Slay Employed, Slay Healey

Your Guide to Navigating Kidney Care and Employment

Kidney Smart.

Charlie, working dialysis patient



Staying Employed While on Dialysis

Table of Contents

- 3 Manage Your Health
- 6 Continue Working
- 8 Navigate Insurance

A job can help support a household, provide medical insurance and other benefits, and be emotionally and socially rewarding. When you learn you have chronic kidney disease (CKD) and might need to start treatment you may wonder, "Can I work while on dialysis?"

For many, the answer is a resounding "yes."

In fact, studies show that people on dialysis who keep their jobs experience the following:

- Lower rate of depression¹
- Fewer hospitalizations²
- Higher score on general health and vitality tests³

Another study revealed that people with kidney disease who work full time are more likely to be placed on the transplant list and receive a kidney transplant than people who don't have a job⁴.

Learning more about kidney disease, dialysis treatment choices, your rights as a worker and insurance options will help you understand how it can be possible to manage your health and continue working. This booklet will give you an overview of those topics, and will provide some resources that are available to support you.

1. Depressed Mood, Usual Activity Level, and Continued Employment after Starting Dialysis. Nancy G. Kutner, Rebecca Zhang, Yijian Huang, and Kirsten L. Johansen, 2012.

- Physical function, employment and quality of life in end-stage renal disease. Black C, Codd MB, Cassidy A, O'Meara YM, School of Physiotherapy, Mater Misericordiae Hospital, University College Dublin, Ireland. http://www.ncbi.nlm.nih.gov/pubmed/108589784. J Nephrol; 13(2):142-9, 2000.
 Dialysis Patients' Mental Health Linked To Heart Health And Longevity. Clinical Journal of the American Society Nephrology (CJASN) April 2012. Ea Wha Kang, MD, PhD, from the Ilsan
- Hospital in Gyeonggi-do, Korea and Mark Unruh, MD, from the University of Pittsburgh Medical Center. 4. Sandhu GS, Khattak M, Pavlakis M, Woodward R, Hanto DW, Wasilewski MA, Dimitri N, Goldfarb-Rumyantzev A. (2013 Jun 30)
- Recipient's unemployment restricts access to renal transplantation. National Center for Biotechnology Information

Educate Yourself about Kidney Disease

Feeling better begins with empowering yourself with knowledge about kidney disease and taking control of your health.

When you have kidney disease, your kidneys are losing their ability to remove waste from your body or balance your fluids. When your kidneys fail and can no longer keep you healthy, it's known as end stage renal disease (ESRD). There are two main treatment options for ESRD: transplantation and dialysis. Dialysis is a process that removes excess fluid and filters waste from the blood. Dialysis treatments must be done on a regular basis to take the place of normal kidney function and there are several types of dialysis to fit your lifestyle (see p. 5 for more information).

Partner closely with your health care team (see p. 4 for more information) as early as possible to help you find a kidney doctor (also called a nephrologist). To learn more about kidney disease, visit **KidneySmart.org**.

Did You Know?

Diabetes and high blood pressure are the two leading causes of kidney disease?1



the world. Even with ESRD, Earl can continue to pursue his passion.

1 USRDS 2011 Atlas of ESRD



Your All-Star Health care Team

Leaning on expert resources can help you manage your kidney disease and overall health. Some or all of the following care team members may make up your health care team.

Primary Care Physicians: Family physicians or Physicians who practice family medicine by trade

Nephrologists: Physicians who specialize in kidney disease (also called kidney doctors)

Nurses: Care team members who will help you schedule your treatments and carry out your kidney doctor's prescribed plan

Kidney Care Dietitians/Renal Dietitians: Dietitians who specialize in eating plans for people with kidney disease, diabetes and high blood pressure

Social Workers: Specialists who can help you and your family with the emotional, financial, career, lifestyle and other non-medical aspects of managing kidney disease

Cardiologists: Physicians who specialize in high blood pressure and other diseases of the heart and blood vessels

Endocrinologists: Physicians who specialize in diabetes and hormone disorders

Kidney Smart Patient Advocates: People who specialize in insurance resources and navigating employment for people with kidney disease

5 Questions to Ask Your Nephrologist

Your nephrologist is your partner in helping you learn how to adapt to dialysis treatments so you can continue working and enjoy the life you deserve. Here are some questions you might want to ask at your next visit:

- 1. What treatment options would best fit my work and lifestyle?
- 2. Once I start dialysis, will I feel better to continue working?
- 3. How often do I need to see you?
- 4. How might my medication affect my performance at work?
- 5. Who should I talk to about my legal rights as an employee?



