



Kidney Failure and Your Work Life



Module 17 – Kidney Failure and Your Work Life

Please Note

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Congratulations, you've finished the quiz! Here are the correct answers so you can see how you did:

Module 17 – Kidney Quiz Answers

d (10)	d (5)
b (6)	c (4)
c (8)	a (3)
c (7)	c (2)
a (6)	b (1)



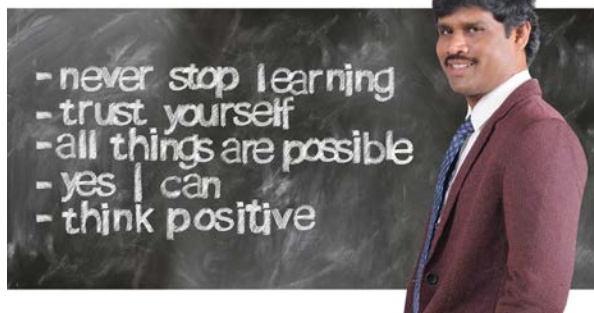
“I work because I was taught from a very young age that to achieve your goals in life, you had to put in the labor. When my kidneys failed and I started dialysis, the thought of not working never crossed my mind.”

Is it possible to work if your kidneys don't? Yes!

People work in all sorts of fields after their kidneys fail, from bar tending to water treatment to banking to driving—and more. Of course, *being able to work does not happen by accident*. If you want—or need—to work, then you have to make work a priority. You boost your chance when you take charge of your care and follow your treatment plan. And, it helps to choose or switch to a **work-friendly treatment**. We'll tell you how.

Since you may live for decades after your kidneys fail, it can make a lot of sense to work. Loved ones or even doctors may urge you to “rest.” But, there are great reasons to work when you can:

- Work can give you a sense of purpose and self-worth.
- Work gives structure to your day and a focus besides your health.
- You can earn more with a job than disability.
- Many jobs offer better health plans at a lower cost than you could get elsewhere.
- Having Medicare plus a work health plan can help you to get a kidney transplant.
- At work, you can keep in touch with colleagues and make new friends.



Choose Work, Not Disability

Think hard before you give up a job. When you are tired or don't feel well, disability can sound good, but the plans are set up to pay *much* less than work does. Social Security Disability Income (SSDI) may pay as little as 40% of what you earn. The more you earn, the less it will replace. You may not owe federal taxes on SSDI, which can help. But, there will still be a big gap between how much you earn now and what your SSDI check would be. And, your bills may not be any lower. In fact, with healthcare costs, they may go up. Later, we'll talk about Social Security and other programs that can help you get back to work if you are on disability.

This module will give you tips to help you keep your job or find a new one. It will also tell you about laws that protect you. So, let's get started!

“I love working, have a passion for what I do & can work it around dialysis! Time is short—lets rock this world!”

Web links throughout this module work best using Acrobat Reader.





"I work because I don't want to waste away. I spent almost 2 months on bed rest waiting to start dialysis. It was really tough to build back up. I have peaks and valleys now, but do as much as I can and hope to never have to stop."

Work-friendly Treatments for Kidney Failure

The most vital choice you can make to keep your job or go back to work is **which treatment to use**. A kidney transplant can help you to work if it is an option for you. That can take time, unless you have a living donor who is a match. Or, you may need some form of dialysis to save your life. The type you choose will affect your quality of life—and whether you will feel up to working.



In the U.S., 89% of people with kidney failure end up on three times a week hemodialysis (HD) in a clinic. We call this *in-center HD*—and it tends to be the *least* work-friendly option.

Why? Because in-center HD:

- Tends to be done during the work day. You may or may not get a choice of treatment time.
- Causes the most symptoms during and after treatments—like cramps, fatigue, and brain fog.
- Requires the most limits on what you can eat and drink, and the most meds.
- Causes the most and longest hospital stays.
- Makes it harder to travel.

Some people DO work while doing in-center HD, either part-time or full-time. It CAN be done—it's just a much bigger challenge. And, there are other options you may not know about.

"I work 45 hours a week and do in-center hemo 12 hours per week. I no longer get disability benefits, but I do love my paycheck!"

So, which treatments are work-friendly?

- **Kidney transplant.** When a new kidney works well, you have more energy and can think more clearly. You have clinic visits—but will not have to fit dialysis treatments into a work week. You may stay out of the hospital more. Your treatment is portable: the new kidney is inside your body. And, you have fewer limits on what you can eat and drink. You do have to take drugs to keep the new kidney, and these can have side effects.



<i>What makes a treatment work-friendly?</i>	<i>Why?</i>
You feel well from day to day, without “ups and downs.”	You have the physical energy to put in a work day.
You get enough treatment to think more clearly.	You can have mental energy and can feel like you contribute.
You can control your treatment schedule.	You can fit in work and treatment—and still have “me” time.
You stay out of the hospital.	You don’t miss as much work time.
You can take your treatment with you to travel.	You can take work trips if you need to—or, of course, vacations.
You can eat and drink with fewer limits.	You can have meals on work trips or with clients or employer/co-workers with less worry about the menu.



- **Kidney-pancreas (KP) transplant.** A KP transplant can be an option if your kidneys fail and you have diabetes. Most often, KPs are done for type 1 diabetes. Some programs will do one for type 2 if you use insulin. A working KP transplant gives you all of the pluses of a kidney transplant. *And*, a healthy pancreas means you will not have diabetes. If you are otherwise healthy and you want to work, a KP transplant can make that more likely. Since a KP transplant is two organs, you may get one faster than just a kidney. Fewer programs do KP transplants than kidney transplants, so you may have to travel to get one.

- **Peritoneal dialysis (PD).** Done by hand or with a cyclor machine at night, PD is gentle and you can do it on your own schedule. You won’t have ups and downs. You can choose your schedule. People who do PD are not in the hospital as often or for as long as those who do in-center HD. You can bring a PD cyclor on an airplane for free. And, a supply company can ship your supplies for free when you travel in the continental U.S.—if you give them enough notice. (Or, they can still ship, but may charge you fees if you travel outside the continental U.S.) And, most people who do PD have fewer diet and fluid limits than those who do standard in-center HD.

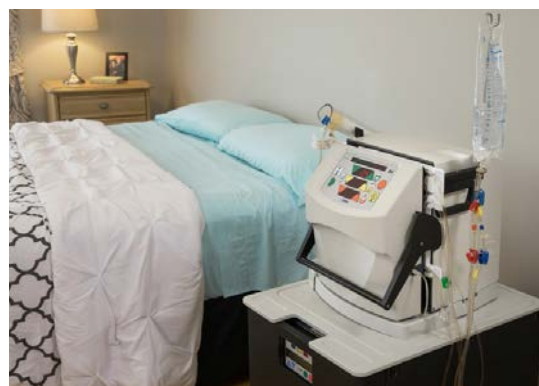




- **Daily home HD.** You can learn to do short (2.5–3.5 hours or so) treatments 4, 5, or 6 days a week on your own schedule. With more frequent HD, you remove less water at each treatment, which is much gentler. You won't have ups and downs, and will have more energy. You also won't need as many meds, and will have fewer food and fluid limits. As with PD, you can bring your machine with you for travel. But, some find that work + daily HD means not enough “me” time. On the plus side, **you may not need a partner to do daily home HD.** If you are able and your doctor and clinic permit it, you can train to do it solo.



the most gentle and effective type of dialysis, with no ups and downs in how you feel. Most who choose this option sleep well, have more energy, take fewer meds, and can eat and drink with few—or no limits. Since treatments take almost no time out of the day, you have a lot more “me” time. Survival with nocturnal HD is about the same as it is for deceased donor transplant, too. Most clinics require a partner.



My Life, My Dialysis Choice is a treatment matcher that can help you see which of the types would fit YOUR life best. You can learn more about transplant and each type of dialysis in [Module 2: Treatment Options for Kidney Failure](#).

