

Keeping Your Job When You Need Dialysis

If you are working full or part-time when you learn that your kidneys are failing, some of your most urgent questions may be about your job. Each year, half of all people who start dialysis in the U.S. are under 65. *You are not alone.* It is possible to feel well enough to work on dialysis *and* to make your treatment schedule fit your job—if you plan ahead. Below, we'll tell you why—and how—to keep your job.

Fight Fatigue with Anemia Treatment

Are you feeling too tired to work *now*, even before you need dialysis? As kidneys fail, they make less of a hormone (*erythropoietin*) that tells your bone marrow to make red blood cells. The result is anemia—a shortage of oxygen-carrying red blood cells. Most people with stage 4 or 5 chronic kidney disease have anemia, which can cause:

- Severe fatigue
- Muscle weakness
- Shortness of breath
- Mental fuzziness
- Feeling cold all the time
- Pale lips, gums, and nail beds
- Erectile dysfunction in men
- Cravings for ice, clay, laundry starch, or dirt (called *pica*)

Anemia can and *should* be treated to give you more energy and prevent damage to your heart. But in a new study, fewer than half of people with chronic kidney disease (CKD) and anemia got treatment.¹ Sadly, some quit their jobs, thinking they'll never feel well enough to work again. By the time they start dialysis and get anemia treatment, it's too late.

Don't let this happen to you! Anemia can happen slowly so you may not notice the symptoms at first. Ask your doctor to test your blood for anemia. If your hemoglobin (red blood cell level) is below normal, ask for

treatment. In most cases, this will be injections of a drug called Aranesp® or Procrit®. Some people may need iron, too.

Earn More than Disability Pays

Permanent vacation...no deadlines, no more boss. Sound good to you? But most people don't know that Social Security Disability Insurance (SSDI) only pays about 35% of what you earn at work.² To prevent fraud, even a private disability plan will replace just 60% of work income (minus SSDI payments).³ This means most people can earn much more money from work than they would get from disability.

Think about it: what would you have to do without if you had just 1/3 or even 2/3 of your current income? Could you keep your home? Your car? Could you eat a meal out or take a trip? Could you help send your kids to college?

Think long and hard before you decide to take disability. Once you do, it can be very hard to go back to work in the future. Most people with CKD qualify for Medicare when their kidneys fail—even when they keep their jobs.

Stay Healthier and Feel Better

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.⁴ And better physical functioning predicts fewer and shorter hospital stays—and a longer life.⁵ Of course, people who feel better in the first place are more likely to work. But a job can also give you a sense of purpose, a place to be, an identity, and income—and those things may help keep you feeling good about yourself and your life.

People with CKD who work are also significantly more likely to have a health plan through work.⁶ An employer group health plan (EGHP) can help pay for treatment and drugs Medicare does not cover. You may be better able to afford to follow your care plan if you keep your job.

Choose a Work-friendly Treatment

Plan ahead. You know your work schedule and whether your job includes travel. If you have a living donor, you may be able to plan to get a kidney transplant before you need dialysis. This is called *preemptive transplant*. If not, choose a form of dialysis that will be “work-friendly” so you can:

- Work during normal work hours
- Travel for work if you need to
- Feel your best between treatments
- Have a normal or near-normal diet

Dialysis centers may offer hemodialysis (HD) three times a week in the evenings or early mornings. For some, this is work-friendly. They may bring a laptop and/or cell phone (if the center allows it) and do some work during treatments. But for others, the “dialysis hangover” caused by removing fluid only three times a week leaves them washed out, with flu-like symptoms after treatments, and fuzzy thinking all the time. The strict in-center HD meal plan and fluid limits also makes it harder to eat business meals out.

Home dialysis—peritoneal dialysis (PD) or home HD—is nearly *always* more work-friendly than in-center HD. You can choose your own treatment schedule that does not conflict with work. You only have to go to the center once a month for check-ups. You can travel for work without having to arrange treatments at another center months in advance. You can eat a more normal diet and have fewer fluid limits. It is not surprising that people who chose home treatments were

significantly more likely to keep their jobs than people who chose in-center HD.⁷

Know Your Home Dialysis Options

There are two types of PD and three types of home HD—and one of these may be a good fit for your job and your lifestyle.

PD uses the lining of the inside of the abdomen (the *peritoneum*) as a sac to hold a sterile fluid (*dialysate*). The fluid flows into the peritoneum through a plastic *catheter* (tube) placed in the wall of the abdomen by a surgeon. Wastes and excess water flow into the dialysate. Used dialysate is drained out and replaced with fresh, in a process called an *exchange*. No needles are used for PD, and your blood never leaves your body. Since your blood is cleaned most or all of the time with PD, you won’t have “dialysis hangover” and your meal plan will be more normal.

- **Continuous ambulatory** (walking around) **PD (CAPD)** – Do exchanges by hand at breakfast, lunch, dinner, and bedtime. Bring a bag to work to do a lunchtime exchange (you’ll need a clean room to avoid infection).
- **Continuous cycling PD** – Use a cycler machine to do exchanges at night while you sleep. You may also need to do one daytime exchange by hand.

