

EMPLOYMENT

A Kidney Patient's Guide to Working & Paying for Treatment



Developed by the
Life Options Rehabilitation Program

Supported by the
Forum of End Stage Renal Disease Networks

Administered by the
Medical Education Institute, Inc.

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The information in this guide is offered as general background for people with kidney disease and does not constitute legal advice. Since government rules and laws cited in this booklet may change, contact the Social Security Administration (SSA) office, the Centers for Medicare and Medicaid Services (CMS), or other appropriate government office for current information. Neither the Forum of End Stage Renal Disease Networks, the Life Options Rehabilitation Program, nor the Medical Education Institute, Inc. are responsible for any loss in connection with, or as a result of, using this guide.

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INTRODUCTION

Introducing the Life Options Rehabilitation Program

In the United States, as many as 19 million people have kidney disease—and most of them do not know it. Every 6 minutes an American starts treatment for kidney failure. That's more than 240 people each day—people like you.

If you are reading this booklet, you or someone you care about probably has kidney disease. You may worry that life will never be the same—or even that life will not be worth living if dialysis is needed. If you are on dialysis, you may be putting your life on hold, waiting for a kidney transplant. But you don't have to wait. You can choose to live a good life with kidney disease or kidney failure. We're here to help you learn how.

The Life Options Rehabilitation Program is dedicated to helping people live long and live well with kidney disease. Life Options does research, develops free, research-based materials, and partners with other organizations to help patients live as fully as possible and reach for their dreams.

Life Options is guided by an advisory group of doctors, nurses, social workers, patients, researchers, dietitians, physical therapists, and others, and Life Options' work is based on the "5 E's:"



- **Encouragement** – Taking an active role in your kidney care will make you feel more hopeful and in control, and help you to do better.
- **Education** – Learning about your kidneys, how to protect them, and treatments for kidney disease will help you manage your health better.
- **Exercise** – Staying active can make you stronger, give you more energy, and improve your overall health and outlook.
- **Employment** – Working will give you more income, independence, a way to meet others, and often health insurance. Going to school, getting training, and volunteering are other ways to feel worthwhile and stay active.
- **Evaluation** – Setting short and long-term goals and tracking your progress will help you succeed.

We've written this booklet to show you some of your *life options* for paying for treatment, learning, working, and enjoying retirement.

Introducing the End Stage Renal Disease Networks

In 1972, when the Medicare End Stage Renal Disease (ESRD) Program was established and the U.S. government began paying for treatment of kidney failure, the ESRD Networks were created to oversee the quality of dialysis care. ESRD Networks' goals include:

- Helping people get treatment for kidney failure
- Helping people with kidney failure get quality care
- Resolving concerns about and improving satisfaction with care
- Helping people with kidney failure to enjoy a higher quality of life
- Encouraging people with kidney failure to take part in vocational rehabilitation programs and to work when possible

Some Network efforts related to working include:

- Collecting data on how many people with kidney failure are working
- Encouraging centers to schedule treatments around work and school
- Teaching people with kidney failure about rehab programs and working
- Offering programs and materials on work topics

If you have a problem with a dialysis or transplant center that you cannot work out with the center staff, call your local ESRD Network. You can

find a map of all of the ESRD Networks and a list of their phone numbers and addresses on page 89 of this booklet.

Parts of This Booklet

This booklet is divided into three parts:

1. Paying for Treatment of Kidney Disease

This section will explain Medicare, Medigap, Medicaid, health insurance, and other resources that can help you pay for care of kidney disease and kidney failure.

2. Living Productively with Kidney Disease

Even if you have health insurance, you may still worry about money. This section will tell you about options for work, school, volunteering, disability programs, and work incentive programs. We will also explain how these options work together.

3. Resources

In the last section of this booklet, you will find a glossary and a number of resources that help people with kidney disease and people with disabilities.

We hope this booklet will give you some of the answers you need. Just knowing what services and benefits are available and how to use them can help you make better choices about work, insurance, and financial planning. This gives you more time to focus on yourself, your family, your future, and your dreams.

Life with Kidney Disease

This booklet covers money and work issues for people at all stages of kidney disease. The Life Options Rehabilitation Program believes this information can show you what to expect so you have more control over your life with kidney disease.

The figure below is the *Life Options Kidney Disease Cycle*. It shows that kidney disease may one day progress to kidney failure. If this happens, you will need to make a choice about what treatment you want: dialysis (peritoneal dialysis or hemodialysis), a kidney transplant, or no treatment.

Once your kidneys fail, you are *always* a kidney patient, even if you have a transplant. Many people with kidney failure find that, over time, they may switch back and forth between different types of dialysis or from dialysis to transplant and back again. Some people have been doing this since the 1960s and are still doing well today!

Computers and Kidney Education

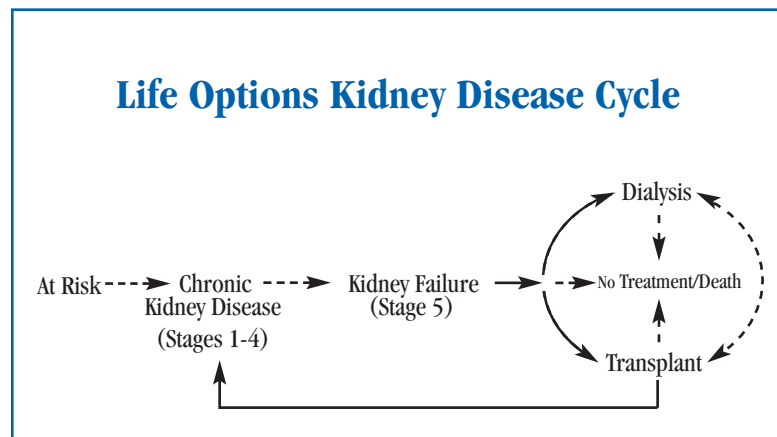
Each year, more Americans buy home computers. Maybe you have one and know how to use the Internet. We list a number of helpful websites in this booklet that offer free, high-quality information.

If you do not have a computer or know how to use one, here is what we suggest:

- Visit your public library and ask the librarian to help you
- Ask a family member or friend to look things up for you or—better yet—teach you how to do it yourself
- Use a computer in your doctor's office, dialysis center, or transplant center. If they don't have a computer for patient use, ask them to add one. Offices upgrade computer equipment often, and may be able to connect an older machine to the Internet for patient education.

If you prefer printed brochures and booklets, call the phone numbers we provide and ask for a copy. Check the

resources lists at the back of this booklet for names of organizations and how to get useful items.



Part I: Paying for Treatment of Kidney Disease

The system of payment for kidney disease and kidney failure is complex. It often involves Medicare, private insurance if you have it, and sometimes Medicaid, Medigap, state programs, and other resources. The three chapters in Part I of this booklet will help you sort out your options and explain how they work together.

- In Chapter 1, *Costs of Kidney Care*, we'll talk about the types of kidney care you are likely to need, like doctor visits, transplant exams, drugs, lab tests, etc.
- In Chapter 2, *Medicare, Medigap, and Medicaid*, we'll explain Medicare, Medigap, and Medicaid.

- Chapter 3, *Health Insurance*, covers health insurance, including what happens if you change or lose your job, and programs for children, military, and Native Americans.

No matter how much we tell you in this booklet, we cannot cover every possible case. Read this section, write a list of questions, and talk to your Medicare claims representative, insurance company billing office, personnel office at work, or social worker to get the answers you need.

CHAPTER 1 — COSTS OF KIDNEY CARE

Like any other chronic illness, kidney disease—at any stage—involves costs. Learning about your rights and responsibilities for these costs is part of having kidney disease and kidney failure. Depending on your stage of kidney disease, the costs of care may include:

- Doctor visits
- Blood and urine tests
- X-rays, ultrasounds, biopsies, and other tests
- Drugs
- Surgery to place a tube in the abdomen for peritoneal dialysis, or surgery to create a special blood vessel (vascular access) for hemodialysis
- Dialysis treatments
- Travel to doctor visits, a transplant center, or dialysis
- A kidney transplant and transplant drugs for the life of the organ

We'll cover each of these briefly in this chapter to give you a better idea of what to expect.

Doctor Visits

At any stage of kidney disease, you may have doctor bills. When the bills arrive, check them to be sure that you or your insurance are not billed twice for the same care, or billed for care

you did not receive. Ask questions if you don't understand a bill.

If you do not have health insurance to cover doctor visits, one of these resources may help you:

- Your spouse or parent (if you are a dependent) may be able to add you to their plan. Choose family coverage when you or your spouse start a new job, in case you need the insurance later.
- Your area may have a free health clinic. Look up the public health department in your local phone book or call the United Way in your area.
- You may be able to get Medicaid, a health insurance program for people with low income. In California, Medicaid is called MediCal.
- Some states have a high-risk insurance pool for people who cannot get other health insurance.

For a kidney transplant, doctor bills may arise for you *and* for a living donor. Medicare will pay for a possible donor's transplant exam. If you do not have Medicare, your insurance may pay some or all of the costs of donor exams. In some cases, you will have to pay for these exams yourself. The cost can be \$1,000 or more, and you may need to have more than one person tested before you find a matching donor who will give you a kidney.

Ask your transplant team what the cost will be so you can plan ahead. If you meet all the requirements, Medicare can be backdated up to one year from the date you file for it, so that the cost of the exams for you and a living donor can be covered.

Blood and Urine Tests

Kidney disease is often found through blood or urine tests. These tests also measure how fast kidney disease is progressing and how well you respond to treatment. When you have blood and urine tests, ask for the results and keep them in a notebook. Learn what each one means so you can track your own health. Medicare pays for many lab tests. If you have other insurance, be sure to have the blood for your lab tests drawn where your insurance will pay.

X-rays, Ultrasounds, Biopsies, and Other Tests

Your doctor may order a number of tests to see what is causing your kidney disease and how your kidney disease is affecting your body. Medicare and/or insurance covers some or all of the costs of these tests, but you may still have out-of-pocket expenses.