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Meet Adrienne. Working on dialysis works for her.

During a hospitalization for a diabetes-related issue, Adrienne learned she had ESRD and that she needed to start dialysis. Adrienne is the CEO of a company that develops specialized homes for adults with developmental disabilities who are transitioning into the community from state institutions. "I'm a card-carrying workaholic so I needed something that allowed me the flexibility for when I do dialysis," Adrienne says. She chose peritoneal dialysis (PD) because the treatments can be done while she is at work or at home.

Find the Right Treatment Option to Fit Your Lifestyle

You have options when it comes to treating your kidney disease. With the help of your nephrologist, you can find the treatment that best fits your everyday needs. From receiving a kidney transplant to dialyzing at home to getting treated at a center, there is an option that's right for you and your lifestyle. You can also choose a center at **Medicare.gov/ DialysisFacilityCompare**.

Did You Know?

Employed dialysis patients are two times more likely to receive a transplant.¹

 Compared to unemployed dialysis patients.
 Sandhu GS, Khattak M, Pavlakis M, Woodward R, Hanto DW, Wasilewski MA, Dimitri N, Goldfarb- Rumyantzev A. Recipient's unemployment restricts access to renal transplantation. Clinical Transplantation. 2013; 27(4): 598-606

Peritoneal Dialysis

Peritoneal dialysis (PD) is one form of home dialysis treatment for patients with ESRD. This needle-free dialysis uses the inner lining of the abdomen to clean your blood. You can do treatments on your schedule, at home or at work. PD is often done for 8 to 10 hours each night while you sleep so you can be free of dialysis during the day. Many people find that the flexibility of PD makes it easier to continue working.

Home Hemodialysis

Patients may choose home hemodialysis (HHD) for its many benefits, including easy-to-use machines and helpful training courses. You can dialyze on your schedule—morning, noon or night—up to six times per week. Each treatment takes about 2 to 3 hours. Patients find that HHD often helps them avoid cramps after treatments.

In-Center Hemodialysis

In-center hemodialysis is for people who prefer to have their treatments at a dialysis center. It gives you the opportunity to interact with your care team and other patients multiple times a week. In-center hemodialysis is done three times a week and each treatment typically lasts for four hours.

In-Center Nocturnal Dialysis

In-center nocturnal dialysis turns nonproductive sleep time into hemodialysis treatment time, giving you your daylight hours back. Receive three 6-to-8-hour dialysis sessions each week at night while you sleep at a dialysis center. This slow, gentle treatment can help improve your appetite and energy level.

Transplant

A kidney transplant is an alternative to dialysis. When you have a transplant, a surgeon implants one healthy kidney from a living or deceased donor. If you don't have a potential living donor, you will need to register with the United Network of Organ Sharing (UNOS.org) or partner with your nephrologist to get a referral to be added to the national transplant waiting list. People who take care of their overall health, adhere to their prescribed medications and go to their regular doctor's visit can live a long, fulfilling life with a transplanted kidney.



A Paycheck and More

Managing CKD and deciding whether or not to keep your job is a personal and, oftentimes, tough decision. Consider these three key factors before making your decision.

- 1. Difference in income when you work vs. don't work: There are income-replacement or alternative insurance options that may help if you choose not to work. However, none of them provide the same level of income that a job does (see p. 9 for more information).
- 2. **Insurance options that are available to you to reduce treatment costs:** A Kidney Smart Patient Advocate can help you explore how dialysis coverage works and the insurance options available to you.
- 3. **Emotional and social factors:** Reflect on your current role, your career goals and if your job provides you with a sense of fulfillment. Think about the friends, coworkers and other personal interactions you may miss. Share with your family and friends information about working on dialysis, and get their input to help with your decision.

Meet Hank. Working on dialysis works for him.

Hank is a chiropractor and a naturopath who continues to work while getting HHD treatments. "I still work because, one, I enjoy it and, two, I love treating my patients," Hank says. He says he feels healthier and happier because he works.

