

# *In* **Patients** **CONTROL**

A Medical Education Institute/Life Options Publication

VOL. 2 | NO. 2

JUNE 2005

## 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.

*In Control* is supported  
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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

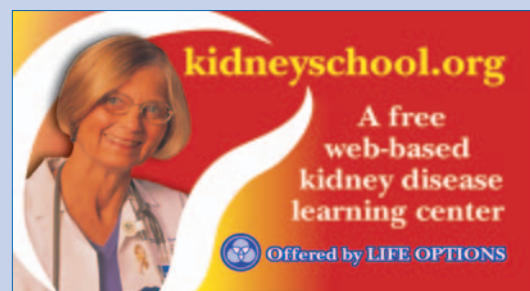
For Carol, following her career dreams came down to knowing what she could do and what she wanted to do. “The first thing to do is to look at your skills, and using VR and other services, find something you can do,” suggests Carol. “It’s okay to know your current or future limits and plan for them—think 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](http://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](http://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](http://www.lifoptions.org).
- *Kidney School Module 12: Staying Active with Kidney Disease*, at [www.kidneyschool.org](http://www.kidneyschool.org).
- To learn about all types of home dialysis, visit Home Dialysis Central, at [www.homedialysis.org](http://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

#### In Control

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