Drugs

Whether you have kidney disease or kidney failure, you will probably have to pay full price for your drugs unless you have Medicaid or private insurance. If you can't afford your drugs, tell

your doctor. He or she may prescribe a cheaper drug, give you samples, or connect you with a drug assistance program. If you are on dialysis or have a transplant, your social worker can be a resource to help you find options to pay for drugs.

Kidney Disease Drugs

Even early in kidney disease, some drugs are important—and they may be costly.

- Certain kinds of blood pressure pills called ACE-inhibitors or ARBs can slow the progression of some types of kidney disease.
- Anemia (a shortage of red blood cells) starts early in kidney disease. It causes severe fatigue and weakness—sometimes bad enough to make you stop working. Anemia can damage your heart if it is not treated, and treatment can give you more energy. Anemia treatment includes injections of a drug called erythropoietin (Aranesp[®], Procrit[®], or EPOGEN[®]). Only about one in four people with kidney disease who has anemia is treated for it before kidney failure.

Kidney Failure Drugs

In kidney failure, blood pressure pills, phosphate binders, and iron may be added to a long list of drugs you take for other health problems, such as bone disease.

Transplant Drugs

A kidney transplant is alien to your body. For this reason, your immune system will try to reject the foreign invader. This battle between your body and the new kidney will go on as long as the kidney is present.

To prevent rejection and loss of the new kidney, you will need to take drugs to suppress your immune system.

According to Medicare, these immunosuppressants cost as much as \$17,000 per year—and must be taken for as long as the kidney is working. Medicare may pay for some transplant drugs, for a period of time. Plan ahead for these costs and talk to your transplant team about your options for drug payment before you have a transplant.

Pharmacy Assistance Programs

Some of your drugs may be made by companies that have programs to help people with low income and no drug insurance:

- The Pharmaceutical Research and Manufacturers of America (PhRMA) prints a list of these programs by drug and company at www.helpingpatients.org.
- The Medicare website (www.medicare.gov/Prescription/Home.asp) has a list of programs to help you pay for prescribed drugs. You can search this list by typing in your zip code or state.

- The American Kidney Fund (AKF) has a program to help some people get discounted drugs. Your social worker can help you apply.
- Some National Kidney Foundation (NKF) chapters help patients pay for some drugs or supplements.

The Medicine Program, at www.medicineprogram.com, charges \$5 per drug to help you apply for pharmacy assistance programs. If programs deny your application, you can ask for your money back.

Discount Drug Cards

If you have Medicare, meet income limits, and don't have prescription drug coverage, some drug companies offer discount drug cards. As of June 2003, these include:

- LillyAnswers (Eli Lilly & Company) – (877) 795-4559 or www.lillyanswers.com
- Novartis Care Card – (866) 974-2273 or www.NovartisCarePlan.com
- Orange Card (GlaxoSmithKline) – (888) 672-6436 or <http://us.gsk.com/card/>
- Pfizer for Living Share Card™ – (800) 717-6005 or www.pfizerforliving.com
- Together Rx™ (Abbott, Aventis, AstraZeneca, Bristol-Myers Squibb, Novartis, GlaxoSmithKline, Janssen, Ortho-McNeil) – (800) 865-7211 or www.together-rx.com

State Medicaid Programs

Medicare has a list of state programs that help pay for drugs for seniors or others who qualify (see www.medicare.gov/Prescription/Home.asp).

Chapter 2 will cover Medicaid in more detail.

Surgery for Dialysis

If your kidney disease progresses, you will be able to plan better if you learn about your treatment options. Unless you can get a transplant before you need dialysis, you will need to have surgery to make peritoneal dialysis or hemodialysis possible. You can read about treatments and types of dialysis accesses at www.kidneyschool.org, or look for kidney classes in your area.

Before you have surgery, ask your doctor or hospital who might bill you and what it will cost. Make sure that you have any insurance forms you need and that the hospital and all doctors are covered by your insurance plan. If you do not have insurance for this surgery, you may need to make a payment plan with the hospital and pay off your bill over time.

Expect to get several bills from doctors, surgeons, and the hospital for your access surgery. Over time, you will get bills for doctors, labs, x-rays, dialysis centers, pharmacies, medical suppliers, and more.

Dialysis Treatments

If your kidneys fail and you need dialysis, you may be able to get Medicare—at any age—through the Medicare End Stage Renal Disease Program. We'll talk about Medicare in Chapter 2. Hemodialysis can cost more than \$56,000 per year, according to Medicare. Peritoneal dialysis can cost more than \$46,000 per year.

Every dialysis center has a social worker. If you have kidney disease and are worried about paying dialysis bills, ask your nephrologist if you can talk with the dialysis social worker. Meeting with the social worker before you start treatment can help you learn about your health insurance and what programs might fill the gaps.

Read Your Medical Bills

When you receive many bills and notices, you might be tempted to pile them in a shoebox and ignore them. Don't! It is your job to read your bills to be sure they are correct.

Each bill should say who is billing you, what the bill is for, and whether insurance has been filed. If not, call the billing office to be sure your insurance information is correct and a claim has been filed. Keep a notebook and write down the date, who you talked to, their phone number, and what was said.

Save your bills or insurance notices—you may need them later. Create a filing system. Keep bills and payment notices together to help you track who has been paid and who has not. You may want to copy payment notices if more than one claim is paid on a notice.

Andy

Husband . . . volunteer . . . public speaker . . . full-time employee. These are just a few of the roles



that 36-year-old Andy Stahmer plays in his life; proof positive that having kidney failure since 1993 has not hampered his active lifestyle.

Andy was diagnosed with kidney disease in 1983, and had a decade to get used to his kidneys failing. “Because my kidney failure took 10 years, I never felt very different once I had to start dialysis,” he says. “I continued working.” Andy has worked at the same radio station since then, currently full-time as a Community Service Coordinator/ Producer—a title he’s held for 5 years. “I know I’m lucky to work full-time, because not everyone on dialysis can,” he says. His current schedule has him working Monday through Friday, 2:00–10:00 p.m., and dialyzing on Monday, Wednesday, and Friday from 6:00–11:00 a.m. (which includes his travel time).

However, working hasn’t been a completely glitch-free process. Several years ago Andy had to switch from peritoneal dialysis to in-center hemodialysis after he started retaining too much fluid. “Switching modalities was a big adjustment. I missed a total of about a month of work,” recalls Andy. “My employer

was great—they didn’t count my sick days and I continued to get paychecks.”

Andy continues working for a variety of reasons. “I work to make money, but also for the self-worth aspect and to give back and pay taxes,” he says. “I know some people don’t have a choice, but it’s hard for me to imagine someone going to dialysis and then staying home all day—that’s too much time to dwell on your illness.”

This desire to give back is also what has led Andy to become an active volunteer. “I received my Medicare statement one month and reviewed the cost of keeping someone on dialysis,” he remembers. “Suddenly I felt the need to give back. Working covers most of my living costs and bills, but I wanted an extra way to give back for what isn’t covered.”

Andy currently serves on the Public Transportation Advisory Committee of Lawrence and is the Kansas representative on the Medicare Rights Center Consumer Advisory Board. He also serves as a presenter for the Missouri Kidney Program, noting, “I know what questions patients have and I’ll come right out and tell them things they want to know.” In what little free time he has, Andy dabbles in amateur radio and also finds time to exercise. “My work is 45 minutes from home, and I try to walk one way at least three times a week,” he says.

Staying active has been the key to success for Andy, and Andy believes the key to success for new kidney patients is getting answers. “Talk to as many people dealing with kidney failure as you can,” advises Andy. “People who are not on dialysis can’t tell you what it’s like—you need to ask people who know first-hand.”

Travel To and From Dialysis

If you decide to do peritoneal dialysis at home, you will need to travel to the clinic for a week or two of training, and then for monthly visits. If you do hemodialysis at a center, you will need a way to get to the center and back at least three times each week. You may have a car and be able to drive yourself. Or, you may need to rely on—and pay for—a bus, taxi, or car service.

There may be some options in your area for rides to and from dialysis. Your dialysis social worker is most likely to know about local resources. Some ideas may include:

- Form a car pool with others who drive to and from treatment.
- Use Easter Seals' Project ACTION Accessible Traveler's Database, which lists transportation services by state and city. Call (202) 347-3066, TDD (202) 347-7385, or visit www.projectaction.org.
- Post an ad on a bulletin board in your grocery store, local senior center, or newspaper.
- Ask at church or your local United Way for a volunteer to drive you. If you can afford it, you might offer to pay for gasoline.
- Check with Medicaid if you receive it: in some states, Medicaid will pay for non-emergency medical transport.
- Your state may have a kidney program that may help pay for transportation.

Kidney Transplant

If you need a kidney transplant, you may be able to get Medicare—at any age—through the Medicare End Stage Renal Disease Program. The date when you apply for Medicare can affect your benefits. We'll talk about Medicare in Chapter 2. According to Medicare, a transplant can cost more than \$85,000.

To begin the transplant process, you will meet with the transplant team to talk about your health and the steps to follow. The social worker will talk with you about emotional, social, work, and money concerns. The social worker and/or financial counselor will explain the costs, talk with you about your current coverage, and tell you what might change as time goes by.

Medicare covers some transplant costs, like:

- The surgery
- A portion of the transplant drugs

Other costs, like travel to and from a transplant center and lodging if the transplant center is away from home, are not covered by Medicare. Some families do fundraising to pay for these costs. Organizations that can help with fundraising include the National Foundation for Transplants (www.transplants.org) and the National Transplant Assistance Fund (www.transplantfund.org).

Finding the Help You Need

It isn't always easy to find the help you need. But, like the people you will meet in this booklet, the more you know, the more answers you can find. And at every step, your social worker, nurse, doctor, Medicare, Social Security, and others are ready to help you. Support groups can help, too. Often, other people with kidney disease can give you tips based on their own lives.

Dialysis Social Worker

Federal rules require every dialysis center and transplant program to have a social worker to help patients cope with the challenges of kidney disease and treatment. Your social worker has clinical training to:

- Talk with you about your background, health and work

history, your family and friends, your money needs and worries, and your goals.

- Offer counseling to you and your family to help you cope with kidney disease and treatment, and help you make the best use of your interests and skills to improve your well-being, job options, and social contacts.
- Work with you and the treatment team to plan the care you get.
- Help you learn about and use federal, state, and local programs when you qualify and need them.