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Understand Your Rights as an Employee with Kidney Disease

Whether you need to take a leave of absence or adjust your workspace, learn about your rights as an employee with kidney disease—and how to exercise them.

Take a Break with a Leave of Absence

If you ever feel like you can't keep working, think about taking time off. A leave of absence can be very helpful if you need to start dialysis or if you just don't feel well. Give yourself peace of mind and figure out how to take a medical leave of absence. Look into your company's leave of absence and sick leave policies, and disability insurance and eligibility. Depending on the size of your company and your employment tenure with your company, you may be eligible to take an unpaid, job-protected leave under the Family and Medical Leave Act (FMLA) for serious medical health conditions as defined by the FMLA. You may also be eligible for a medical leave of absence according to state law and your company policies.

To qualify for FMLA, you must have worked for a total of at least 12 months and 1,250 hours over those 12 months for a public agency, public or private school, or company with 50 or more employees within a 75-mile radius. Up to 12 weeks of unpaid leave can be taken at one time or in increments during a given 12-month period.

Short-term disability (STD) provides payment to replace a portion of your lost income for six months to a year. Check with your employer for STD availability and plan benefits.

Long-term disability (LTD) provides payment if you are unable to work for an extended period of time. Compensation usually begins after paid sick leave and STD have run out and continues until the end of your disability or the end of your plan—whichever comes first. Check with your employer for LTD availability and plan benefits.

Explore Accommodations within Your Work Place

Employees on dialysis may also have rights under the Americans with Disabilities Act (ADA). Your employer may be able to make reasonable accommodations that help you stay employed. Learn your rights by calling your state's workforce commission or the U.S. Equal Employment Opportunity Commission (EEOC). Find help with ADA issues via your employer, the Job Accommodation Network or through the EEOC.

Helpful Employment Resources	
Family and Medical Leave Act	DOL.gov/WHD/FMLA
Job Accommodation Network	AskJan.org
U.S. Department of Justice Guide to Disability Rights Laws	ADA.gov
U.S. Equal Employment Opportunity Commission	EEOC.gov





Staying Employed While on Dialysis

A Kidney Smart Patient Advocate can help you explore how dialysis coverage works and the insurance options available to you.

A Patient Advocate can assist you in understanding the following:

- Out-of-pocket maximum payments, co-pays, deductibles and premiums related to insurance
- Consolidated Omnibus Budget Reconciliation Act (COBRA)
- Medicare and Secondary Payor (MSP) coverage
- Short- and long-term disability
- Social Security
- Your rights regarding FMLA and ADA
- Dialysis costs not covered by insurance

Employer Insurance Benefits

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People on dialysis who continue to work may receive insurance through their employer, which can provide the following:

- Better access to doctors
- Full family coverage
- Lower out-of-pocket medical expenses

Accommodation and Action Tools

Use these helpful tools to help guide you through important conversations with your doctor and/or employer so that you can feel prepared to take time off and ask for certain accommodations at the workplace.

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Click for attachments.

Think Through the Financial Impact of Not Working

As you decide whether to continue working or quit your job, consider the financial impact of not working. The following income-replacement or alternative insurance options may help, but none of them come close to providing the income that a job provides.

Social Security Disability Insurance

If Social Security Disability Insurance is available to you, it may cover only 30 to 40 percent of your current wages. The Social Security Administration (SSA) provides calculators to estimate disability benefits. Access those calculators by visiting SSA.gov/Planners/Calculators.

Social Security Disability and Working Scenarios

Understanding potential options and healthcare coverage through Social Security Disability Insurance (SSDI) doesn't have to be difficult or overwhelming. To better illustrate, let's look at a handful of scenarios:

	Scer	nario	А	В	С
	Current wages per year ¹	Approximate income and/or benefits	Continue working (without SSDI)	SSDI only ^{2,3}	SSDI + work ^{2,3,4}
4	¢12.000	Per Year	\$12,000	\$8,184	\$20,184
1	\$12,000	Per Month	\$1,000	\$682	\$1,682
2	3 \$40,000	Per Year	\$20,000	\$11,280	
2		Per Month	\$1,667	\$940	
2		Per Year	\$40,000	\$16,140	Does not apply (due to monthly
3		Per Month	\$3,333	\$1,345	income "substantial" per SSA) ⁵
4		Per Year	\$60,000	\$20,988	per 00/1)
4	\$60,000	Per Month	\$5,000	\$1,749	