- **Standard home HD.** Some people do home HD 3 or 4 days per week for about 4–5 hours at a time. These treatments can be done on your own schedule. You can use a standard machine or a smaller machine. You would need a partner.
- **Nocturnal HD.** HD can be done at night *while you sleep*—at home, or some clinics offer this three times a week. Nocturnal HD is

My Life, My Dialysis Choice

A program of the non-profit NKF

Dialysis can affect every part of your life.

Use this free web tool! It will help you choose the right treatment for YOU.

Feel your best and live the way you want.

[Get Started](#)

www.MyDialysisChoice.org

Yo Escojo Mi Vida, Yo Escojo Mi Diálisis
está disponible en español también.



“From personal experience, keep working as long as you can. It’ll remind you what you’re living for. Full-time disability can suck.”

How to Get the Treatment You Want

It can feel overwhelming to sort out how to get to a treatment that will help you to keep or find a job. Just take one step at a time. Here are the steps to get a transplant and to start or switch to home dialysis.

Steps to a Kidney or KP Transplant

1. Go to a transplant program and have lots of medical tests to be sure you are healthy enough to get a transplant. Your doctor can refer you or you can call the program yourself. Ask your doctor or clinic staff which programs are in a range you can travel to, and call them. You can be listed at more than one program—as long as each program allows it. Don’t want to miss work? Ask the program(s) you talk with to set up as many tests as they can for the same day.

Where to Find U.S. Kidney Transplant Programs

See which transplant programs are close to you and which ones have the shortest wait times and best results!

www.srtr.org/transplant-centers/



- 2. Show that you have a health plan and a way to pay for your costly meds.** You *must* take meds each day to keep a new kidney safe from your immune system. Medicare pays for most of your health costs, like tests and meds—for 3 years after a transplant. You will need to have a plan for how to get health care once Medicare stops, which could be through a job. Once you are 65, Medicare will still cover you. Or, when you are disabled for a reason other than your kidneys, Medicare will still cover you, too.
- 3. Find a living donor.** Share your story! Someone may offer you a living donor kidney. If someone is a match for your blood and tissue type, and is willing to donate, it is much faster, and the kidney may last longer. In fact, it is best to get a transplant as soon as you can—you do not have to start dialysis first. (*Don’t ask for a kidney, though—this can scare people away.*) NOTE: You can have a living donor for a kidney, but not for a pancreas. Some people get each organ from a different donor. But, this means two surgeries and recoveries. So, most people get a KP transplant from one deceased donor. Medicare covers a KP transplant.





- 4. Or, wait for a deceased donor.** You can be on the national list for a deceased donor kidney for years. You may get calls where you are one of several people in line for that kidney—but do not get it. The “list” is not a first come first served, it is based on how good the match is between you and a kidney.

Any of these choices can speed up the wait process. You will be asked if you will accept:

- A kidney from a “increased risk” donor who, say, used street drugs or was in prison.
- A Hepatitis C kidney—and then get drugs to cure the disease.
- An HIV positive kidney.
- A kidney from an older donor.

When you need more than one organ, the wait tends to be much shorter, too. A transplant is not a cure: most do fail in time. But, some people have had the same transplant for as long as 40 years.

Waiting can sap your morale. Hang in there, and talk to your fellow patients. They can help you through the disappointment.

- 5. Have the transplant.** A transplant is major surgery, with a large incision. You should know when you wake up if a new kidney is making urine. Some kidneys are “sleepy” and take some time to wake up and start to work. You may even need dialysis until that happens. A few kidneys don’t work at all, but this is rare. As with any surgery, there is a risk of complications, or even death.

- 6. Recover.** After you get a transplant, you will need to have help at home while you recover. Expect to have pain, and to need help to walk and get meals for at least a week or two once you go home from the hospital. You will have frequent follow-up visits at first that space out over time. You may not be able to lift more than 10 lbs. or drive for up to 6 weeks, so you will need rides to the clinic.

Can I Make In-center HD More Work-friendly?

When you do in-center HD and you want to work, get the best treatment you can. This means:

- Follow your fluid limits
- Follow your meal plan
- Take your meds as prescribed
- Get as much treatment as you can, as gently as you can (this tool can help: (<https://www.homedialysis.org/ufr-calculator>))

Besides these, ask for a schedule that will let you work. This may mean an early morning, early evening, or nocturnal shift. Tuesday, Thursday,

I want to take off this much fluid:
 Liters

My weight:
 Kilograms

My treatments are this long:
 Hours

My doctor says I have heart problems:
☐ Yes

Fill in the fields on the left to see your ultrafiltration rate.

Saturday schedules only take two days out of a work week, not three.



As you take the meds, you will learn how they affect you. Tell your doctor about any side-effects you notice. Some will go away in time. Some will require a change of drug, dose, or timing. Some you may need to get used to for at least a while. Others you will take for as long as you have the transplant. Once your doctor clears you, you can go back to work if you have a job.

Steps to PD or Home HD:

It is your right to change treatments—or clinics or doctors—to get the care you need. Some people run into resistance from clinic staff if they say they are going to switch. Don't let anyone scare you away from the treatment option you want! Making your life better really is worth it.

1. Use *My Life, My Dialysis Choice* to see which treatments may fit your life best.

Ask your doctor if there are any health reasons that you could not do one or more of the options you want. Make sure your doctor knows what matters to you and what you value most.

2. Find a clinic near you that offers the treatment(s) you want. Go to: <https://homedialysis.org/clinics/search>. Call your health plan to see which of the clinics are in your plan network. Call those clinics and ask to talk to the home training nurse. You will want to have a list of questions ready, like:

- How long does training tend to take?
- Can I come visit the program?
- Do you train in groups, or just one-on-one?
- Can I do training before or after my work hours or on weekends?
- Can I be trained in my home instead of at the clinic?

- If I need a partner, how much of my training must s/he attend?

3. Complete the training. This part is hard—learning something new and complex can be scary and frustrating. The good news is, there is support to help. Join the [Home Dialysis Central Facebook discussion group](#). More than 5,300 members have been in your shoes and can help you get through training and succeed at home. Make training and your first weeks at home easier if you:

- **Clear the decks.** Take anything you don't have to do off your calendar.
- **Cook meals ahead for the week**—or ask friends for casseroles or order take-out foods on your diet.
- **Tell your training nurse how you learn best.** Some people like to see all the steps first, others prefer to learn them one at a time. You may want to be hands-on, or to read first and then try something.
- **Find support.** Ask to talk to other home patients from your clinic. Having a fellow mentor to call with questions—plus your training nurse, your clinic social worker, and your supply company—can ease your mind.

4. Set up your treatment room. Your training nurse and/or a technician from your clinic will come and look at your home. They will help you see where it may make sense to store your supplies and put a machine, if you need one. They will look at whether you need any changes to your plumbing and wiring if you plan to do HD. When you rent your home, you may need the landlord to sign off for wiring or plumbing changes for HD. The





nurse and tech can help explain what the machine does and how it works, and how you will handle the medical waste and empty supply boxes. Ask others how they set up their rooms. There are lots of photos online to give you good ideas for how to use the space well and have what you need at hand.

- 5. Receive your machine and first supply shipment.** The first shipment will be the largest. You will need to clear out a closet, or space under a bed or along a wall to fit in a shocking number of boxes. Don't panic! If your space is small, you may be able to get delivery twice a month instead of just once. Your delivery person may bring in the boxes, rotate stock, and stack them. If not, you may want to open the boxes to bring the bags in. Break down the sturdy boxes and recycle them, or give them away on Freeecycle.org to people who are moving.
- 6. Start dialyzing at home.** Expect to feel overwhelmed at times. You can do this! When you first go home, you will wonder what you got yourself into. It takes time to get into a routine that will work for you. Promise to give it at least 6 months at home—by that time (or sooner!), you will be doing great. You can shift your treatment schedule around to suit your home and work life, as long as you do all of the treatments your doctor prescribes.