The laws and rules for work, Medicare, insurance, Social Security, and disability can be confusing and change often. You need to keep up with changes that may affect you. Your social worker or financial counselor can help you.

Speak Out

Many laws that help patients with kidney disease exist because people with kidney disease like you told their elected officials how much these benefits are needed. You can play a role in keeping federal and state officials updated about how important these benefits are.

To contact your elected officials, call your local public library to find their names and addresses. You can also contact your local League of Women Voters for a list of local, state, and federal elected officials, or find them on www.congress.org.

Join the American Association of Kidney Patients (AAKP) at (800) 749-2257, your local chapter of the National Kidney Foundation (NKF) and its Patient and Family Council at (800) 622-9010, or sign up to be a legislative volunteer at (800) 889-9559 or by visiting www.kidney.org/general/pubpol/volunteer_network.cfm.

Let your voice be heard!

CHAPTER 2 — MEDICARE, MEDIGAP, AND MEDICAID

Medicare is a federal health insurance program for people age 65 and older and for some younger people with disabilities. Medicare is not based on how much money you make or how much money you have in savings.

In 1972, Congress created the Medicare End Stage Renal Disease (ESRD) Program. About 93% of people with kidney failure have Medicare under the Medicare ESRD Program. Once you have Medicare, you can get care for any health problem Medicare covers, not just kidney disease.

Eligibility for the Medicare ESRD Program

To qualify for the Medicare ESRD Program, you must:

- Have kidney failure, and
- Qualify for Social Security under your own work record, or

- Be the spouse (sometimes ex-spouse) or child of someone with enough work credits to qualify for Social Security benefits.

Understanding Your Work Credits

Work credits are based on how much you earn from work during each 3-month quarter of a year. If you earn enough money, you get one credit for that quarter. You can earn up to four credits for each year you worked.

Social Security will tell you how many work credits you have. Visit www.socialsecurity.gov/online-services, or call (800) 772-1213 and ask for Form SSA-7004 to see your Social Security record. Private companies will charge you a fee to find this information, but it's free when you do it yourself.

Your Age	Work Credits You Need for Social Security (unless blind*)
Under 24	6 credits in the last 3 years before disability
24–31	Worked half the time from age 21 until disabled
31–42	20 credits in the <i>last 10 years</i> before being disabled
44–60	20 credits in the <i>last 10 years</i> , plus 2 credits for every 2 years over 44
62 & older	40 credits

**A blind person needs 1 work credit per year after age 21 until the year he/she became disabled due to blindness, but never more than 40 credits.*

Accepting Medicare

When doctors and other healthcare providers “accept Medicare,” it means that Medicare pays them directly. It also means they agree to limit your out-of-pocket bill. For Medicare-covered services, you will only have to pay the difference between what Medicare allows for a covered service and what Medicare and any other insurance does not pay.

Not all health care services are covered by Medicare. If you knowingly receive services that are not covered by Medicare, a provider can bill you for them. If you did not know that the charges were not covered, the provider cannot bill you for them.

Services that are *not* covered include a home dialysis helper, lost pay for missed work, lodging during training or treatment, non-emergency transport, and charges over Medicare’s approved rate.

Medicare Part A and Part B

Medicare Part A

Medicare has two parts. Part A pays for inpatient hospital care (room and board, drugs, machines, supplies, labs, etc.) and for transplant testing and surgery. You must pay a deductible—and maybe a daily charge—for each benefit period. A benefit period starts the day you enter a hospital or skilled nursing

home and ends 60 days after you leave. If you are out of the hospital for 61 or more days and then go back, you will have to pay another Part A deductible.

Medicare Part A is free if you or your spouse have enough work credits. If not, in some cases you may be able to buy it. Call Social Security at (800) 772-1213 to see if you can.

Medicare Part B

Part B pays for other medical and outpatient services—like dialysis and doctor’s fees—after you meet a yearly deductible. If you don’t have other health insurance, Medicare Part B pays 80% of the approved rate for doctors or dialysis at home or in a center (see tables, on next 2 pages).

You pay a monthly premium for Medicare Part B. The monthly premium for 2003 is \$58.70. This amount may change in January 2004. For up-to-date information on the current Medicare Part B premium, call Social Security at (800) 772-1213, visit www.medicare.gov or talk to your dialysis or transplant social worker.

You must have Medicare Part A the month of your transplant to *ever* have Medicare Part B pay for your transplant drugs. You can keep Medicare coverage and Part B coverage for your transplant drugs if you’re at least 65 or are disabled. If you have

Medicare *only* because of kidney failure, your Medicare Part A plus your Part B coverage for transplant drugs will end 36 months after the month of your transplant. If you lose Medicare and get it later due to age or disability,

you can get Part B coverage for transplant drugs again. Plan how you will pay for your transplant drugs long before your Medicare Part B ends. Your social worker can help you look at options.

Dialysis Services Covered by Medicare

Dialysis Service/Supply	Medicare Part A (Hospital)	Medicare Part B (Medical)
Inpatient hospital services	100% after deductible	—
Dialysis in a clinic	—	80% after deductible
Home/self-care training	—	80% after deductible
Home dialysis machine/supplies	—	80% after deductible
Certain home support services	—	80% after deductible
Some drugs for home dialysis	—	80% after deductible
EPOGEN®, Procrit®, Aranesp®	—	80% after deductible
Doctor services	—	80% after deductible
Lab tests, x-rays	—	80% after deductible
Ambulance transportation	—	80% after deductible

Transplant Services Covered by Medicare

Transplant Service/Supply	Medicare Part A (Hospital)	Medicare Part B (Medical)
Inpatient services	100% after deductible	—
Kidney registration fee	100% after deductible	—
Your lab tests	100% after deductible	—
Your donor's lab tests	100% after deductible	—
Locating cadaver kidney	100% after deductible	—
Your kidney donor's care	100% after deductible	—
Doctor care for you	—	80% after deductible
Doctor care for your donor	—	100% after deductible
Transplant drugs	—	80% after deductible

Other Services Covered by Medicare

Service/Supply	Medicare Part A (Hospital)	Medicare Part B (Medical)
Blood, after first 3 pints	100% after deductible, if inpatient	80% after deductible, if outpatient
Physical, occupational, or speech therapy	—	80% after deductible, to annual limit
Nutrition counseling for kidney disease or diabetes	—	80% after deductible
Blood sugar monitor and supplies for diabetics	—	80% after deductible
Therapeutic diabetic shoes	—	80% after deductible
Insulin pumps and supplies	—	80% after deductible
Diabetes education in some cases	—	80% after deductible
Glaucoma exam	—	80% after deductible
Flu and pneumonia shots	—	100% after deductible
Hepatitis B shot	—	80% after deductible
Preventive diabetic foot care	—	80% after deductible
Bone mass measurement in some cases	—	80% after deductible
Breast (women 40 and older), cervical and vaginal cancer exams (all women)	—	100% of lab test; 80% of exams, no deductible
Prostate cancer exam (men 50 and older)	—	100% of lab test; 80% of exam, no deductible
Colorectal cancer exam Colonoscopy (any age) Sigmoidoscopy (age 50 or older)	—	75% after deductible
Medical equipment	—	80% after deductible

When to Apply for Medicare

Do you have good work insurance now? You may think you don't need Medicare. But your insurance status may change if you are laid off, change jobs, or take a long sick leave. And dialysis is costly enough that over a period of years, you could exceed your lifetime insurance limit. Also, Medicare will only pay for transplant drugs if you have Medicare Part B when you get the kidney transplant. Think ahead and be sure you protect yourself. Chapter 3 on *Health Insurance* will cover this decision in more detail.

If you had Medicare before your kidneys failed and you are paying a premium surcharge for late enrollment in Medicare Part B, go to Social Security and file for Medicare based on having kidney failure. Since this is a new reason to have Medicare, the extra fee will be dropped and you will pay the regular premium for Medicare Part B.

If you did not have Medicare before your kidneys failed, but you want it now, you will have to decide when to apply. Your Medicare benefits and premium costs are based on when you apply and if you apply for Part A and Part B at the same time or at different times. Here are some options:

1. Sign up for Part A and Part B together when you start dialysis or have a transplant.

Pro

- You must have Medicare Part A the month of your transplant to *ever* have Medicare Part B pay for transplant drugs.
- If you have Medicare and other health insurance, you will pay less out-of-pocket for any medical bill that Medicare covers.
- If you already have Medicare and become eligible for COBRA, your employer must offer it to you.
- You will have Medicare to fall back on if your other insurance doesn't pay for something that Medicare covers or if you lose your other coverage and can't afford COBRA.

Con

- You have to pay the Part B premium (\$58.70/month in 2003).

2. Sign up for Part A right away, and Part B later.

Pro

- You don't pay the Part B premium until you sign up for Part B.

Con

- You can only sign up for Part B from January through March of each year for coverage as of July 1 of the year you enroll.
- A 10% surcharge will be added to your monthly premium for each 12-month period you could have had Part B but did not. You will

pay this surcharge for as long as you have Medicare Part B. In 2003, if you signed up 12 months after you were first eligible for Part B, you would pay an extra 10%, or \$5.90 a month.

How to Apply for Medicare

Medicare coverage for kidney failure is not automatic. You have to apply for it. To find out if you qualify for the Medicare ESRD Program, call (800) 633-4227 or read about Medicare on the Internet at www.medicare.gov. Look up local addresses and phone numbers in your phone book or at www.socialsecurity.gov/locator.

When you call Social Security, write down the name, title, date, location, and advice of the staff person you talk to. This way you can check your notes and call back with questions. If you have questions the staff person can't answer, ask for a supervisor or someone who knows the rules for people with kidney disease. Social Security has so many programs and rules that it's easy for staff to get confused.