1. In all scenarios, we are assuming the patient is 45 years old and that he/she is not blind.

A subscription of the beneficiary qualified for SSDI, and all of his/her wages qualified for SSDI.
 Calculation is based on Social Security Quick Calculator. Based on 2019 information. https://www.ssa.gov/OACT/quickcalc.
 As of 2019, SSDI rules state that beneficiaries are able to work for 36 months while still receiving SSDI benefits, unless the income is considered "substantial" by Social Security

http://www.ssa.gov/ pubs/EN-05-10095.pdf. 5. As of 2019, Social Security defines "substantial" as monthly income of more than \$1,220 per month for non-blind individuals. \$2040 for blind individuals.

https://www.ssa.gov/oact/cola/sga.html



COBRA

COBRA insurance coverage may be an option if your employer has more than 20 employees, you've stopped working or had your work hours reduced, or you've experienced a life-changing event such as divorce. COBRA allows you to maintain your employer group health plan (private insurance) for up to 18 months after you stop working. When you sign up for COBRA, you must pay the health insurance premium you paid before you left your job plus the amount the former employer was paying for you. There may be outside premium assistance programs available to those who qualify.

Medicare

Medicare isn't just for people who are 65 or older. It's also available for people of any age with ESRD who need a transplant or dialysis and meet the following requirements:

- Paid the required amount in Social Security and Medicare taxes through their job
- Are the spouse or a dependent of someone who qualifies for Medicare because they have paid the required amount into Social Security

Medicare will pay 80 percent of covered medical costs and you will be responsible for the other 20 percent.

Medicaid

Medicaid eligibility criteria and plan coverage are state-specific, and typically based on a combination of financial and medical need. Medicaid benefits will cover only services rendered by providers who accept Medicaid and typically will not cover services outside your state.

Options for Taking a Leave of Absence

Your leave options are based on a number of factors, including the types of insurance offered by your company, what kind of work you do, how long you have worked for your employer and the size of your company. Speak to your employer to learn what's available to you. The options described below are meant only to illustrate what may be possible.

MAY RETURN TO WORK						
Day 0	Weeks 0-12	Weeks 2-52		eeks 0-12 Weeks 2-52 After 52 V		52 Weeks
Working	Family Medical Leave (FMLA)	Short-term Disability (STD)	Long-term Disability (LTD)	Termination	COBRA	
Use vacation or sick leave	Apply for FMLA	STD application form from employer	LTD request after STD is exhausted	Employer sends COBRA info within 30 days	COBRA is activated after election is completed and payment is received	
	12 weeks of leave in a 12-month period	May require physician sign-off	May require physician sign-off	You have 60 days to complete election	COBRA plan is identical to employer plan	
				You have 45 days from election date to send payment	Plan will last 18-36 months, depending on Social Security Disability determination	

Stay employed, stay healthy. Learn more by calling a Kidney Smart Patient Advocate at **1-888-260-0086**.

Working with Kidney Disease Checklist

Having a plan of action will help you take control of your kidney health while continuing to work. Use this checklist to get started.

Learn More about Kidney Disease

Contact your Kidney Smart educator or visit KidneySmart.org.

Build Your Support Network

Lean on Your Kidney Care Team:

- Ask about ways to feel your best with kidney disease.
- Discuss treatment options that fit your active lifestyle.
- Talk through the suggested questions with your nephrologist on p. 4.

Speak with Your Family and Friends

- Ask someone to attend kidney disease education classes and/or doctor's appointments with you.
- Share with your family and friends information about working on dialysis.

Speak with a Patient Advocate

- Ask for resources on workers' rights.
- Request information about maximizing insurance.
- Make a plan to address your work and insurance needs.

When the Time Is Right, Talk with Your Employer

- Discuss the option of taking leave for medical reasons.
- Discuss any workplace accommodations you may require.
- Utilize the Accommodation Tool and Action Plan found on pages p. 8.



Build Your Support Network

These resources may help you connect with people who understand what you're going through:

PEERS: 1-855-653-7337 or Kidney.org/Patients/Peers

Renal Support Network HOPEline: 1-800-579-1970



2000 16th St. Denver, CO 80202

Get help answering your employment and kidney disease questions. Contact the Patient Advocate Helpline at 1-888-405-8915.