"I work because I try to do everything in my power to not be a sick person."

Where to Find U.S. Home Dialysis Programs

There are nearly 7,500 dialysis clinics in the U.S., but most offer only standard in-center HD. About one in three has PD. About one in 10 has home HD. And, even fewer offer in-center nocturnal.

Search this database (www.homedialysis.org/clinics/search) to see which clinics near you offer one or more work-friendly home options. If you live close to a state line, the clinic closest to you may be in another state, so keep that in mind. And, check with your health plan to be sure that a program you find is in your plan's network of care.



"I refuse to allow myself to be 'sick,' so I work as much and as hard as anyone else (in fact in my office of 30 I have taken the fewest sick days)."

You can work with kidney failure, no matter what treatment you choose. But, some options make your work life easier to manage. Transplant and home dialysis are more work-friendly than standard in-center treatments. Yes, these options mean that you have a lot to learn. You can learn more about each of them in [Module 2: Treatment Options for Kidney Failure](#).



How to Keep Your Job

It is almost always easier to keep a job you have, where you and your work are known, than to try to find a new job. Next are some tips to help you keep working.

Stay as Healthy as You Can

Working with a chronic illness can be a challenge—and you may have more than one illness. The better you feel from day to day, the more likely you are to keep your job. All of these aspects of lifestyle can help you to feel your best. Which of these do you do?

■ Eat a good diet.

We build our cells out of the food we put into our bodies. With a transplant or home dialysis, you may have fewer (or no) limits on what you can eat or drink. So, make your food count. Cook from scratch when you can—it doesn't have to be fancy. Scrambled eggs and a salad is a better choice than a frozen microwave meal—and just as quick to prepare. Drink



water or tea instead of soda. Eat more fresh vegetables and fruits. Choose foods with short (or no) ingredient lists. Avoid canned foods.

- **Stay active.** If you get exercise on the job, great! If not, fit in what you can. Build it into your day—park further away if you can walk a bit more without pain. Take the stairs. Join a gym, with your doctor's okay. Walk your dog. If you sit all day, at least stand up out of your chair each hour if you can.



- **Sleep well.** Sleep clears toxins out of your brain and helps give you energy for the day ahead. People who sleep 7 or 8 hours a night tend to live longer than those who sleep less than 6 or more than 9 hours. If you don't sleep well, you can find tips and ideas about how to improve your sleep in [Module 12: Staying Active](#). Treatments you do at night can affect your sleep until you get used to them. Talk to others who do those treatments to find out what helped them.
- **Get all of your prescribed treatment.** Transplant? Take your meds as ordered. Dialysis? Do all of the treatments you are supposed to. In general, the more treatment you get, the better you will feel and the longer you may live.





- **Manage your symptoms.** Kidney symptoms can make it hard to work. You can manage most of these, with help from your doctor, so be sure to share them. Print this table of symptoms to bring to your next visit.

What You Can Do for Symptoms You May Have

Fatigue

Do you wake up tired and stay that way all day, even if you take a nap? Or, do you fall asleep without warning? Tell your doctor. Include when

Symptoms/Problems That May Bother You	I Rarely Have This	I Often Have This	I Always Have This	This Makes it Hard to Work
Fatigue, lack of energy*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Faint, dizzy, weak*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Can't think clearly*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Short of breath*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling washed out after dialysis*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain from a hernia*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muscle cramps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching, dry skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Swollen hands, feet, or face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upset stomach or vomiting*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Food tastes like metal; no appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling cold even when others are warm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping too much or too little*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ammonia breath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Foamy or bubbly urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel pressure when making urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting up at night to make urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urine that is brown, red, or purple	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicine side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**These symptoms/problems may be the most likely to make it harder to work.*



you feel tired, how often, how much it limits your daily life, and what you have tried that has not helped. You may need a sleep study or other tests to get at the root of the problem. Try not to nap during the day, or it may be harder to sleep at night. Some of these can cause fatigue:

- **Anemia** is a common cause of fatigue. Your doctor can order blood tests. Learn more about anemia in [Module 6: Anemia and Kidney Disease](#).
- **Some meds.** Ask your doctor or pharmacist if any of your meds have fatigue as a side effect.
- **HD treatments that remove too much water—or take it out too quickly—can make you feel washed out and tired.** You may have cramps or headaches. You might be sick to your stomach. It may take hours to feel well again. ***This is not normal and should never happen.*** Follow salt and fluid limits if you have them, so you do not gain more water weight than can safely be removed at one treatment. Use this tool (<https://homedialysis.org/home-dialysis-basics/ufr-calculator>) to see if your treatment is safe for you.

- **PD cyclers can cause “drain pain” that makes it hard to sleep well.** A catheter can get stuck against the wall of your belly, which hurts. A surgeon can put in a wire and move the catheter. Or, ask your nurse about the “tidal” setting on the cycler. This leaves some fluid in for the last dwell, which can “float” the catheter so it doesn’t hurt.

Feeling Weak or Dizzy

No matter what kind of work you do or want to do, being weak or dizzy can be a safety risk.

- **Your blood pressure may be too low.** It’s wise to have a blood pressure cuff at home, so you can see what it is. Write down the numbers, and let your doctor know. If your treatment makes your blood pressure drop a lot, it may be pulling too much water out of your blood. This is more likely if you still make urine.



- **Your blood sugar may be too high or too low.** Dialysis can change your blood sugar. If you have diabetes, your meds may stay in your blood longer. Your blood sugar can drop. When you feel dizzy or weak, test your sugar.





Tell your doctor what you learn. Even if you do not have diabetes, a change in blood sugar during an HD treatment can cause headaches. A snack before or during treatment may help.

- **Your electrolyte levels may be off.** Dialysis should help to balance the salts in your blood that carry electrical signals. These “electrolytes” must be kept in a tight range all the time. If they are too high or too low, you can feel dizzy or weak. Ask for a blood test.
- **Your meds may cause side effects.** The more meds you take, the more chance there is for them to interact badly and make you dizzy. Your clinic will do a med review from time to time. This can help to see if you are on the right meds at the right doses. You can also ask a pharmacist to look over your med list and doses to see if anything looks as if it might be a problem.
- **You may need to move more.** When we don’t use our muscles, they grow weak—and this can happen quickly. With your doctor’s okay, get moving! Find something you like and start doing it. Even a few minutes a day is better than nothing. Find a friend to walk with, join a gym and lift light weights, take a dance class. You can learn more in [Module 12: Staying Active with Kidney Disease](#).

Brain Fog

You want to be sharp on the job, and feel as if you add value. Kidney disease can affect your memory, thinking, and focus.

- **Some causes of CKD may be more likely to cause brain fog than others.** Diabetes. Arthritis or Lupus. MS. Chronic fatigue syndrome. Even low levels of thyroid hormone or heart or blood vessel disease may cause a



lack of focus. Treating these underlying health problems as well as possible may help.

- **Anemia is a well-known cause of brain fog.** On dialysis, this shortage of oxygen-carrying red blood cells is not treated to the same levels as healthy people have. But, get the best treatment you can to make a difference. Exercise can also help.
- **Cancer and/or chemo can affect how well you think.** These problems may go away in time, once treatment is done. If they go on, see your doctor. Using memory tips like checklists, alarms, or reminder apps can help while you wait.
- **Nutrition and sleep matter!** Your brain uses a lot of your energy, so when your energy level is low, it is hard to think clearly. Eat real food—fresh or frozen. (Stay within the limits your doctor gives you, of course.) Processed or fast food give you calories, but not much else. If you don’t sleep well, learn what you can do in [Module 12: Staying Active with Kidney Disease](#).
- **Not enough dialysis.** “Adequate” means just enough to get by. But, if you need to think clearly to do your job, you may need more than the minimum. More days and hours of dialysis feels more like having healthy kidneys.