Steps to Apply for Medicare:

- 1.** Make sure your dialysis center or transplant program fills out a CMS-2728 form. This form tells Social Security that you started dialysis or had a transplant. You and your doctor must both sign this form.
- 2.** Call Social Security at (800) 772-1213 or Medicare at (800) 633-4227 to get a Form CMS-43 (*Application for Health Insurance Benefits Under Medicare for Individuals with Kidney Disease*) to apply for Medicare.
- 3.** The representative will give you options for paying your premium if you don't get a Social Security or Railroad Retirement check.
- 4.** Once you are approved, you will get a Medicare card in the mail. Show it to any healthcare providers, and tell them about all the health coverage you have.

If You Are Turned Down for Medicare

Your best source for help if you are turned down for Medicare is your Social Security claims representative. You can find his or her name and phone number on your denial letter. You should qualify if you have enough work credits and if Social Security has your CMS-2728 (*Chronic Renal Disease Medical Evidence Report*) form.

- If you were denied Medicare because you don't have enough work credits, ask the claims representative if you qualify under your spouse's work record—even if you are divorced.
- If Social Security does not have your 2728 form, get a copy from your dialysis or transplant center and send it to them.

Treatment You Choose	Soonest Medicare Starts
<ul style="list-style-type: none"> • Home hemodialysis • Home peritoneal dialysis • Self-care dialysis at a center 	<p><i>If you...</i>start home or self-care training before your third full month of dialysis</p> <p><i>Medicare starts</i> . . . on the first day of your first month of dialysis</p> <p><i>Example:</i> Start dialysis: January 31 Start training: March 31 Start Medicare: January 1</p>
<ul style="list-style-type: none"> • In-center hemodialysis 	<p><i>If you...</i>start in-center dialysis</p> <p><i>Medicare starts</i> . . . on the first day of the third full month after your first treatment</p> <p><i>Example:</i> Start dialysis: January 31 Start Medicare: April 1</p>
<ul style="list-style-type: none"> • Kidney or kidney-pancreas transplant as first treatment for kidney failure 	<p><i>If you...</i>get a kidney or kidney-pancreas transplant</p> <p><i>Medicare starts</i> . . . on the first day of the month you get your transplant, or up to 2 months <i>before</i> your transplant if you are evaluated and transplanted within 2 months</p> <p><i>Example:</i> Get an inpatient transplant evaluation: February 15 Get a transplant: April 1 Start Medicare: February 1</p>

When Medicare Coverage Starts

The table above shows when your coverage will start, based on the kidney disease treatment you choose. The date will be on your card to the right of where it says Hospital (Part A) and Medical (Part B).

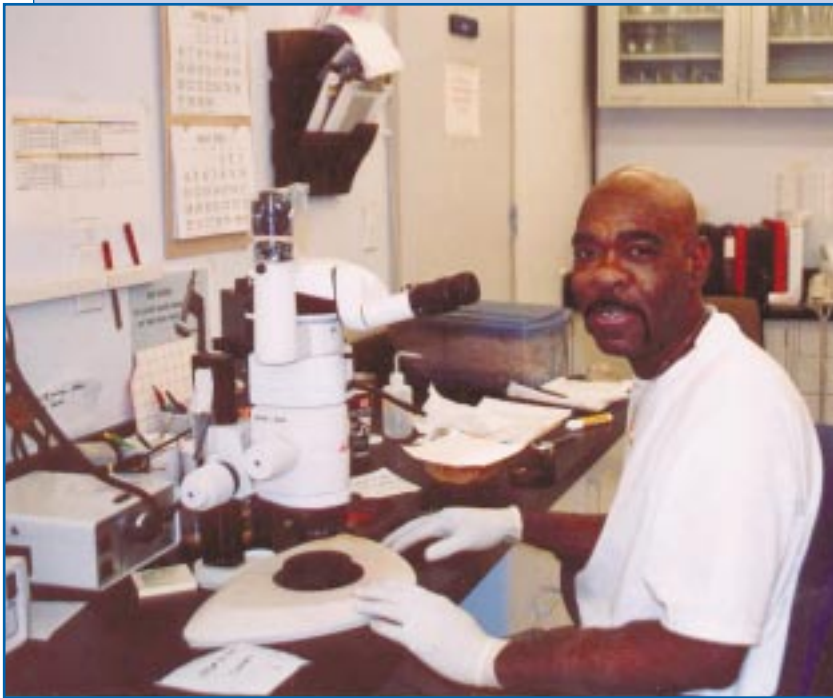
When Medicare Coverage Ends

How long you can keep Medicare depends on whether you have Medicare

just for kidney failure or if you also have Medicare due to age or disability other than kidney failure. It also depends on the treatment you use.

If you only have Medicare because of ESRD, then your coverage will end 12 months after the month you have your last dialysis treatment, or 36 months after the month you have a transplant.

Mickey



In 2000, Mickey Sledge's kidneys failed, but that hasn't slowed him down one bit! "I keep a positive attitude and always think forward," says Mickey, a hemodialysis patient from Phoenix, Arizona.

When he was first diagnosed with kidney disease, Mickey felt very ill. "My legs, knees, and feet swelled up and it was hard to go to work, but I pushed myself," he recalls. "Other than a little time for check-ups and appointments, I have never taken time off because of my kidney disease."

Mickey works full-time as a Biological Research Technician, for the U.S. Department

of Agriculture, conducting experiments on insects in a lab. "I live by myself so I need to continue working," he says. "Working keeps me involved and less stressed out about my kidney disease. By working, I am basically able to stay in tune with reality."

Being on in-center hemodialysis means that Mickey needs a work schedule that fits his treatment schedule. Luckily, his employer has been very supportive in this process. "They have helped me out with my need for a flexible schedule at work," says Mickey. "I work

Tuesday through Saturday from 6 a.m.–2:30 p.m. and I go to dialysis at about 3 p.m. on Mondays, Wednesdays, and Fridays."

A "very athletic" 46-year-old, Mickey enjoys jogging, tennis, racquetball, walking, as well as riding an exercise bike while on the dialysis machine. He has also found time to enjoy another of his passions: airbrushing. "I am an artist, and do t-shirt airbrushing in my free time. In fact, I just entered a t-shirt contest at my dialysis center, which I hope to win!"

To learn more about Medicare, see *Medicare and You* (Pub. No. CMS-10050) and *Medicare Coverage of Kidney Dialysis and Kidney Transplant Services* (Pub. No. CMS-10128).

Medicare + Choice Plans

Medicare + Choice plans include HMOs, private fee-for-service plans, and Preferred Provider Organizations (PPOs). Medicare + Choice plans can cover things regular Medicare does not, such as drugs and travel to and from dialysis. The government pays these plans a fixed amount each month for each person they insure. You may have to use the plan's doctors or hospitals, and you may need a referral to see a specialist. Medicare + Choice plans may charge a co-payment for some services that are not covered by any other source. They may charge a co-payment per dialysis treatment. Ask your plan what you will have to pay for dialysis.

Medicare + Choice plans contract with Medicare on a yearly basis. At the end of a year, they can choose not to renew their contract. If you have Medicare + Choice, learn what to do if your plan decides not to renew its Medicare contract by going on-line at www.medicare.gov, or by calling (800) 633-4227. TTY users can call (877) 486-2048.

Currently, if you already have kidney failure before enrolling, you cannot enroll in a Medicare + Choice plan. This ban may be lifted in the future.

Billing for Medicare Premiums

Your Medicare Part B premium will be taken out of your check if you get disability or retirement benefits from Social Security or the Railroad Retirement Board.

Otherwise, Medicare will bill you every 3 months. Your first bill will not come for a few months. Set aside the money for your premium every month so that when you get your first bill, you have the money to pay it.

Medicare Premium Help

Your state may pay all or part of your Medicare Part A or Part B premiums if you have low income. In some cases, it can also pay deductibles and other costs through a Medicare savings program.

Tip

Didn't have Medicare Part A the month of your transplant, and just found out you can never get Medicare Part B to pay for transplant drugs? Contact Social Security within 1 year of your transplant. Social Security can backdate Medicare Part A coverage as much as 12 months. Because Medicare Part B pays for transplant drugs, you must pay your Medicare Part B premium any month you want this coverage. ***You must have Medicare Part A for the month of your transplant to have your Medicare Part B ever pay for your transplant drugs for that transplant.***

To qualify, you must earn less than \$4,000 (\$6,000 for a couple). Your other “resources”—cash, stocks, bonds, and life insurance—must also meet certain limits. The home you live in, furniture, burial plan, and one car do not count as resources.

States offer these plans:

- **Qualified Medicare Beneficiary** (QMB) pays the full Medicare Part A and B premiums, deductibles and coinsurance, plus you may be able to get full Medicaid.
- **Specified Low-Income Medicare Beneficiary** (SLMB) pays the full Medicare Part B premium, and you may be able to get full Medicaid.
- **Qualifying Individual** (QI-1) pays the Part B premium, but states limit the number of people they can help. You cannot have Medicaid with this program.
- **Qualified Disabled and Working Individuals** (QDWI or QWDI) can pay part of the Medicare Part A premium. In some states, disabled people who work can get Medicaid (see the *Ticket to Work* section on page 69).

Tip

Ask for a free copy of *Medicare Coverage of Kidney Dialysis and Kidney Transplant Services* (Pub. No. CMS-10128). It's available by calling (800) 633-4227 or on-line at www.medicare.gov/Publications/Pubs/pdf/10128.pdf. The booklet explains what Medicare is, what it covers, and how it works if you have health insurance through an employer.

Income limits for these programs change every April. Some states let you have more income than others. You can read about some states' Medicare savings programs at www.medicare.gov/Contacts/Related/MSPs.asp. If you think you may qualify, call Medicare at (800) 633-4227 or visit www.medicare.gov/contacts/home.asp.

Your Rights Under Medicare

If you have Medicare, you have the right to:

- Get the medical care you need to diagnose and treat your health problem.
- Be fully informed of your treatment and any charges that are not covered before you agree to the service.
- Have a review, reconsideration, or appeal of a service that Medicare denies.

If a Medicare Claim Is Denied

Call the doctor's office to be sure that the claim was filed correctly, if your Medicare claim is denied. Your Medicare Explanation of Benefits notice and/or the Medicare booklet you get each year tells you how to appeal a claim denial. It also includes how much time you have to appeal.