Peritoneal Dialysis: Accommodation Tool

TREATMENT OPTION	MANUAL (CAPD)	CYCLER (CCPD)
WHERE	Performed at home, at work or on vacation. Usually does not require a care partner.	Performed at home, at work or on vacation. Usually does not require a care partner.
FREQUENCY/ DURATION	Daily, 3-5 times per day. Each manual exchange takes approximately 30 minutes.	Daily. Multiple exchanges using a machine. Each session takes approximately 8 to 10 hours and is usually done while sleeping. (Some patients may require an additional daytime exchange).
INITIAL ACCOMMODATIONS (Start this conversation with your employer)	 Same-day surgery for PD catheter placement typically takes a few days for recovery. Once catheter heals (typically 2 to 4 weeks), training begins and will continue for approximately 8 to 15 days. 	 Same-day surgery for PD catheter placement typically takes a few days for recovery. Once catheter heals (typically 2 to 4 weeks), training begins and will continue for approximately 8 to 15 days.
ONGOING ACCOMMODATIONS (Continue this dialogue with your employer)	 Typically done during the day, it is necessary to do exchanges in a clean room with a closed door and windows. Going to the dialysis center for labs and doctor visits typically occurs twice a month at a minimum. 	 Though typically done at night, a clean room to perform PD with the door and windows closed is necessary. Going to the dialysis center for labs and doctor visits typically occurs twice a month at a minimum.

Demonstrative example only. Actual schedule may vary for each individual and provider. This example does not include hospital stays or other ongoing healthcare visits. Your health care provider will evaluate for additional accommodations based on medical need/as condition evolves.

Questions for my doctor:

When can I return to work after my access surgery?
When can I use my catheter?
How will I take care of my PD catheter?
How often will I need to see my doctor after treatment starts?
How often will I need to complete labs after treatment starts?

Questions for my employer/human resources:

What are my FMLA benefits?
What are my short-term disability benefits?
What are my long-term disability benefits?
How many vacation days, sick days or personal leave days do I have available?
Can accommodations be made to complete my PD exchanges during the workday?
Can accommodations be made for my training/treatment schedule?

Questions for my dialysis center (If you and your doctor have decided on a dialysis center):

How long will it take to complete training?
Will training be full days or half days/What is my training schedule?
Can you accommodate my working schedule?
Will I be trained in CAPD (manual) or CCPD (cycler)?
Will my treatment type/accommodation needs potentially change over time?
Do you offer evening and Saturday training sessions?



Hemodialysis: Accommodation Tool

TREATMENT OPTION	IN-CENTER (ICHD)	HOME (HHD)
WHERE	Performed in a dialysis center. Can be done with the assistance of center staff or done as self-care.	Performed at home, offering a more flexible schedule. Can be done with a care partner or on your own.
FREQUENCY/ DURATION	Standard Standard treatments (daytime; typically 3 to 5 hours, 3 times per week) Nocturnal Nocturnal treatments (nighttime; typically 6 to 10 hours, 3 times per week). Late Shift Late shift treatments (third shift around 4 p.m.; typically 3-5 hours, 3 times per week).	 Short daily Short daily treatments (typically 2.5 to 3.5 hours, 4-6 days per week). Traditional Traditional treatments (typically 4 hours, 3 times per week). Nocturnal Nocturnal treatments (typically overnight; 7 to 8 hours, 3 to 6 days per week).
INITIAL ACCOMMODATIONS (Start this conversation with your employer)	Surgery and recovery for access placement is typically a few days.	 Surgery and recovery for access placement is typically a few days. Once access heals (typically 1-2 months), training begins 4 to 5 hours/day, 5 days/ week, for 3 to 6 weeks.
ONGOING ACCOMMODATIONS (Continue this dialogue with your employer)	 Treatment begins once access heals (typically 2-3 months) 3 times per week. Schedule choices typically are: Mondays/Wednesdays/Fridays or Tuesdays/Thursdays/Saturdays. 	 Doctor visits and labs usually once per month. Treatment schedule.

Demonstrative example only. Actual schedule may vary for each individual and provider. This example does not include hospital stays or other ongoing healthcare visits. Your health care provider will evaluate for additional accommodations based on medical need/as condition evolves.