No one wants to give up more of their days to treatment—but some options are done at night while you sleep.

- **Don't be stunned.** Organ stunning occurs in HD treatments when water is pulled out of your blood too quickly, or too much is removed. Painful muscle cramps are one sign that this is happening. You may feel as if you have the flu for hours after a treatment. Studies show that your brain can be stunned by too-harsh HD treatments. Be sure yours are gentle! Use this tool to see if each treatment is safe. (www.homedialysis.org/ufr-calculator).

Shortness of Breath

When you can't catch your breath, it's hard to do anything at all. Breathing can become your whole focus. Talk to your doctor. There are things you can do to ease your breathing.

- **Don't get waterlogged.** Excess water in your body can settle in your lungs. It is vital for your treatment to remove the right amount of water—gently. Not too much. Not too little. And, not harshly! Follow fluid limits if you have them, and limit salt and sugar. (Both can make you thirsty.) Know your weight and how you feel when you have too much water in your body. You may see this as swollen hands, feet, ankles, or face—or feel it in your breathing.
- **Anemia can make you feel breathless.** With too few red blood cells to carry oxygen, you can feel short of breath with anemia. Talk to your doctor to be sure it is treated as well as it can be. You can learn more in [Module 6: Anemia and Kidney Disease](#).



- **Keep your heart healthy.** When excess water builds up in your body, it puts stress on your heart. In time—or if your heart is stunned by harsh HD treatments—the main pumping chamber can start to fail. Damage to your left ventricle can make it weak and flabby. Not enough blood will fit into your heart, and the extra backs up into your lungs. This problem, left ventricular hypertrophy (LVH) can mean that you won't qualify for a transplant. Exercise (with your doctor's okay) is good for your whole body—including your heart. PD or gentle HD do not cause harm to your heart. Chest pain or muscle cramps during or after treatment are warning signs. You can learn more in [Module 13: Heart Health and Blood Pressure](#).

Feeling Washed Out After Dialysis

On standard HD or sometimes daily HD, you may feel washed out after a treatment. This can last for hours, and can happen if you drink more fluid than you can safely remove in one session. (People who do PD can have some symptoms, but this is not one of them.)

- **Find out if any of your meds have thirst or dry mouth as a side effect.** When you are thirsty, it is hard to limit your fluids. Your doctor may be able to choose a drug that won't have that problem.





- **Keep your blood sugar in control.** High blood sugar can cause thirst.
- **Do an extra treatment to take off fluid.** Your clinic may let you do this, or for home HD, never skip 2 days in a row.
- **Be sure your ultrafiltration rate is safe.** UFR is how fast water is pulled out of your blood. A lower UFR is less likely to stun your organs and cause harm. Use this tool to see if each treatment is safe. (www.homedialysis.org/ufr-calculator).

Hernia

A hernia is a weak spot or gap in a muscle in your belly or groin. You can be born with a hernia. Or, you can develop one later in life. Heavy lifting can lead to hernias, and so can pregnancy. When you do PD, the fluid in your belly puts pressure on your muscle wall from the inside. This can lead to a hernia. If you see a new bulge, tell your doctor.

- **Ask your doctor *when* you need to have surgery.** Most hernias need to be fixed, but some can wait for a while. There is a rare risk that part of your bowel will get caught in a hernia, which could cut off its blood supply. This is a medical emergency called a “strangulated” hernia. Most of the time, you can set up a hernia repair for a time that will work for you and your job.

- **Find out if you have a weight limit.** A weight limit may affect your job if you need to move things from place to place.
- **Talk to the surgeon about how the repair will be done.** Many people have had problems when synthetic mesh was used to fix a hernia. If mesh is your best option, you can ask for animal tissue mesh, which your body will absorb.
- **Plan your treatment option for after surgery.** You may be able to keep doing PD with low-volume exchanges while you stay flat. Or, your doctor may want you to do HD for a while until you heal.

Upset Stomach or Vomiting

Kidney disease can cause nausea and vomiting, which can make it hard to focus on work. You would need to stop what you are doing to go to the restroom. Co-workers could be nervous to be around you for fear they might catch what you have.



- **Ask to see your blood test results.** When wastes build up, you can have nausea and vomiting.
- **Find out if any of the meds you take have a side effect of nausea or vomiting.** Some drugs can cause this, and there may be substitutes your doctor could prescribe.



- **Talk to your doctor to see if there may be other causes.** Problems like slow gastric emptying, reflux, gallbladder disease, an ulcer, etc. can cause nausea or vomiting.

Sleeping Too Much or Too Little

You may have a hard time falling asleep. Or, you may wake in the night and have trouble falling back to sleep, or waking up and staying awake for the day. Poor sleep can cause fatigue, depression, irritability, poor mental focus, and work errors. Poor sleep can raise your blood sugar if you have diabetes, too.

- **Check drugs you take for side effects of sleep problems.** A number of drugs can cause you to feel very sleepy—or too wide awake to fall asleep.
- **Get tested for sleep apnea and restless leg syndrome.** Either of these can cause poor sleep.
- **Learn about good “sleep patterns”** in [Module 12: *Staying Active with Kidney Disease*](#).
- **Learn ways to relax.** Relaxation therapy can teach you to relax each muscle in your body, from your feet to your head to help you fall asleep. Biofeedback tracks stress with a sensor,



so you can see your level of stress and try to reduce it.

- **Try cognitive behavioral therapy (CBT).** CBT can teach you how your thoughts affect how you feel and act. When you learn how to turn negative thoughts into positive ones, you can feel and do better.

Be a Player on Your Care Team

When you see your doctor and the rest of your care team, tell them how much it matters to you to keep your job. They focus on your health and may not think about things in your life that you care about—like work. Here are some tips.

- Keep a notebook of questions you want to ask and the answers you get.

“My husband had a great employer when he was diagnosed with kidney failure. His employer let him work half-days for the month it took us to complete training for home hemo. When a transplant came up, his employer kept his job for him through the 2-month recovery and let his fellow employees contribute PTO hours. We were very thankful for how we were treated by them. A year after his transplant, he was laid off due to a slowdown in work. Even that turned out to be a blessing, as he qualified for re-training/one year of schooling. He is now back working full-time with benefits. It is possible, so don’t lose hope!”





- Ask the doctor to tell you things in plain language. Ask questions if you don't understand.
- If you don't sleep well, see if your doctor has any thoughts.
- Share side effects that affect your work. Your doctor may change the dose or timing of a med, switch meds, or tweak your treatment so it works better for you.
- Track your blood tests and find out what it means when they are out of range. Learn how in [Module 7: Understanding Kidney Lab Tests](#).

Use the Family and Medical Leave Act (FMLA)

When you need time off from work for doctor visits, tests, etc., FMLA may help. FMLA lets you take up to 12 weeks of leave in a year to care for yourself or a close family member. You don't have to take FMLA leave all at once—you can take less than a full day at a time. Hospital stays, home dialysis training, in-center treatments, or a transplant are other reasons to take FMLA if you can.

FMLA leave is not paid. An employer can require you to use paid time off first. But, when you use FMLA leave, it protects your right to come back to your job, and your right to promotions, raises, and a health plan. You might have to pay for the employer part of your health plan, though, while you are on leave—not just your part.

What to Tell an Employer About Your Health

You do not have to tell an employer about your health at all. *No law or rule makes you do this.* Can you show up when you need to be at work? Do your job tasks as well as you can? Treat customers and coworkers well, so your company looks good? Then, you are the kind of worker an employer should want. Most of the time, a boss wants to keep a good worker. Even if you feel you are not at 100%, what you know and can do can mean that an employer should want to keep you. Hiring and training new staff is costly, and takes time.