Ask your doctor or provider to write a letter to support your need for the service. You can also ask the State Health Insurance Counseling and Assistance Program

(SHIP) for help in appealing a claim denial. Find your state’s SHIP at www.medicare.gov/Contacts/Related/Ships.asp or in the booklet *Medicare and You*, available from Social Security offices.

Medigap Insurance

Medigap plans can help pay costs left over after Medicare pays. These might be deductibles, coinsurance, doctor bills, dialysis, and other care. Private health insurance companies offer Medigap plans. Only people with Medicare can get Medigap.

Who Qualifies for Medigap

By federal law, insurance companies must offer Medigap plans to people age 65 years or over, even if they have health problems—**as long as they apply in the first 6 months after getting Medicare**. This is the “open enrollment period” and may be longer in some states.

Some states also require Medigap plans to cover disabled people of any age or those who have Medicare because of the Medicare ESRD Program. Check with your state insurance department to see if your state does this. If not, you might want to let your state legislator know that this is a problem for you.

Medigap Plans

There are ten basic Medigap plans, labeled by the letters A through J. The letter code makes it easier to shop around because one company’s “A” plan is the same as other “A” plans, except for the premium. (Minnesota, Wisconsin, and Massachusetts do not use the A-J labels.) All plans are not offered in every state. Contact your state insurance department to find out what Medigap coverage is sold in your state. The table below shows what the plans cover.

Benefits	A	B	C	D	E	F	G	H	I	J
Basic benefits	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Skilled nursing coinsurance			✓	✓	✓	✓	✓	✓	✓	✓
Part A deductible		✓	✓	✓	✓	✓	✓	✓	✓	✓
Part B deductible			✓			✓				✓
Excess charge over Part B allowable						100%	80%		100%	100%
Foreign travel (emergency only)			✓	✓	✓	✓	✓	✓	✓	✓
At-home recovery				✓			✓		✓	✓
Prescribed drugs 50% of charge								Limit \$1,250	Limit \$1,250	Limit \$3,000
Preventive care					✓					✓

Lydia

“For anyone on dialysis who wants to keep active, everyday work is possible,” says 59-year-old Lydia White, from Warsaw, Missouri. “Working will keep you alert, active, self-satisfied, and a fully rounded person as opposed to a ‘patient.’”

Currently a proofreader for her local weekly newspaper, as well as for the daily Clinton, MO newspaper, non-stop Lydia also runs an antique shop out of her home and volunteers at a local animal shelter thrift shop. “Part-time work is a better option for many people on dialysis; if you have a down-time in energy after your treatment, you can switch your work time and rest,” she says. Lydia—whose hobbies include arrowhead hunting, duplicate bridge, and reading—is lucky to have a family in the newspaper business; she is able to work as little or as much as she can.

However, Lydia’s volunteering requires her to make choices about what she takes time to do.

“Before I had kidney failure, I was active on the board of the local animal shelter and with other, not-for-profit community groups,” she says. “Now, there are not as many hours in the day to work or volunteer due to dialysis time and my energy limits.” Lydia suggests that anyone wishing to do volunteer work first talk about his or her limits with the group’s president or leader. “Organizations will often work with you—there is always a spot for a willing volunteer.”

Lydia, who has lupus, began hemodialysis right after her kidneys failed in January of 2000. She did have some hurdles to cross in the weeks after her diagnosis. “At first, I had a 3-week hospital stay, after which I had a stroke,” she recalls. “My leg strength was weak and I had to exercise to get that back. It took about a year to feel like myself again.”

In 2002, with her nephrologist’s support, Lydia switched to peritoneal dialysis (PD) and has been happy with her treatment choice. “I wanted more control over my life,” she explains.

Lydia likes having a schedule that allows her to work, volunteer, and remain in charge of her life. “Ultimately, you need to decide who’s going to run your life,” she says. “Perhaps you have some limits, but you are still a fully-functioning adult with something to give to the world.”



Check Your Medigap Plan

Before you buy a Medigap plan, read it carefully to be sure it covers what you need and can afford. Check to see if it has limits for outpatient treatments, like dialysis. Read about these plans in the *Guide to Health Insurance for People with Medicare* (Pub. No. CMS-02110). Some state insurance departments publish in print or on the Internet what plans are sold in the state, what limits they have, and how much they cost. Compare Medigap plans in your state at www.medicare.gov/mgcompare/home.asp.

Medicaid (Medical Assistance)

In most states, if you do not make much money and do not have property or much savings, you may get Medicaid, or Medical Assistance (MA). Medicaid pays Medicare premiums, Medicare Part A and Part B deductibles, and some costs not paid by Medicare, like **prescription drugs** and medical transport.

If you get Temporary Assistance to Needy Families (TANF) or Supplemental Security Income (SSI), you can get Medicaid in most states. Ask your state Medicaid office whether you need to fill out a Medicaid application or not. You can find your state's Medicaid office at www.nasmd.org/members.htm.

Medicaid Medically Needy Program

Even if your income is over the state's guideline, you may be able to get Medicaid if you have high medical bills. This is called the Medically Needy program. When you apply, show your bills to the Medicaid caseworker. He or she will tell you which bills you must pay. Medicaid can be billed for any other bills you get. People on Medicaid must show proof of their medical costs every 1–6 months.

The Pickle Amendment

You may also be able to get Medicaid under the Pickle Amendment. This law helps people who lose Medicaid due to cost-of-living increases in their disability payments. You may be able to get Medicaid if all of the following are true:

- You had both Social Security Disability Income (SSDI) and Supplemental Security Income (SSI) in any month after April, 1977
- You are now receiving Social Security retirement or disability
- You are not now eligible for SSI
- You would be eligible for SSI now if the cost-of-living increases to your Social Security benefits were not counted as part of your income

The National Center on Poverty Law describes this law at www.povertylaw.org/pln/pln_articles/pickle.cfm.

Medicaid Buy-in Program

In some states, if you are **disabled and you work**, you can get Medicaid under a “Medicaid buy-in” program. You may have to pay a premium, and you may be able to get Medicaid for your family, too. Call (800) 633-4227 or visit *www.nasmd.org/members.htm* to find the phone number of your local Medicaid office. You can find a map showing which states have Medicaid buy-in by visiting *www.socialsecurity.gov/work/ResourcesToolkit/Health/states.html*.

CHAPTER 3 — HEALTH INSURANCE

Most people can get Medicare when their kidneys fail. When you have a second health insurance policy—often from an employer—the two policies may coordinate benefits. They do this to be sure that you do not get more than 100% of the cost of your medical care.

Primary and Secondary Payment

When you have two health insurance plans, one is primary—it pays first and pays more. The other is secondary—it pays all or part of the cost that the first one did not pay. Even with two plans, you may still have out-of-pocket costs.

Medicare has an “allowable rate” for each outpatient healthcare cost. In most cases, when Medicare is the first payer, it will pay 80% of that rate. But doctors or hospitals may charge more. For example, Medicare may allow \$200 for an X-ray. It pays 80% of this rate, or \$160. This leaves you with \$40 to pay. But if the X-ray center charges \$300, Medicare will still pay \$160. Now you may be left to pay

\$140. Your secondary insurance may pay some or all of this balance.

If you have employer group health insurance when your kidneys fail, this health insurance is primary for the first 30 months from the date on your Medicare card—whether or not you take Medicare. For questions about who should pay first, call the Medicare Coordination of Benefits Customer Service Center at (800) 999-1118.

Telling Care Providers About Your Insurance

Keep your healthcare providers, doctor, and dialysis or transplant center up-to-date about your insurance. This will help them bill correctly—which may leave less for you to pay. Be sure to tell them if:

- Your health coverage or insurance company changes
- Your health insurance company drops your kidney doctor or dialysis or transplant center from its provider list
- You get a job with health insurance
- You can no longer get health insurance as an employee or a dependent
- You get or lose Medicare
- You get or lose Medigap
- You get or lose Medicaid
- You get or lose state kidney program benefits

Tip

To get a booklet called *Medicare and Other Health Benefits: Your Guide to Who Pays First* (Pub. No. CMS-02179), call (800) 633-4227 or visit www.medicare.gov/publications/pubs/pdf/msp.pdf.

Although you may be embarrassed, tell your healthcare providers if you are having a problem paying their bills. No one can help you if they don't know you are having problems. You may be able to have some bills reduced, find other sources to help pay, or set up a payment plan that will keep your credit in good shape and avoid collectors calling you.

Taking Medicare if You Have Employer Health Insurance

If your health insurance offers very good coverage for dialysis and/or transplant, you may not want to pay Medicare premiums until you have to—at the end of 30 months, when your health insurance is no longer primary. There are a number of people you can talk to about reasons for and against taking Medicare, including:

- Your Social Security claims person
- Employee benefits office
- Dialysis or transplant social worker
- Financial counselor

As you decide, ask yourself these questions:

Q: Do I have individual health insurance or a group plan?

If you have an individual insurance plan, it is wise to sign up for Medicare. Individual insurance often does not cover as much or pay as well as group insurance. Medicare will be billed first. Then your individual plan may pay

some or all of the charges Medicare does not cover, so you pay less.

Q: Does my health plan pay all or most of my medical bills?

Some companies have low yearly deductibles, co-payments, and coinsurance. A deductible is an amount you must pay before insurance will pay. Co-payments are what you pay for each visit. Coinsurance is the amount you pay out-of-pocket after insurance pays its share. If you have to pay these, you might want to apply for Medicare, which may pay some of these bills. Or, you might change to another employee insurance option during your next “open enrollment period.”

Q: Could my medical bills use up my yearly or lifetime maximum benefit?

A yearly limit of \$30,000 or a lifetime maximum limit of \$500,000 may sound like a lot of money. But it does not take long for medical bills to add up. If your employer offers an option for an unlimited lifetime maximum, sign up for it during your next “open enrollment period” if you can afford it.

Q: Will my current health insurance pay for dialysis when I travel?

Many health insurance companies will pay for dialysis when you are away from home. But others—especially managed care organizations (MCOs) or health maintenance organizations

(HMOs)—may only pay for out-of-town dialysis in an emergency. Vacations are not an emergency. If your insurance won't pay, Medicare may pay part of the cost of dialysis when you travel in the U.S. Some individual, group, and Medigap insurance companies will pay for dialysis outside the United States.