Home HD uses a plastic filter called a *dialyzer* to clean the blood. You’ll learn to place two needles into your *access* (a connection between a vein and artery, most often in an arm). You’ll connect tubing to the needles to bring your blood to and from the dialyzer. A dialysis machine will control the speed of blood flow and keep you safe. Most programs require you to have a partner who’ll train with you and be there for treatments in case you need a hand.

- **Nocturnal home HD (NHHd)** – Do treatments at night while you sleep, 3-6

nights per week. NHD leaves your days free for work, and offers a near-normal diet and fluids, with fewer drugs needed and no “dialysis hangover.”

- **Daily home HD (DHHD)** – Do short (2-3 hour) treatments 5-6 days a week in the early morning or after dinner while you watch TV. The frequent treatments prevent “dialysis hangover,” and the diet is more normal than in-center HD.
- **Conventional home HD** – Do standard, 3-5 hour treatments on your own schedule at home. Dialyze longer if you need to remove more fluid and wastes.

Find a Center that Offers Your Choice

Most of the 4,700 dialysis centers in the U.S. offer in-center HD only. You may have to do some homework to find a center that offers a more work-friendly option. About one in three U.S. centers offers PD, and about one in ten offers home HD.

You may also need to change doctors if your doctor does not support your choice. Research shows that people who choose their dialysis option *themselves* live longer *and* are more likely to get a transplant than people whose doctor chooses for them, or even those who work with their care teams to make a choice.⁸ This makes sense, since you’re the one who must live with your choice each day.

On the Home Dialysis Central website at:

www.homedialysis.org/v1/centers/search.php

there is a list of each center in the U.S. that trains people to do home treatments. You can look up your town, or even a whole state, and find the closest centers. If you live near a state border, the nearest center may be in the next state.

Home Dialysis Central coverage maps, at <http://www.homedialysis.org/v1/types/maps.shtml> can show you where the centers are. Each center is in a circle that represents a 120-mile

drive—about 2 hours, because a home dialysis center can be as far away as you can go once a month for clinic visits. Most people are willing to drive a couple of hours to get the treatment they want.

Plan for Your Training and Set-up Needs

It takes a week or two to train for PD. Most programs will do a home visit to help you choose a room for PD exchanges and figure out where you will store your supplies.

You may be able to use regular vacation or sick days to have your PD catheter placed and recover and to train for PD. If you know this is coming, you can plan to save your vacation or sick days. Or, if your company is large enough (50 or more employees), you may be able to use the Family and Medical Leave Act (FMLA) to request unpaid time off. Plan to have one clinic visit per month to check your blood pressure, do blood tests, review your treatment logs, and see if any changes are needed to your treatments. If you get an infection, you will likely miss work time.

Training for home HD takes longer—usually 3-8 weeks, depending on which machine is used. Many programs require a home visit. In some cases, plumbing and wiring changes may be needed to make the machine work in your home. Some centers will pay for this and some will pass it along to you.

You may need to take a temporary leave of absence from work for your access surgery and home HD training, unless you have enough vacation or sick time. Your home HD partner will also need to take some time off work, since training is mostly offered during work hours. Talk with the home training nurse if this is a problem. You may be able to arrange a training schedule that will minimize time lost from work.

Conclusion

CKD will change your life—but how much and in what ways is at least partly up to you. Plan ahead and choose a work-friendly treatment to feel your best and reduce the impact of CKD on your lifestyle and income.

To Learn More, Download and Read:

- *A Kidney Patient's Guide to Working and Paying for Treatment*
<http://www.lifeoptions.org/catalog/pdfs/booklets/employment.pdf>
- *Your Kidney Treatment? Your Choice!*
<http://www.homedialysis.org/v1/rotating/pdfs/ChoosingKidneyTreatment.pdf>

¹ Bailie GR, Eisele G, Liu L, Roys E, Kiser M, Finkelstein F, Wolfe R, Port F, Burrows-Hudson S, Saran R. Patterns of medication use in the RRI-CKD study: focus on medications with cardiovascular effects. *Nephrol Dial Transplant*. 2005 Jun;20(6):1110-5.

² Personal communication between Beth Witten and John Mullins, Social Security Administration, February 3, 2006

³ Insurance Information Institute website: <http://www.iii.org/individuals/disability/lossofincome/>

⁴ Blake C, Codd MB, Cassidy A, O'Meara YM. Physical function, employment and quality of life in end-stage renal disease. *J Nephrol*; 13(2):142-9, 2000.

⁵ Lowrie EG, Curtin RB, LePain N, Schatell D. Medical outcomes study short form-36: a consistent and powerful predictor of morbidity and mortality in dialysis patients. *Am J Kidney Dis*. 2003 Jun;41(6):1286-92.

⁶ USRDS special data request, May 20, 2003. The data reported here were supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. government.

⁷ Witten B, Schatell DR, Becker BN. Relationship of ESRD working-age patient employment to treatment modality. Poster presented at the American Society of Nephrology meeting, St. Louis, MO, October 31, 2004. (Abstract) *J Am Soc Nephrol*. 2004; 15:633A.

⁸ Stack AG, Martin DR. Association of patient autonomy with increased transplantation and survival among new dialysis patients in the United States. *Am J Kidney Dis* 45(4):730-742, 2005