Can I Use FMLA Leave?

If you can check all three of these boxes, you may qualify:

- ☐ **My employer has 50+ staff within 75 miles of a workplace.**
- ☐ **I worked at least 1,250 hours for this employer in the past 12 months.**
- ☐ **I worked at least 12 months for this employer in the past 7+ years.**

For FMLA, try to tell your employer 30 days in advance. When you can't give 30 days, give as much notice as you can. Follow your HR steps to ask for leave. You don't need to tell an employer what your health problem is, but you do need to

give enough background for HR to know if your leave is FMLA-covered. You might say:

- “I need regular doctor and clinic visits.”
- “I'll need to take time off three times a week starting at 4:00pm.”
- “I'll need to be off for surgery and recovery for a month or so.”

Your employer may ask you to get your doctor to fill out a FMLA form. You'll have 15 days to return it. Your employer must let you know within 5 days of starting your leave if it is approved for FMLA. If not, your employer has to tell you why not.

Ask for an Accommodation If You Need One

You can ask for help to do your job when your health gets in the way. Kidney failure “counts” as a disability. This means that when your kidneys fail, the federal *Americans with Disabilities Act* (ADA) may protect you. Your company must have at least 15 workers. Your state may have laws to help you, too, even if you work for a smaller company. Under the ADA, employers must make some “accommodations”—it's the law. There are limits, though. What you ask for can't be a big burden to do, or cost too much. You can ask verbally or in writing. Just be sure to say that you need it due to your disability. Check the ones that might help you:

- ☐ An anti-fatigue mat or a stand-lean stool if you need to stand
- ☐ A stool so you can sit down for some tasks
- ☐ A scooter to get around large buildings
- ☐ An ergonomic work station so you can save energy
- ☐ Speech to text software if you can't use your hands to type
- ☐ Sound to text software if you can't hear





"I work because I both want to and need to. I can't imagine sitting home every day. I would lose my mind. I also happen to love my job and feel like I give back."

- ☐ Doors that open with a button, or a tweak to the hinges so you don't have to push as hard
- ☐ Change your job to trade some tasks for others you can do
- ☐ Change a policy to let you work in a way that does not tire you out
- ☐ Extra rest breaks or a longer lunch time to do a PD exchange
- ☐ A change in your work schedule or hours per week to allow time off for dialysis
- ☐ Moving your work space so it is closer to something you need, like a restroom
- ☐ A private place to do a manual PD exchange (e.g., a bathroom with a door that locks)
- ☐ A service animal at your work station
- ☐ A workstation space heater if anemia leaves you cold
- ☐ Work from home on some days to avoid the need to travel

"I work because I enjoy my job. I am a teacher. I work to keep a roof over my and my daughter's heads. I work because I am stubborn and won't let kidney disease take over my life."

You can ask your boss if there are open jobs in the company that match your skills, too. It's best to keep a job with an employer who knows you, when you can.

Once you ask for an accommodation, your boss should talk with you to learn more about what you need so a change can work for both of you. Rarely, a boss may ignore your request. In this case, write to HR to ask again—and this time be sure to mention the ADA. Tell them why your accommodation would not be a burden or cost much. If HR won't help, you can escalate.

Get your care team on board! Make sure they know how important working is to you. While work may matter to you, ***your care team won't know this unless you tell them.***

"I wish I hadn't stopped working, because finding a job again is extremely difficult."

When you have a health plan through work, keeping your job helps you and your clinic. So, they should be on board to give you the support you need. Even if your job does not come with a health plan, it still gives you income, structure to your day, a sense of accomplishment, and much more. When you earn more through work, your Social Security benefit will be higher when you retire. It is worth working when you feel well enough. Choose or switch to a work-friendly treatment. And, know that there are laws to protect you if you need them.



What You Can Do About Job Discrimination

Employers who worry that the company's health plan premiums will rise for everyone because of your costly health problem may try to force you out. Even if your work is just as good as it was, you may find that your reviews are not as good. It can be a challenge to prove discrimination vs. poor performance. Keep records that show the high level of your work. See if coworkers will vouch for you. Ask around to see if others have been treated like you are. Don't feel guilty! Half of all Americans have at least one chronic disease. You are not alone. Bring your concerns up with your boss. Keep notes, so you can share details and dates.

Your next step may be to call the Equal Employment Opportunity Commission (EEOC) at (800) 669-6820. The EEOC has upheld the work rights of people on dialysis. The *Fiscus v. Walmart* case found that the ADA protects those on dialysis.



An employee rights attorney may be able to help you. These lawyers advocate for workers' rights of workers. Look for a link at the back of this module to find one near you.

States have civil rights agencies to enforce laws that protect workers. You can find your state's agency in the back of this module.

How to Get Back to Work

Getting back to work after any sort of break takes a plan. You want to feel well, know what sort of a job you want, and do your homework. The good news is, there is a lot of help out there that you may not know about. Here are some tips to get you started.

"I work because it helps my mental health. Working makes me feel better. I have to work to preserve my sanity. It's hard, but for me it's worth it. Plus, I like to shop!"



Be Physically Ready to Work

Moving more can help you build up the energy you need to get through a work day. To work, you need to feel as good as you can from day to day. You need to have an energy level you can count





on. Learn more in [Module 12: *Staying Active with Kidney Disease*](#). You may be able to keep doing the same kind of work you were doing, with or without accommodation. Or, you may need to prepare for a new kind of job.

Be Emotionally Ready to Work

Anxiety or depression can sap your energy to find or do a job. And, either can make it hard to put your best foot forward to an employer. Most of all, believe in yourself and in what you can do. When you feel confident, you help others to see your value. You can also try:

- Yoga, tai chi, or meditation may calm your mind.
- Joining a support group.
- Talking with a mental health professional. Some health plans cover counseling or mental health centers near you may have sliding scale fees based on your income.
- Meeting with your clinic social worker. S/he is trained to do counseling and does not cost extra.



Have a Treatment Schedule that Allows You to Work

A transplant is the most work-friendly treatment, because it only takes time out of the work day for clinic visits. Home dialysis is next, in part because you get to choose the days and times. You can change the days and times to fit your work schedule.

Find Out Which Jobs Might Suit You

To go back to work in your same field, be sure your skills and knowledge are up to date. Find out what has gone on since you left, and see if you need to take a refresher course. Or, you may want—or need—to switch jobs. The work and life skills you have may transfer to something new in ways you may not have thought of. Public and private vocational rehab programs have counselors who can assess you to find out if you need more education or retraining to get a job that fits your needs, skills, and values.

Boost Your Job Chances with Education

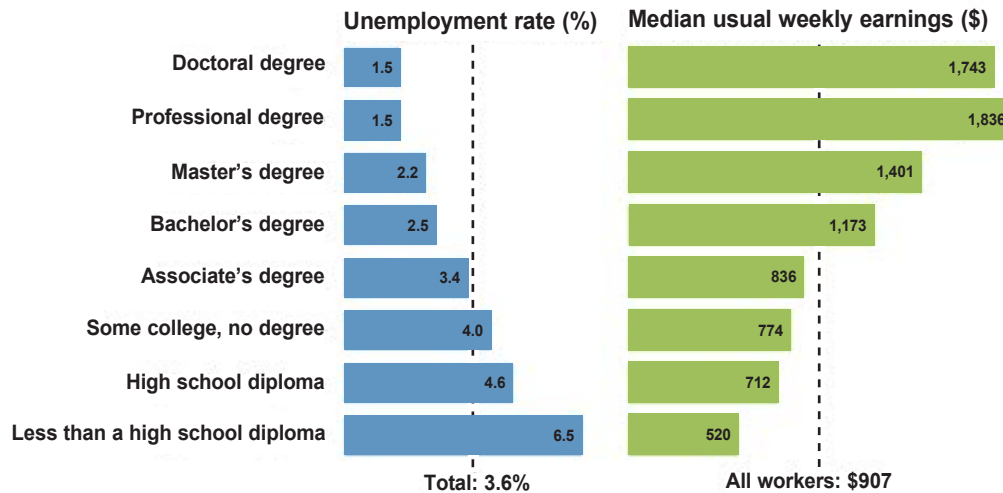
The Bureau of Labor Statistics tracks education and weekly earnings. According to their records, more education is linked to higher weekly earnings as shown in the bar graph on the next page.