Q: Will my insurance pay for dialysis or a transplant where I want it?

It depends. Your insurance—especially MCOs and HMOs—may only pay for treatment at certain dialysis centers. Some will only pay for a transplant at a “center of excellence”—a center that can show very good results. Other insurance plans may let you choose where you go for a dialysis or transplant.

Q: How long will my health insurance be my primary payer?

Some plans require you to apply for Medicare if you qualify for it, or you could lose your coverage. Know your plan. If you don't understand what your insurance covers, ask the company benefits staff to explain it.

Q: What if my company changes insurance during the 30 months that it is my primary payer?

You might have to change doctors or transplant programs during the 30 months your employer group plan

is primary if your company changes insurance. This can be upsetting if you have to explain your health history over and over. Some people choose to use Medicare as their primary payer and pay 20% to see doctors and other providers they prefer.

Q: Could I lose my group coverage during the 30 months that it is my primary payer?

If you have Medicare and you lose your employer group coverage, most employers must offer you and your dependents coverage for at least 18 months under COBRA (you will need to pay premiums). If you do not have Medicare and you take it later, your employer can stop your COBRA health coverage. (See *COBRA information* on page 35.)

Changing Jobs

If you or your spouse change jobs and have an “open enrollment period” for health insurance, sign up as soon as you can. If you do, the longest you will wait for your new group plan to cover any health problem you have is 12 months. There can be an 18-month wait for a pre-existing health problem for people who do not sign up during open enrollment. Even if your new plan does not pay for a pre-existing condition right away, it should pay for care for a new health problem.

A new job may offer new benefits that help you set aside money for health care costs. When you or a spouse change jobs, ask about any new benefits. They may make your life or your finances easier.

Saving for Non-Covered Medical Expenses

Your employer may offer a **flexible-spending account**. This allows you to guess how much you might owe in medical and dental bills each year and have money taken out of each paycheck. This pre-tax money is put in a special account. When you pay medical bills, you send proof to your employer, and get a check from your account. You lose any money that you do not use.

You may also have a **medical savings account**. You set aside money for future medical expenses or health insurance deductibles into this account, tax-free. Until you need it, the money earns interest that is also tax-free. When you have medical bills, you get money to pay your bills. With this account, you can invest what is left if you don't use it up.

Losing a Job: Your COBRA Rights

If you lose your job, you may be able to keep your health insurance coverage under the government's Consolidated Omnibus Budget Reconciliation Act (COBRA). You will have to pay the premiums (see the table on page 36).

COBRA applies to companies that had 20 or more full or part-time employees on at least half the work days in the last year. You may qualify for COBRA if you are an employee, spouse, or child *AND* if you have an event that causes you to lose your health coverage.

COBRA Rules:

- 1.** Your employer must notify you of your right to COBRA within 14 days.
- 2.** You have 60 days to decide whether to take COBRA.
- 3.** Your coverage must be the same as the coverage of current workers.
- 4.** You must pay your first premium within 45 days of choosing coverage.
- 5.** If your company closes or goes bankrupt and has no health plan, your COBRA ends. If the company offers another health plan to employees, you qualify for that plan under COBRA too.
- 6.** If you have Medicare before you qualify for COBRA, your employer must continue COBRA. If you get Medicare later, your employer does not have to continue COBRA. There is no law that says your employer can't continue to offer you COBRA if he/she wishes.

For questions about COBRA for non-government workers, visit www.dol.gov/ebsa/faqs/faq_consumer_cobra.html.

Federal government workers may qualify for **Temporary Continuation of Coverage** (TCC), which is like COBRA.

You can read about TCC at www.opm.gov/insure/health/tcc/index.asp. Ask your office for a copy of *Temporary Continuation of Coverage Under the Federal Employees Health Benefits Program* (RI 79-27). When your dependent no longer qualifies for your coverage, your employer does not have to tell him or her about TCC coverage—so be sure to ask.

If you (or your spouse) leave a job that gives you health insurance,

watch out for plans that convert your health insurance from a group to an individual plan. Because these so-called “conversion plans” are not group plans, you may lose your rights to health insurance portability (see *HIPAA*, below). Individual plans may cost more and have fewer benefits. Before you take this individual coverage, ask whether any groups you belong to offer group health coverage to members.

COBRA Information

What Is the COBRA Qualifying Event	Who Is Covered	COBRA Coverage and Premium
Employee loses job Employee works fewer hours (either voluntary or not)	Employee Spouse Dependent child	May get COBRA for 18 months. Pay 102% of the premium (employer and employee share). ----- May get COBRA 11 extra months if found disabled within 60 days of getting COBRA. Pay 150% of the premium (employer and employee share) for 11 months.
Couple divorces or separates Employee dies Employee gets Medicare	Spouse Dependent child	May get COBRA for 36 months. Pay 102% of the premium (employer and employee share).
Child no longer considered dependent (by health plan definition)	Young adult	May get COBRA for 36 months. Pay 102% of the premium (employer and employee share).

Taking Your Health Insurance with You

It can be hard to find new health insurance with a *pre-existing condition*—any health problem you have been diagnosed with or treated for in the past 6 months.

The Health Insurance Portability and Accountability Act (HIPAA) may help you and your family get health insurance. **Under HIPAA, you cannot be turned down for coverage just because of a health problem.**

Premiums can be higher if you already had a health problem.

HIPAA:

- Gives you more options for insurance if you lose or change jobs
- Shortens your wait (to 12 months) for coverage to pay for pre-existing health problem. This wait may be satisfied by your previous insurance.
- Allows you to renew your coverage in some cases.

Rules that Apply to HIPAA

Several rules apply before you can be covered by HIPAA:

- You must have at least 18 months of creditable insurance. Most past coverage you had can meet this waiting period, as long as you did not go without coverage for 63 days or more.
- Your coverage must be under a group plan, government plan, or church plan, including:

- Group health plans, even self-insured (2 employees or more in most cases, but some states apply this to groups of one)
 - Medicare
 - Medicaid
 - Student health insurance
 - Military sponsored health coverage
 - Indian Health Service coverage
 - State high risk health plan
 - State or local government health plan
- You cannot qualify for another group plan, Medicare, or Medicaid
 - You cannot have other health insurance
 - You must have paid your previous health insurance premiums
 - You must have used up your COBRA (or state continuation)

Using HIPAA Rights

Ask for a “certificate of creditable coverage” in writing from your last insurance company. This gives the dates you were covered, your policy number, and the names and addresses of all people insured on your policy. Your new health insurance company needs this to see if you are covered by HIPAA. You may have a waiting period for any services you did not have in your last plan. For a fact sheet on HIPAA, see www.dol.gov/ebsa/newsroom/fshipaa.html.

When you are covered by HIPAA, you may be able to buy certain Medigap plans (A, B, C, or F) in some states, even after the first 6 months of Medicare coverage. Contact your state insurance department to see if this applies to you.

State-level Resources for the Uninsured

Your state insurance department can tell you about health insurance options in your state and laws that shorten any waiting period for pre-existing conditions. You can find a list of state health insurance departments on-line at www.naic.org/state_contacts/sid_websites.htm or call the National Association of Insurance Commissioners at (816) 842-3600. Your social worker may know of options, too.

State kidney programs help some people with kidney disease pay for their care. They are usually funded by state tax dollars. In 2003, there were 22 programs. Funding levels, services, and eligibility varies from state to state. Some programs only help with charges for medical care. Others help pay for such things as drugs, dialysis or transplant-related travel, and insurance premiums.

Your social worker can tell you what services your state kidney program provides and whether or not you might qualify. A state kidney program may

be able to help you when no one else can. (See page 90 to find your state.)

State high-risk insurance pools

can offer insurance to people who cannot find coverage anywhere else.

To qualify, you must:

- Be turned down for any health insurance, or
- Be denied coverage for your pre-existing condition, or
- Pay premiums that cost more than the risk pool charges

You may not be able to join a risk pool if you have Medicare or Medicaid. High-risk health insurance costs more than other coverage, but may be worth it. Call your state insurance department or commissioner to find out if you qualify. For links to states that have high-risk insurance pools, see www.healthinsurance.org/riskpoolinfo.html, or call the National Association of Insurance Commissioners at (816) 783-8500.

State Child Health Insurance Program (SCHIP)

Every state has a program to insure infants, children, and teens who don't have other insurance. It can help children in working families and children of some immigrants. At the very least, SCHIP pays for prescribed drugs, doctors, and hospitals. Some states pay for dental, vision, and medical equipment.

State rules vary, but in general children 18 and under can be insured as long as their family earns less than the state income limit for families. Families must renew coverage every 6–12 months. To find out more about this program, call toll-free (877) KIDS-NOW, read fact sheets at www.insurekidsnow.org, or find your state's SCHIP at www.insurekidsnow.gov/states.htm.

Health Coverage for Military, Dependents, or Veterans

There are health insurance benefits for active duty military and dependents, for retired military and their families, and for veterans. Each of these is described below.

Benefits for People on Active Military Duty

If you are on active duty, a family member of someone on active duty, or retired from the military or a dependent, you may qualify for TRICARE. Read about TRICARE at www.tricare.osd.mil/TricareHandbook/. Under the TRICARE pharmacy program, you pay nothing for drugs you get from a military treatment facility. You pay a small co-payment at any network pharmacy or the TRICARE mail order pharmacy. You can buy drugs at a non-network pharmacy for a small co-payment or 20% of its price. TRICARE also has a dental program.

Premiums and co-payments are based on the military person's pay grade.

- **TRICARE Prime** is a managed care plan, which is mandatory for active duty military. The military urges families of those on active duty and military retirees to sign up for TRICARE Prime, too. There are no premiums, deductibles, or other costs. You choose a primary case manager from a list and the case manager approves your care.

