Rogers says. “To build trust, you need to understand your patient population—know the community—and start where they’re coming from,” she Rogers. “We work on building trust right from the start. We all ‘sing the same song,’ and we include lots of interaction and time for questions.”

Finally, Rogers has also found that two educational tools help make these messages even more effective.

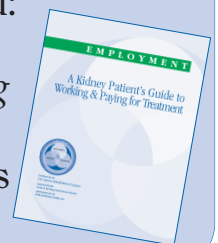
- **Patient examples** — “You need to find someone the patients can relate to,” she advises. “Match the demographics as best you can. Don’t just bring out the shining star; you’ll lose credibility,” she warns.
- **Readable educational materials** — “Reading level is important. Our first materials were filled with medical terms and jargon,” remembers Rogers. “The patients couldn’t really understand them. So, we rewrote our booklet at a 6th-grade reading level...now information is more accessible.”

Real World Results

The messages and team approach that Kaiser has put in place are definitely working for CKD patients. “The majority of patients that entered our CKD program with jobs are still working,” Rogers reports. 🌟

For More Information...

For more information about kidney disease and working read: *Employment: A Kidney Patient’s Guide to Working & Paying for Treatment*, available from Life Options at www.lifeoptions.org.



(continued from page S1)

CKD and Job Retention

- **Predialysis job loss.** People with CKD often give up their jobs before they start dialysis. Among patients who started dialysis between 1995 and 2001, more than 22,000—about one in three—*stopped working in the six months prior to starting treatment.* Once these jobs are lost, it is extremely difficult for patients to return to work or find a new job. Clearly, the time to intervene and help patients retain their jobs comes well *before* they reach end-stage.
- **Modality choice.** Work-friendly treatments help patients keep their jobs. Working patients were significantly more likely to choose peritoneal dialysis or transplant than in-center hemodialysis.¹

Intervention Strategies

Improving job retention among people with CKD will require effort from patients and providers. Patients need to recognize the positive impact work can have on their lives, and advocate for treatments that will allow them to keep working. Providers need to address job retention *before* patients reach stage 5 CKD, treat medical problems early, and offer work-friendly treatment modalities. Specifically, providers can:

Manage anemia – appropriate treatment for anemia early in CKD can combat fatigue and give patients the energy they need to keep working.

Encourage employment – staff attitudes and expectations about employment strongly influence patients.^{2,3,8} Taking disability should *not* be presented as the first or best option, but rather as a last resort.

Offer work-friendly dialysis – it is easier for patients to keep their jobs if they can fit dialysis into their work schedules. This means evening or early morning shifts, or modalities like home hemodialysis, PD, or transplant that offer flexibility. 🌐

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Quiz Answers

1. True
2. True
3. False. A nephrologist can refer you to a social worker or VR counselor.
4. True
5. True

Kaiser... (continued from page S2)

According to Chemeski, “our CKD program has evolved from focusing on ESRD to identifying and managing the CKD population early on....” Under the direction of Dr. Mark Rutkowski, the Kaiser team at Baldwin Park plans to continue its focus on CKD. Says Dr. Rutkowski, “we believe that preparing a patient for ESRD needs

this type of intensive intervention since there is really no equivalent in all of medicine.” 🌐

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Keeping Your Job with Kidney Disease

While the symptoms of chronic kidney disease (CKD) can make it hard to work, many working-age people with CKD keep their jobs and are glad they did. Keeping your job will help you keep your confidence, your way of life, and according to research, may even help you live longer.

Keep Working

Symptoms are one of the main reasons people with CKD quit their jobs. But quitting your job and going on disability is not always the best answer. Many people who do this regret it later and wish they had taken a leave of absence instead. Keeping your job lets you stay in touch with your work friends, and keep your health insurance, your income, and the lifestyle you're used to.

As your kidneys fail, it is common to feel tired, weak, and short of breath. These

symptoms are often caused by anemia (a shortage of oxygen-carrying red blood cells), which can and should be treated.

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Talk to your doctor about testing your blood for anemia, and ask about treatment options.

When you have health problems and need to take some time off from work, there are programs that can help you keep your job. Sick leave, part-time or flexible scheduling, short-term disability, the Family and Medical Leave Act, and working from home are some options that may be open to you. Before quitting your job, ask your nephrologist to refer you to a social worker or see a vocational rehabilitation counselor.

Choose a work-friendly treatment—like peritoneal dialysis or home hemodialysis—or ask for an in-center shift that will fit your work schedule. And, if your kidneys *do* fail and you have to start dialysis, you can still keep your job! Home treatments may also give you more dialysis time, so you *feel* well enough to keep working.

Vocational Rehabilitation (VR)

VR counselors can advise you about training and work options, and even workplace changes that can help you keep your job. To find your local VR agency, ask your social worker, check the yellow pages of

(continued on page P4)

Carol: Dialyzing to Live and Work

Even as a young adult with kidney disease, Carol knew that she would have a job as an adult. “I knew I needed a job that used my mental skills because my physical skills were limited,” she recalls. “My goal was always to have the best life possible with kidney disease—and for me, that also meant having a job.”

Planning for Home Dialysis

Diagnosed with kidney disease at age 14, Carol, now 44, was told to learn all she could about dialysis. “Once I did, I knew that some day I wanted to do my dialysis at home,” she explains. “It would offer me more freedom and a better future.” Carol began in-center hemodialysis at 15, and by 16 had received her first transplant.