More years on the job tend to bring higher pay—and more education can also help you find a job and bump up your income.

Trade, college, or advanced degree *in an in-demand field* may be a good investment. The fields in demand change all the time; you can search with Google to see what's hot now.



Unemployment rates and earnings by educational attainment, 2017



Note: Data are for persons age 25 and over. Earnings are for full-time wage and salary workers.
Source: U.S. Bureau of Labor Statistics, Current Population Survey.

“We may need to use our old skills in new ways. A floor nurse may need to look at work as a case manager. Or, an accountant may use other skills to run a small business. Vocational rehabilitation may be able to help. Employers may be more than happy to accommodate a good employee. Or we may be able to turn a hobby into a paid job. The motivator has to be a better quality of life, not just looking at a number of hours paid per week.”

Volunteer to Build Skills

Volunteer work can be a good step toward getting back to paid work in your own field or a new one. You can help a non-profit and find out what you enjoy and where your strengths are at the same time. You can make new contacts, too—which can help if you will need new references. Tasks may be able to be done on your own schedule. You will need to be able to honor your time commitment, though. So, you may want to start with just a few hours a week and build up as you see how your stamina is.

How do you find a group to volunteer for? Think about what you love and are passionate about: Children? The environment? People with kidney disease? Animals? Social justice? There are one or more groups for just about any cause you can





imagine. Google your interests and call local groups that fit to see what they need.

Temp-to-Hire Work or an Internship

Temp work can get you in the door. It gives you a chance to see if you like a company and the work you would do—while you earn money. A temp agency will find you jobs and pay you. Assignments can last from a day to a few months. A company that likes your work and has an open job may choose to hire you. Even if they don't, you can make contacts and update your references. Internships are also a way to try on a job for size and build your contacts. Internships should be paid, though some still are not.

Follow the Path to a New Job

Some of the steps for finding a new job are the same for most of us, with or without health issues. We have summed them up here. And, you can learn more from books like, *What Color is*

Your Parachute, or from websites. The key to success is to keep in mind what YOU bring to an employer—not what they can do for you.

Freshen Up Your Resumé

Someone from HR may spend just a few seconds with each resumé when a big pile of them come in for a job. Improve your chance for an interview by using each of these steps:



- Avoid **graphics or borders** — they detract from information about you.
- Use a **classic, easy to read font**, and clear headers.
- Put your **contact information** (address, email, phone number) at the top so an employer can find it fast.
- When you have little **experience**, add a one sentence job objective.
- If you have a year or more of **experience** in a field, include a short summary to highlight your best assets.
- List your **education** first, but only list your GPA when it is 3.0 or higher.



- Use **action words** to describe what you've done—and focus on the results you've gotten.
- Bold your **title** or the company name, whichever has more clout, and add a bullet list of what you did.
- Use the **exact buzz words or phrases** from job listings, like “team player,” self-starter,” “leader,” etc., are clues to what HR departments will look for. Include them as-is to boost your chance for an interview.

Keep the **length** of your resumé to two pages or less, unless you have decades of work and apply for a very senior job.

- Triple check **spelling** and grammar. A mistake in a resumé will look like lack of attention to detail.
- Keep the **format** consistent. Have the same points in the same order for each job or skill you include.
- Have someone you trust **review** your resumé to see whether it makes sense, or could be stronger.

Research Possible Employers

Today, it is easy to research employers. Use Google to find open job listings. Read reviews by employees or former employees. You can even see what salaries may be for positions like the ones you are looking for. You can search for the top companies near you, too.

Once you know where you might want to work, seek out people who work there now, and ask for an **informational interview**. You can find targets online, through other people you know, or through your school. This is not a job interview.



Your goal is to learn more about what a job in that field might be like from day to day. In just 20 minutes or so, you can find out things like:

- What are the most rewarding parts about working in this field?
- How did you choose this company vs. other competitors?
- What is the company culture like?
- What skills do you think have helped you the most in your position?
- What would you advise me to do to get started in this field?

Respect people's time. Stop asking questions when you said you would—and, send a thank you note afterward. Email is fine.

Network

Once your skills and contacts are up to date, you can start to network. Many jobs are never advertised—and people often like to work with someone they know. Which of these ways to network might you want to try?





- **Tell family, friends, neighbors, and people you meet** that you are looking for work.
- **Reach out to contacts from your work days**, especially those who gave you a good reference.
- **Set up a profile on LinkedIn.com** to connect with people. Some of your contacts may have moved on to new jobs where they could help you. You can ask people you know to link you to others they know, too.
- **Search online job boards.** Narrow your search by adding filters for job type; full-time, part-time, or contract; a salary range; and location. Look under Resources for some job boards.

Interview

Practice your interview skills to ease your nerves. Look for some common questions online and ask a friend to help you. Ask your friend to tell you how you did. If you have been out of work for a year or less, don't bring it up in a cover letter or interview. If you are asked, focus on things that you did during a gap. Perhaps you took care of children or parents, volunteered, tutored, or coached. Maybe you learned a new skill or language, or grew your contacts. If you have not done anything during the gap to put on your resume, start now.

In a real interview, keep the employer's needs in mind. Focus on what you *can* do—not on what you can't. Help the interviewer see what you bring that will help the company to thrive.

Companies need to find workers who have a set of "hard skills." These are skills that you go to school or get a certificate for, like a degree or a software program. "Soft skills," on the other hand, help you to work well with others. These are in high demand, since a lot of work is done by groups of people. So, when two candidates both have the same hard skills, the one with more soft skills may get the job. Know your soft skills—and think of a few stories you can share to show how you use them.

Which of these soft skills would you say you have?

- ❑ **A great attitude.** I stay positive, even when I hit challenges.
- ❑ **A strong work ethic.** I believe in the value of hard work.
- ❑ **A desire to contribute.** I want to be a part of something bigger than myself, and to make a difference.
- ❑ **Big picture thinker.** I look for patterns, and like to sort out goals, strategies, objectives, and tactics.
- ❑ **Communication skills.** I can explain complex topics, motivate a team, or share tough news in a caring way.
- ❑ **Conscientious.** I keep track of my tasks and make sure they are done and passed on to the next person.
- ❑ **Creative.** I look at things differently than other people, and come up with new ways to solve problems.
- ❑ **Decisive.** I consider all of the options and use the data I have to make good choices.



- ❑ **Detail oriented.** I like to connect the dots to be sure each process goes as smoothly as it can.
- ❑ **Flexible.** I am open minded and willing to look at things in new ways.
- ❑ **Friendly.** I am approachable, and like to hear the views of others.
- ❑ **Humble.** I make sure to give others public credit for their ideas.
- ❑ **Self-starter.** I don't need someone to hold my hand—I will jump right in and get started.
- ❑ **Integrity.** I can be trusted to always do the right thing.
- ❑ **Leader.** I can motivate a team to work harder and smarter and get more done.
- ❑ **Negotiator.** I am good at seeing common ground between people and finding the win-win.
- ❑ **Responsible.** The buck stops with me: I own my projects and see them from start to finish.
- ❑ **Mentor.** I enjoy guiding others to help them achieve their best work.
- ❑ **Team player.** I know when to talk and when to listen, and how to get the best performance out of my team.
- ❑ **Time manager.** I can work under pressure and meet deadlines, even when there are lots of moving parts.