Benefits for Military Dependents and Retirees

Families of active duty military and military retirees can show their military ID and use both of the other plans, depending on the providers they see:

- **TRICARE Extra** has no enrollment fee or premium for families of those on active duty. There is an annual cap on what you pay, and the healthcare provider files the paperwork. For the directory of providers in the network see www.tricare.osd.mil/provider_directory.html.
 - Military retirees under age 65 and their dependents pay a yearly premium of \$230 for one or \$460 for a family (2003 costs).
 - Family members of someone on active duty pay a deductible and 15% of the cost of care when seeing a network provider.
 - Military retirees or dependents pay 20% of the cost of care.

- **TRICARE Standard (formerly CHAMPUS)** covers many but not all services. There is an annual cap on what you pay. You file your own claims.

- Families of those on active duty and military retirees under 65 and their dependents can see an approved provider.
- Families of those on active duty pay a deductible, a co-payment, and 20% of the cost of care.
- Retirees and their dependents pay a deductible, a co-payment, and 25% of the cost of care.

Military retirees age 65 or older with Medicare Part B automatically get *TRICARE for Life (TFL)*. TFL works like a Medigap plan. TFL also covers things Medicare doesn't cover, like drugs.

CHAMPVA

Some spouses and children who are not eligible for TRICARE may be eligible for CHAMPVA if one of the following is true:

- The veteran relative was 100% permanently and totally disabled from a service-related disability
- The veteran was 100% permanently and totally disabled from a service-related condition when he/she died
- The veteran relative died of his/her service-connected disability
- The military relative was killed in action

CHAMPVA covers most medical care, including prescribed drugs and works like a Medigap plan if you have Medicare. For more information on CHAMPVA, see www.va.gov/bac/champva/champva.html or write:

VA Health Administration Center
CHAMPVA
P.O. Box 65023
Denver CO 80206-9023
(800) 733-8387

Benefits for Veterans

As a veteran, you may be able to receive preventive and primary care benefits paid for in whole or part by the VA. When you apply, you will be assigned to a priority group based on your service history, disability status, income, or other health benefits you have. As of 2003, the VA is *not* enrolling higher-income veterans unless they have service-connected disabilities. Once enrolled, you may have to pay a co-payment for services, but other insurance may pay your co-payment.

To apply, complete a VA 10-10 EZ form. You can get this form from your local VA healthcare center or by calling toll-free (877) 222-VETS. You can complete the form on-line at www.va.gov/1010ez.htm.

Once enrolled, you can get services from a VA healthcare center or in some cases from other providers paid by the VA. Covered services include

inpatient and many outpatient services, certain prescribed and over-the-counter drugs (with a co-payment per drug for each 30-day supply), counseling for you and your family, certain rehabilitation services, travel in some cases, and more. To learn more about any VA benefits, see www.tricare.osd.mil/beneficiary/default.cfm.

Indian Health Service (IHS)

In general, you may get health care from the Indian Health Services if you are an enrolled member of a federally recognized Tribe. For more information, contact the IHS:

Indian Health Service
The Reyes Building
801 Thompson Avenue, Suite 400
Rockville, MD 20852-1627
(301) 443-3024
www.ihb.gov/GeneralWeb/HelpCenter/CustomServices/elig.asp

If you live on or near a reservation, you can get services at IHS contract clinics. To apply, bring proof of your Indian status from the Bureau of Indian Affairs to an IHS health center. To find out more, see www.ihb.gov or call your area office.

Part II:

Living Productively with Kidney Disease

With kidney disease, you may feel weak, tired, lose your appetite, or have other symptoms, like swelling or itching. You may need to take new drugs. If your kidneys fail, you will need dialysis or a transplant and surgery to put in a dialysis access or a new kidney. All of this can affect your activities—including work.

The Social Security Administration knows that kidney failure, and in some cases kidney disease, can affect your ability to work—but people with kidney disease do keep their jobs.

In this section, we will cover work, volunteering, school, and keeping up an active retirement life with kidney disease.

- Chapter 4, *Keeping a Job with Kidney Disease*, explains your rights and options in the workplace and ways to deal with health setbacks.
- Chapter 5, *Understanding Disability Programs*, covers Social Security Disability and Supplemental

Security Income programs that can replace some of your income if you cannot work.

- Chapter 6, *Finding a New Job*, will help you sell your abilities, aim for the job you want, and learn how to gain new work skills.
- Chapter 7, *Vocational Rehabilitation and Work Incentive Programs*, includes vocational rehabilitation, working with SSI and SSDI work incentives, and the new Ticket to Work program.
- Chapter 8, *School Options for Students*, describes programs to help young children stay in school and to help older youth pay for college.
- Chapter 9, *Staying Active in Retirement*, offers options for working, volunteering, and living a fulfilling life with kidney disease in the senior years.

CHAPTER 4 — KEEPING A JOB WITH KIDNEY DISEASE

If you are working when you learn you have kidney disease, do what you can to keep your job. While this can be a challenge, giving up your job now can make it much harder for you to go back to work later when you will probably be feeling better.

Ask your doctor to describe kidney disease to your employer and focus on what you *can* do. For you, a steady income and health insurance means fewer money worries. For your employer, keeping a valued worker may be less risky than finding and training someone new.

Talk with your family, doctor, social worker, or a vocational rehabilitation (VR) counselor about how to keep your job. Even if your kidneys don't work, you may still do the same job you did before. You may be able to do the same job with a little extra help. Or, you may be able to do another job for your

company. Talk with your employer if you need help to keep your job.

Common Myths About Working with Kidney Disease

Your health can change over time. Because of this, you may move back and forth between having a job and being on short- or long-term disability.

Most people—including employers—know very little about kidney disease and its treatment. As you learn, you may need to teach others, including family and friends, teachers and students, employers and co-workers. Below is a table that may help you convince others that you can be a good employee.

Responsibilities to an Employer

Good workers come to work on time, do a quality job, meet their deadlines, and let their employers know when

Employers May Believe...	The Department of Labor Says...
On-the-job safety is a concern when hiring workers with disabilities.	Disabled people do not have more accidents, so hiring them does not raise worker's compensation costs to employers.
Workers with disabilities produce less.	A DuPont study shows that disabled workers produce as well or better than other workers.
Workers with disabilities are costly to accommodate.	Most disabled workers do not need special accommodations. When they do, most accommodations cost less than \$500.
Workers with disabilities miss too much work.	A DuPont study shows that disabled people do not miss more work than other employees.

they have doctors' appointments or are sick and not able to do work as expected. Ask for special equipment, flexible scheduling, or extra breaks if you need any of these to get the job done or keep your job.

You never know when you may need to sell yourself to your employer to keep your job or get a raise or promotion. Track any time you take off for vacation, illness, or treatment. Note any time you make up. Keep a list of assigned and completed projects. If you can, track how much money your projects have brought to your company.

Keep records of any compliments from your supervisor, co-workers, or customers and copies of written evaluations. These can help you show your current employer or a future one that you are a good worker.

Fighting Fatigue

As your kidneys fail, or if you have a failing kidney transplant, you may have more symptoms. You may even think about quitting your job and applying for disability. Many people who do this regret it later and wish they had taken a leave of absence to get used to dialysis. Disability often pays less than you would earn by working. This means you may have to make more lifestyle changes and worry more about making ends meet.

One of the symptoms of kidney disease or kidney failure that can be overwhelming is feeling very tired and weak—sometimes even too tired to go about your daily activities. Some fatigue may be caused by a build-up of toxins in your blood. But for many people with kidney disease, fatigue is caused by anemia, which can—and should—be treated.

Before you give up your job due to fatigue, ask your doctor to check your red blood cell count. If you have anemia, ask for treatment. It may take a few weeks to notice the results when anemia is treated, but you will feel better and more able to work.

Dealing with Health Setbacks

As much as you may want to work, some health problems may arise that will make you take some time off work. This may include access surgery or fixing access problems, starting dialysis, biopsies of a new kidney, infections, or even other illnesses. If you have a health setback that affects your work, there are some programs that can help you keep your job.

Sick Leave

Many companies offer sick leave. If you are ill, call your supervisor. Ask your doctor to give you a letter, if needed. Some employers do not know that kidney disease may make

you feel too ill to work at times, so you may need to ask your doctor or social worker to talk to your supervisor.

Are you running out of sick time? Some companies or agencies allow workers to donate unused sick leave to other employees with serious illnesses.

Part-time or Flexible Scheduling

Working part-time may allow you to keep your job, keep some benefits, recover from a health setback, and get back on track. Or, you may want to reduce your work schedule to give you more time to fit in dialysis or doctor's visits, or to deal with having less stamina.

Some people with kidney disease have been able to work out flexible scheduling with their employers. For example, you might schedule hemodialysis for Tuesday, Thursday, Saturday. Then you could work 9 hours on Mondays, Wednesdays, and Fridays and 6.5 hours on Tuesdays and Thursdays to reach 40 hours per week.

Work from Home

Some types of work don't need to be done at an office. Insurance claims adjusting, freelance writing or editing, research, web design, database management, party planning, piecework, a news clipping service, and assembly are some examples. Maybe you could bring a laptop computer and a cell phone to dialysis or doctor's visits and make use of that time to get work done.

Take a Demotion

A less stressful job may mean working fewer hours and making things easier on yourself. While your pay would be less, your responsibility would be less as well, and you would probably keep your benefits.

Company Short-term Disability

As you get close to needing dialysis or a transplant, or if you have a health setback, you may feel like you won't be able to keep working. Rather than quit, think about taking a short-term leave to get used to dialysis or recover from a transplant. A brief disability leave can give you time to get used to your new treatment. Most people who start treatment feel better in a few weeks. With only a brief leave, you will still have a job to come back to.

Check your company benefits to see if short-term disability insurance is offered to you. This insurance can help pay the bills during a short-term disability leave.

Most employers know that a kidney transplant is major surgery. Anyone who has a transplant will miss some work. Expect to take time off for doctors' visits after a transplant, too. You will have fewer doctors' visits as time goes by.

Family and Medical Leave Act (FMLA)

This federal law lets some workers take up to 12 weeks of unpaid leave

per year if they or a family member have a serious health problem. To qualify for FMLA leave, you or your family member must meet all of the following:

- You work for a government agency, school, or company with 50 employees working within 75 miles
- You have worked for the company for at least 12 months
- You worked at least 1,250 hours in the last year (about 25 hours/week)

When possible, ask for FMLA leave at least 30 days ahead or as soon as you know you'll need it. Your employer can ask you to get your doctor to certify that you really need the leave.