Questions for my Doctor before I speak with my Employer:

When I can return to work after my surgery?
When can I use my catheter/fistula/graft?
How often will I need to see my doctor after treatment starts?
How often will I need to complete labs after treatment starts?

Questions for my Employer/Human Resources:

What are my FMLA benefits?
What are my short-term disability benefits?
What are my long-term disability benefits?
How many vacation days, sick days or personal leave days do I have available?
Can accommodations be made for my treatment schedule?
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Questions for my Dialysis Center (If you and your doctor have decided on a Dialysis Center):

How long will it take to complete training? (If HHD)
Will training be full days or half days/What is my training schedule? (If HHD)
Can you accommodate my working schedule?
What will my treatment schedule be? (If ICHD)
Do you offer nocturnal or late-start shifts? (If ICHD)



Kidney Transplant: Accommodation Tool

TREATMENT OPTION	KIDNEY TRANSPLANT
WHERE	Kidney transplant center.
FREQUENCY/ DURATION	Most transplant patients can consider returning to work after approximately 6 to 8 weeks, although this timeline varies by individual.
INITIAL ACCOMMODATIONS (Start this conversation with your employer)	Referral and transplant evaluation.Surgery and recovery typically 6 to 8 weeks.
ONGOING ACCOMMODATIONS (Continue this dialogue with your employer)	Doctor's visits.

Demonstrative example only. Actual schedule may vary for each individual and provider. This example does not include hospital stays or other ongoing healthcare visits. Your health care provider will evaluate for additional accommodations based on medical need/as condition evolves.

Questions for my doctor:

When can I return to work after my transplant surgery?	
When do I need to see my doctor after transplant?	
When will I need to complete labs after transplant?	

Questions for my Employer/Human Resources:

What are my FMLA benefits?
What are my short-term disability benefits?
What are my long-term disability benefits?
How many vacation days, sick days or personal leave days do I have available?
Can accommodations be made for my transplant (time off for evaluation, transplant recovery and ongoing doctor visits)?
Questions for Transplant Center:



Resources for patients

- 1. Employee's Practical Guide to Requesting and Negotiating Reasonable Accommodations Under the ADA: https://askjan.org/Eeguide/EeGuide.pdf
- Ask JAN Fact Sheet and contact information: 1-800-526-7234; http://askjan.org/media/JAN_Fact_Sheet.pdf
- 3. Accommodation ideas for individuals with renal/kidney disease: http://askjan.org/soar/other/renal.html
- 4. Accommodation and Compliance Series: Employees with Diabetes: http://askjan.org/media/Diabetes.html
- 5. Additional information about ADA at the ADA Information Line: 1-800-514-0301; www.ada.gov
- 6. Employee's Guide to FMLA: https://www.dol.gov/whd/fmla/employeeguide.pdf
- 7. Additional information about FMLA: 1-866-4-USWAGE (TTY: 1-877-889-5627); www.dol.gov/esa/whd/fmla/
- 8. Additional transplant information from UNOS Patient Services Line: 1-888-894-6361; https://optn.transplant.hrsa.gov/learn/patient-education/



Action Plan

Using the information you gathered from the Accommodation Tool, you can create your own Action Plan. This plan should be an ongoing conversation with your doctor and employer. Here is an example of an Action Plan:

ACCOMMODATIONS I NEED (Example)	ACCOMMODATIONS/BENEFITS I WILL USE (Example)
Initial: Time off for surgery/recovery	Discussing with my employer about my time-off benefits that may include vacation, sick and/or personal days, the Family and Medical Leave Act (FMLA), and short-term or long-term disability.
Initial: Training for PD/adjusting to treatments	Working with my employer for an accommodation request to mod- ify my work schedule to allow for center visits twice a month for ap- proximately 2 hours per visit once training is completed and stable.
Ongoing: Clean room	Working with my employer for an accommodation request for a clean room to do an exchange.
Ongoing: Doctor's visits and labs	Working with my employer for an accommodation request to modi- fy my work schedule to allow for center visits twice a month.

In the table below, you can use the information from the Accommodation Tool to help you come up with your own Action Plan.

ACCOMMODATIONS I NEED (After speaking with my doctor/dialysis center)	ACCOMMODATIONS/BENEFITS I WILL USE (After speaking with my employer/human resources)