How to Take a Drug Test When You Don't Make Urine

Employers can test you for drugs or alcohol. They have to treat all prospects or workers the same way, and they must follow the law. In some states, employers can do random tests. In others, they must have a reason to think that you may be using drugs. Drugs that you use on your own time can show up on these tests—and can keep you from being hired, or get you fired.

Urine is the most common type of test. When you don't make urine and you want the job, you will need to make a choice. You can tell a tester that your kidneys don't work and ask if you can do the test another way. Or, you can just ask for a different test



without saying why you need one. The tester may or may not be able to help you, but it's worth a try.

- A **saliva** test is easy to do and gives fast results.
- Less common tests include **blood**, **sweat**, or **hair**.

The ADA does let employers do drug tests before a job offer is made. They do have to warn you that they will ask for a test. Prescribed drugs you take may show up on drug tests. Employers can't use a positive result for an ADA-protected health problem to not hire you. But, in this case, you would need to share that you have kidney disease. An employee rights attorney can tell you whether your drug test was legal.





Should you mention your health in an interview?

- **Some people do.** They say they would not want to work for a company that would not hire them due to kidney disease.
- **Some people do not.** They choose to prove themselves to an employer before they talk about their health.

The choice is yours. Remember, you do not have to say anything at all. No law or rule requires you to.

Resources to Help You Find or Land a Job

Vocational Rehabilitation (VR)

The purpose of VR is to help people get back to work. When you apply, a screening person will want to know about:

- Your health and how it limits you
- What sort of work you have done before
- Your interests, skills, and what you enjoy
- Why you need help to find a job
- What services you will need to help you.

A VR counselor may never have worked with someone who is on dialysis or has a kidney transplant. Expect to have to teach him or her about your health challenges. S/he may believe that:

1. Kidney failure is terminal.
2. You can't work when you need dialysis.
3. You don't need help to find a job when you have a kidney transplant.

None of these are true! Ask your dialysis clinic or transplant social worker to advocate for you if you can't get through.

When you meet with VR, be on time for all of your appointments. This helps to show that you would value a job. Your clinic may need to change your appointment or treatment time.

Some state VR agencies have more funds than others. All of them must at least test your work skills and ask you your needs, and goals. Each state has three levels of priority:

1. The most significantly disabled
2. Significantly disabled
3. Others

Kidney failure counts as a "significant disability," so when you get SSI or SSDI checks, you are at least level 2. When you qualify, state VR counselors can help you to:

- Make a plan for services
- Pay for classes or work training or retraining
- Make changes to your home so you can work there
- Get special equipment you need to work
- Help you find and keep a job



Tax Credits for Your Employer

The Work Opportunity Tax Credit (WOTC) can bring from \$2,400 to \$9,600 for employers who hire you, if you:

- Get SSI
- Get Temporary Assistance to Needy Families (TANF)
- Get SNAP (food stamps)
- Have been out of work for at least 27 weeks
- Received or get help from VR or an employment network service
- Are a veteran
- Are an ex-felon in your first year of conviction or release

Tell an employer if you are in one of these groups! S/he may not know about this benefit.



Social Security Work Incentive Programs

When you get SSI or SSDI, you can ease back in with one or more of many work incentive programs. Each program is listed in the table on the next two pages. Dollar amounts change every year.

Conclusion

We hope you have learned some new ways to think about yourself and your skill set. You are unique and you have value! Kidney disease should not stop you from reaching your dreams, even if one of your dreams is to keep your job or find a new one.

You can do this! Find helpful web links in the Personal Plan at the end.





Program	SSI	SSDI
Trial Work Period You can work and earn as much as you can for 9 months in a 5-year time frame—and still get a full check. As of 2020, you use one trial work month when you earn \$910+ or work 80+ hours that month. Dollar amounts change each year.		✓
Extended Period of Eligibility This lasts for 36 months after you use up your 9-trial work months. You can still get a full check for each month your earnings are not “substantial.” In 2020, that means less than \$1,260, or \$2,110 if you are legally blind. Dollar amounts change each year.		✓
Continuation of Medicare You get to keep Medicare if you work while on dialysis. With a transplant, you lose it after 3 years unless you are 65 or older or disabled by some other cause. This program lets you can keep Part A for free for 7.75 years after the 9 months of trial work—even though your SSDI checks will stop. Having Part A lets you have Part B if you pay the premium.		✓
Unincurred Business Expenses When you are self-employed, the IRS only lets you count costs that you paid for or owe. Social Security follows IRS rules most of the time. But, with this program, they deduct some business-related costs you did not have to pay for. Then, they look to see if your work earnings count as “substantial.” These include goods or services someone gives you to help your business. They can deduct the value of a computer, phone, or work equipment Vocational Rehab gives you. They can deduct the value of free rent or unpaid work friends or family do for your business, too.		✓
Special SSI Payments for People Who Work (Section 1619a) You can keep your work earnings and some SSI cash until you reach a “break-even point.” To see when your earnings from work will stop your SSI cash, double the SSI federal benefit for the year (\$783 in 2020) and add \$85. In 2020, this is \$1,651. Dollar amounts change each year. You can find the federal SSI benefit for this year at www.ssa.gov/oact/cola/SSI.html .	✓	
Medicaid While Working (Section 1619b) You may be able to keep Medicaid even if you lose your SSI cash. This program lets you have a higher income than those who don’t work. Exactly how much you can earn varies by state. See www.ssa.gov/disabilityresearch/wi/1619b.htm .	✓	
Earned Income Exclusion Social Security excludes the first \$65 you earn from work each month. They also deduct \$20 from any unearned income you receive, such as from SSI. www.ssa.gov/oact/cola/incomexcluded.html	✓	



Module 17 – Kidney Failure and Your Work Life

Program	SSI	SSDI
Student Earned Income Exclusion If you are under age 22, Social Security will pay your full SSI check any month you are in school, working, and earn up to \$1,900. This will go on until you make \$7,670 in 2020. Dollar amounts change each year.	✓	
Expedited Reinstatement For 5 years, Social Security can re-start your checks with no wait when you have to stop working. The cause must be the same health problem that got you SSI or SSDI in the first place.	✓	✓
Impairment-Related Work Expenses (IRWE) IRWE are costs you must pay to be able to work when you are disabled. If Social Security approves them, IRWE lower how much they will count of your work earnings when you get SSI or SSDI. There are lots of examples of IRWE: Prescribed drugs and health plan copays. A home dialysis helper. Feeding and caring for a service dog. A driver or taxi to get to work if you can't drive due to your disability.	✓	✓
Continued Payment under Vocational Rehabilitation or Similar Program (Section 301) You can keep SSI or SSDI if your health improves while you are in a VR program. <i>(NOTE: If you are getting SSDI after your transplant, you can keep Medicare more than 36 months, as long as you are in a VR program that is expected to get you a job where you make too much to get SSDI.)</i>	✓	✓
Plan to Achieve Self-Support (PASS) You can set aside some of your resources or cash from SSI or SSDI in some cases into a separate account for a work goal that will reduce or end SSI or SSDI. A work goal might be to start a business, go to school, or get training for a job where you will earn too much to keep getting SSI or SSDI. You can talk with someone to set up a PASS at www.socialsecurity.gov/disabilityresearch/wi/passcadre.htm .	✓	✓





Take the Kidney Quiz!

You'll see how much you're learning if you take our quick kidney quiz. It's just 10 questions. How about it? (Answers are on page 17-3.)