All through her teen years, Carol lived the life of an active teenager, and worked, too. “I had an Avon® sales route and did magazine phone sales, lifeguarding, and once I started college I worked as a waitress and bartender,” Carol recalls. “This was in the ‘70s when treatment took more time and I *still* earned income as a productive member of society and volunteered in the community.”

When Carol’s first transplant failed, she began in-center hemodialysis. “After a few years, I decided to move closer to my mother. We bought a large home, planning for home hemodialysis, but before I had a chance to move, I received a second transplant.” When that transplant failed, Carol knew home dialysis would be her treatment of choice. “It wasn’t always simple or easy to do home dialysis, but I knew it would enhance my freedom and quality of life.”

A Job that Works

Carol finished her Bachelor’s degree with a partial scholarship from vocational rehabilitation (VR), and then completed her Master’s degree in less than three years while working two jobs. Carol has worked as a manager for the Department of Veteran’s Affairs for more than 16 years. Her job has a hectic schedule and a lot of travel, which equals “more than 40 hours a week.”

When her transplant failed, Carol told her employer that she would need two months leave time to train for home dialysis. “They were supportive,” she relays, “because

they knew I would have fewer needs down the road.” Now, nearly nine years later, Carol rarely takes time off due to her health. “Before, if I had to miss my in-center treatment time, I’d end up taking the next day off to do it.”

Carol does have some special needs, which have always been met. “I give my employer written notes from my care team to make them aware of my needs,” Carol says. “For example, I am blind in one eye and they got me a larger phone and computer screen.”

Despite some hard days, it has “absolutely never” crossed Carol’s mind to quit her job. “To be honest, I don’t understand how people don’t work—to have the life I want, I need financial resources,” she shares. “Even when I’m off work I never stop working; I can always be reached by phone, fax, and e-mail.”

Tips for Success

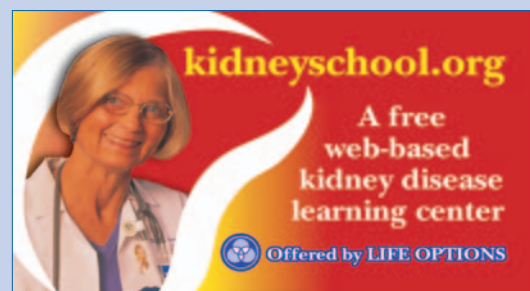
For Carol, following her career dreams came down to knowing what she could do and what she wanted to do. “The first thing to do is to look at your skills, and using VR and other services, find something you can do,” suggests Carol. “It’s okay to know your current or future limits and plan for them—think about how you can take your current job and change it if you need to.”

Earlier in her career, Carol had ups and downs in the job hunt process. “I would bring up my kidney failure and insurance needs to an employer and I could tell by

their expression they weren’t interested,” recalls Carol. “But my health care sustains my life and if someone is not supportive, I don’t want to work for them anyway.”

Carol suggests calling a potential employer for a pre-interview to learn more about the job. “If you interview and are called back for a second interview, *then* be upfront—see if your health is something they can support with time off, schedule needs, health insurance and so on.”

For Carol, keeping her job has been a reason to get out of bed. “You don’t always feel great, but looking nice and having a job to go to helps you feel like you still play a vital role in life,” she explains. “I don’t live my life so that I can do dialysis—I do dialysis so that with the support of my family and friends, I can have this great life!” 🌟



For More Information...

For more information about staying healthy enough to work with kidney disease, visit: Kidney School Module 12: *Staying Active with Kidney Disease* at www.kidneyschool.org.

Keeping Your Job with Kidney Disease

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the phone book, or visit the Social Security website at www.socialsecurity.gov/work/ServiceProviders/rehabproviders.html. Be persistent and don't give up on VR—counselors have heavy workloads.

Disability and Returning to Work

If you are on disability now, and want to ease back into working, you may qualify for Social Security work incentive programs that can help you. If you'd like to learn more about going back to work, talk to your social worker or call Social Security toll-free at (800) 772-1213 (TTY 800-325-0778).

Can't Work?

Even though the pluses of keeping a job with CKD are clear, sometimes it is just not possible. But people who volunteer,

are active in church groups, attend school, and/or take part in hobbies also benefit by meeting with other people and feeling better about themselves. ♻️

For More Information...

If you'd like to learn more about keeping your job with kidney disease, check out these resources:

- *Employment: A Kidney Patient's Guide to Working & Paying for Treatment*, at www.lifoptions.org.
- *Kidney School Module 12: Staying Active with Kidney Disease*, at www.kidneyschool.org.
- To learn about all types of home dialysis, visit Home Dialysis Central, at www.homedialysis.org.

Job Retention Quiz

Now that you've read about kidney disease and working, let's see how much you've learned! See if you can answer the questions below (the answers are on page S8).

1. Keeping your job will help you keep your way of life and may even help you live longer. True False
2. Feeling tired, weak, and short of breath are all symptoms of anemia. True False
3. A dietitian can refer you to a social worker or VR counselor. True False
4. Home dialysis may help you feel well enough to keep working. True False
5. VR counselors can advise you about training that can help you keep your job. True False

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