- 1. Why is it a good idea to keep your job if you can?**
 - a) Work will tire you out so you don't mind dialysis as much.
 - b) Work boosts your self-worth and your income.
 - c) Work keeps you from watching TV all day.
 - d) Work is a bad idea. You should focus on your treatment.
- 2. What makes a treatment work-friendly?**
 - a) It drains your energy and takes a lot of time.
 - b) It gives you cramps and brain fog.
 - c) It lets you feel well and control your schedule.
 - d) It limits what you can eat and drink and makes it hard to travel.
- 3. Which is the least work-friendly treatment for kidney failure?**
 - a) In-center dialysis
 - b) Home hemodialysis
 - c) Peritoneal dialysis
 - d) Transplant
- 4. How much may Social Security Disability Insurance replace of your work earnings?**
 - a) 80%
 - b) 60%
 - c) 40%
 - d) 20%
- 5. What is one thing you SHOULD NOT do to make in-center dialysis more work friendly?**
 - a) Follow your fluid limits.
 - b) Follow your meal plan.
 - c) Take your meds as prescribed.
 - d) Come late or leave early.
- 6. Which treatment choice makes you wait 3 months to get Medicare?**
 - a) In-center dialysis
 - b) Transplant
 - c) Home hemodialysis
 - d) Peritoneal dialysis
- 7. Feeling fatigued, dizzy, or washed out are symptoms that may bother you. What do they all have in common?**
 - a) Everyone with kidney disease gets them.
 - b) Each of them can be treated with a pill.
 - c) They can limit work and may be caused by harsh treatments.
 - d) They can all cause an itchy rash.
- 8. Which of these is an accommodation an employer might make to help you keep a job?**
 - a) Buy you an RV for work travel.
 - b) Get you first class plane tickets.
 - c) Give you a stool so you can sit down.
 - d) All of the above.
 - e) None of the above.
- 9. If you get SSI or SSDI, will you lose your check right away if you go back to work?**
 - a) Yes
 - b) No
- 10. What is a way to help you keep your job?**
 - a) Seek time off under the Family Medical Leave Act if you qualify for it instead of applying for SSI or SSDI
 - b) Ask for a workplace accommodation if needed
 - c) Know your rights and use the Americans with Disabilities Act if you need to
 - d) All of the above



Your Work Life Personal Plan

Work-friendly treatments

Check the ones you want to ask your care team about:

- | | |
|--|---|
| <input type="checkbox"/> Kidney or kidney-pancreas (KP) transplant | <input type="checkbox"/> Standard home HD |
| <input type="checkbox"/> Peritoneal dialysis | <input type="checkbox"/> Nocturnal HD (home or at a clinic) |
| <input type="checkbox"/> Daily home HD | |

Steps to a kidney or kidney-pancreas transplant

If you think a transplant is right for you, here are the **steps**:

1. Find a transplant program near you
2. Talk to transplant program and take medical tests to get on the list
3. Have a health plan
4. Find a living donor or wait for a deceased donor
5. Have the transplant
6. Recover

Steps to PD or home HD

If you need or choose dialysis, find the right treatment for you. It is your right to change treatments—or clinics or doctors—to get the care you need. Don't let anyone scare you away from the option you want! Making your life better is worth it. Here are the **steps**:

1. Use [*My Life, My Dialysis Choice*](#).
2. Find a clinic near you that offers the treatment(s) you want at www.homedialysis.org/clinics/search.
3. Complete the training:
 - Clear the decks
 - Cook meals ahead for the week—or ask friends for casseroles or order take-out foods on your diet.
 - Tell your training nurse how you learn best.
 - Find support. www.facebook.com/groups/HomeDialysisCentral.
4. Set up your treatment room.
5. Receive your machine and first supply shipment.
6. Start dialyzing at home.

How to keep your Job

It is almost always easier to keep a job you have, where you and your work are known, than it is to try to find a new job. So:

1. Stay as healthy as you can. On hemodialysis, use this tool to be sure your treatment removes water safely and gently: www.homedialysis.org/ufr-calculator
2. Talk to your care team about any symptoms you have to see what you can do.
3. Use the Family and Medical Leave Act if you need to and your employer qualifies.
4. Ask for an accommodation if you need one.





How to get back to work or find a new job

1. Freshen up your resumé
2. Research possible employers
3. Network and interview
4. Use resources to help

Symptoms/Problems That May Bother You	I Rarely Have This	I Often Have This	I Always Have This	This Makes it Hard to Work
Fatigue, lack of energy*				
Faint, dizzy, weak*				
Can't think clearly*				
Short of breath*				
Feeling washed out after dialysis*				
Pain from a hernia*				
Muscle cramps				
Itching, dry skin				
Swollen hands, feet, or face				
Upset stomach or vomiting*				
Food tastes like metal; no appetite				
Feeling cold even when others are warm				
Sleeping too much or too little*				
Ammonia breath				
Foamy or bubbly urine				
Feel pressure when making urine				
Getting up at night to make urine				
Urine that is brown, red, or purple				
Medicine side effects				

*These symptoms/problems may be the most likely to make it harder to work.

Make sure to mention your hard and soft skills (below) to employers:

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> A great attitude | <input type="checkbox"/> Decisive | <input type="checkbox"/> Leader |
| <input type="checkbox"/> A strong work ethic | <input type="checkbox"/> Detail oriented | <input type="checkbox"/> Negotiator |
| <input type="checkbox"/> A desire to contribute | <input type="checkbox"/> Flexible | <input type="checkbox"/> Responsible |
| <input type="checkbox"/> Big picture thinker | <input type="checkbox"/> Friendly | <input type="checkbox"/> Mentor |
| <input type="checkbox"/> Communication skills | <input type="checkbox"/> Humble | <input type="checkbox"/> Team player |
| <input type="checkbox"/> Conscientious | <input type="checkbox"/> Self-starter | <input type="checkbox"/> Time manager |
| <input type="checkbox"/> Creative | <input type="checkbox"/> Integrity | |



Work-friendly Treatment Options

- *What Every Patient Needs to Know About Transplant*: www.unos.org/wp-content/uploads/unos/WEPNTK.pdf
- *My Life, My Dialysis Choice* treatment matcher: www.mydialysischoice.org/.
- *Help, I Need Dialysis!* book: www.lifeoptions.org/resource-library/help-i-need-dialysis/.

How to Keep a Job

- Learn more about the Family and Medical Leave Act: www.dol.gov/whd/fmla/employeeeguide.pdf
- Read about laws the EEOC enforces and how to file a discrimination complaint: www.eeoc.gov/employees/index.cfm.
- EEOC fact sheet on the ADA: www.eeoc.gov/facts/fs-ada.pdf.
- Find a lawyer near you and ask for a free call: www.lawyers.findlaw.com/lawyer/practice/employment-law-employee
- Learn your state laws that protect workers: www.civilrights.findlaw.com/enforcing-your-civil-rights/state-civil-rights-offices.html.

How to Find a New Job

- Learn about training, do self-tests to see what your skills are, and find jobs at CareerOneStop: www.careeronestop.org/
- Find help to reach your vocational goals: www.choosework.ssa.gov/findhelp/.
- Search Volunteer Match to find options near you: www.volunteermatch.org/.
- Look for internships: www.internships.com.
- Learn about the Fair Labor Standards Act and for-profit internships: www.dol.gov/whd/regs/compliance/whdfs71.pdf.
- Ready to create or update your resumé: www.careeronestop.org/JobSearch/Resumes/resumes.aspx
- Write a great resumé: www.theinterviewguys.com/objective-for-resume/
- Look for online reviews of schools on the Better Business Bureau site: www.bbb.org.
- The Department of Education tells you about student loans and grants: www.ed.gov/.
- Find the 20 fastest growing jobs and their salaries at www.bls.gov/ooh/fastest-growing.htm.

Online Job Boards

- CareerBuilder - www.careerbuilder.com
- Glassdoor - www.glassdoor.com
- Indeed - www.indeed.com
- Monster Jobs - www.monster.com
- ZipRecruiter - www.ziprecruiter.com