You can take all 12 weeks of FMLA leave at one time, take time on certain days until you use up your FMLA leave, or even take as little as 15 minutes each day. Your employer can ask you to use vacation time and sick days as part of your FMLA leave. While you are on leave, your employer must hold your job or a like one with the same pay, benefits, and working conditions. Your employer must keep you on the group health plan—but you may have to pay the premium.

Tip

In 2003, 11 states had laws that are similar to or better than the FMLA. For links to these states, see www.dol.gov/esa/programs/wbd/state/fmla/index.htm.

The U.S. Department of Labor's Wage and Hour Division enforces this law.

To find out more information:

- Call the FMLA Help Line at (800) 959-FMLA
- Look up district offices at www.dol.gov/dol/location.htm
- Find FMLA resources www.dol.gov/esa/wbd/fmla/
- Read an FMLA fact sheet at www.dol.gov/esa/regs/compliance/wbd/wbdfs28.htm
- Check out frequently asked FMLA questions at www.dol.gov/elaws/esa/fmla/faq.asp

Call your local office of the Department of Labor to learn more, or write:

U.S. Department of Labor
Employment Standards Admin.
Wage and Hour Division
Frances Perkins Building
200 Constitution Avenue NW
Washington, DC 20210

Dialysis Schedules and Work

With dialysis in a center, it may be a challenge to get a schedule that fits with work or school. Ask for what you need. There may be fewer options in a very full center. But if enough patients ask for early morning or late afternoon or evening hours, dialysis centers may extend their hours for working patients or students, or give them

first choice of the shifts they have. Some centers already do this when patients ask.

Dialysis Centers and Working Patients

Talk with your center's social worker, nurse, or administrator about your work or school schedule. You may find that they want you to work or stay in school as much as you do.

If you have employer group insurance when you start dialysis, that insurance is primary for your first 30 months of in-center dialysis or 33 months of home or self-care dialysis—and they reimburse your dialysis center more than Medicare. *You* don't pay any more, but your center makes more money. This may convince them to work with you so you can keep your job.

Finding a Different Dialysis Center

If the center where you receive dialysis now will not work with you to allow you to keep your job, you may be able to change centers. Depending on where you live and on your insurance plan, there may be a number of dialysis centers that could offer you treatment. You may need to change doctors to change centers.

To find out the locations of other centers near you, visit www.wheredialysis.com, or www.dialysisfinder.com. You can

compare the quality of care at your center to other nearby centers by visiting Medicare's Dialysis Facility Compare website: www.medicare.gov/dialysis/home.asp.

Choosing Home Dialysis

Home dialysis gives you much more freedom to choose your own schedule and even to get more dialysis treatment so you feel well enough to keep working. Depending on where you live, you may have one or more of several options:

- **Peritoneal dialysis** (PD) cleans your blood by using the lining of your abdomen as an artificial kidney. Wastes go into a special fluid in a process called an "exchange." Four to five exchanges may be done daily. Usually one will need to be done at work in a clean, private room during a break or lunch. Ask your boss about using the room. You will need a week or two of training to do PD, and storage space for boxes of supplies.
- **Automated peritoneal dialysis** (APD) or **continuous cycling peritoneal dialysis** (CCPD) uses a machine to do many exchanges at night, leaving your days free. Some people need to do one exchange at work, too. You will need a week or two of training, and usually must learn to do manual PD first.

- **Home hemodialysis** is often done for 3–5 hours per treatment, 3 days a week on your schedule. New machines are now on the market to make setting up and cleaning the machine much easier, and reduce the amount of space you need for storing supplies. If you choose home hemodialysis, you will need about 6 weeks of training, and may need someone with you at each treatment as a helper.
- **Short daily hemodialysis** is done for 2 to 3 hours per day, 6 days a week. This is new, and may not be offered in your area. With more frequent treatments, people often feel better and avoid the good days and not-so-good days of 3-days-per-week hemodialysis. New machines designed for home use make this treatment much easier to do. You will need a few weeks of training.
- **Nocturnal home hemodialysis** is done 6 nights a week while you sleep, leaving your days free except for machine set-up and clean-up. This is also new and may not be offered in your area. People who use nocturnal home hemodialysis get much more treatment than with other types of dialysis, and usually feel very good. The diet and fluid limits are also much less for this type of treatment. You will need a few weeks of training.

To find out which centers near you are approved by Medicare to offer home dialysis options, visit www.nephron.com/usacgi.html and do an “advanced search.” First, choose how you want to search—by region, city, Network, or facility. Next, under Step 3, choose one type of dialysis at a time that you want to learn about. If you want to learn about another type, do a new search.

Your Rights Under Federal Law

People with health problems can face challenges in finding and keeping jobs. You will have to deal with the effects of your illness on your work. You may also have to deal with how others see you because of your illness. It is very important for you to believe you can work in spite of your health.

Employers who know little about kidney disease or other disabilities may believe myths. Since you need a chance to prove your *abilities*, there are laws to protect you.

Rehabilitation Act, Sections 501 and 505

If your health limits at least one major life activity and you work for or want to work for the **federal government**, this Act protects you. Your disability can get you extra points when you apply, and it helps if you worked with vocational rehabilitation to get a job.

Spencer



“When I was first diagnosed with kidney disease my doctor told me I wouldn’t be able to work—well, I have a drive for proving the doctors wrong,” laughs Spencer Ellis, 44.

Spencer has been on hemodialysis since 1996, the same year he was told he had kidney disease. On the advice of his doctor he stopped working, and it didn’t take long for depression to set in. “I got tired of sitting around the house and felt I wasn’t contributing to the family,” recalls Spencer. “I needed to work. I didn’t care if I made a quarter, but I needed to have a feeling of self-worth.”

Prior to having kidney disease, Spencer was working a mostly physical job doing maintenance

and housekeeping at a nursing home. “I didn’t think I could do physical work anymore, but as I gained knowledge I realized that just because there are some things I can’t do, I’m not physically handicapped.”

So Spencer set out to find a job. “I took it upon myself and started applying for jobs. I appreciated the help of vocational rehabilitation services, but I decided to go on my own to get things going,” says Spencer.

Spencer now works part-time as a municipal security guard for the public library system. He enjoys staying active and meeting people, plus has an added benefit of his job: “I can do a lot of research about kidney disease because of working in a library,” he says. Spencer also keeps active by exercising.

“I thought there was no way I could do an exercise program, and now I am on my 4th year of cycling while on dialysis,” he explains. “I’ve lost weight, have a better heart rate, and haven’t had leg cramps since ‘97!”

Married for 21 years and the father of three children, Spencer enjoys going to his children’s school plays, doing lawn work, and working on his car. He also speaks at kidney disease meetings about his experiences. “You’re not confined to a dialysis chair 4 days out of the week,” advises Spencer. “It’s all about where you set your limits and goals. Live for life and go from there!”

Age Discrimination in Employment Act

This law applies to companies with 20 or more workers. If you are **40 or older**, the ADEA protects you from work discrimination. Age is rarely a proven qualification for work.

Americans with Disabilities Act, Titles I and V

Employers who have 15 or more employees must make minor changes, called “accommodations” to help people with disabilities work. Employers do not have to make changes that cost too much or that change job functions. Examples of “reasonable” things people with kidney disease may need include:

- A clean room to do a PD exchange
- Flexible work hours to keep doctors’ appointments or go to dialysis
- A chair to sit in or tools so you can do the job
- An extra rest break

Under the ADA, you do not have to tell any employer what your disability is, as long as you can do the key tasks on a job. You must tell your employer you have a disability (but not what it is) if you need accommodation. You need to know the “essential functions” of the job so you can say if you need accommodation. Any accommodation you need won’t cost much.

Your doctor may suggest you limit or avoid certain types of work. Listen to

your body cues that tell you when to slow down or stop. Ask your doctor to help your employer understand how you can work with kidney disease.

Offer to make up missed work time, when you can. If you need a workplace change, be sure to ask. Your employer does not need to give you anything you haven’t asked for. Some other protections of this law include:

- When you apply, a potential employer can ask if you can do the “essential functions” of the job with or without accommodation. *If you believe you can, you do not have to say that you have kidney disease.*
- An employer cannot ask you to fill out a health history form or take a health exam unless they *first* make you a job offer.
- An employer can only make you take a health exam if *everyone* hired for the job must take one.
- An employer *can* ask you to take a drug test. If you do not make urine, ask if you can give a blood or hair sample for this test.

Civil Rights Act, Title VII

The law applies to employers with 15 or more employees. It prohibits discrimination on the basis of race, color, religion, sex, or national origin.

Equal Pay Act

This law applies to employers of any size. Under the “equal pay for equal

You Have	Accommodations You Might Need	What You Can Do
Kidney disease	<ul style="list-style-type: none"> • Lab tests: 1–2 hours off • MD visits: 1–2 hours off 	Schedule MD visits to avoid lost work time
Peritoneal dialysis	<ul style="list-style-type: none"> • Catheter surgery/recovery: 2–5 days • PD training: 1 week • Clean room: 30–45 minutes/day • Minimal supply storage • MD visits: 2–3 hours a month 	Schedule surgery to avoid lost work time, use sick leave for training
Hemodialysis starting soon	<ul style="list-style-type: none"> • Access surgery/recovery: 2–5 days • No weight-bearing across access arm 	Schedule surgery to miss less work, start dialysis before you get too sick
In-center Hemodialysis	<ul style="list-style-type: none"> • Treatment: 4–5 hours, 3 times a week • Notice of work hours change • Chair to sit down • 1 month notice to travel • No weight-bearing across access arm 	Ask for a shift to reduce missed work, protect access at work, plan ahead for work travel
Home hemodialysis (HHD)	<ul style="list-style-type: none"> • Training: 4–5 hours off for 6 weeks on MWF • Clinic visits: 2–3 hours off per month • Notice of work hour change • No weight-bearing across access arm 	Ask center to schedule training around work time, protect access at work
Live donor kidney transplant	<ul style="list-style-type: none"> • Evaluation: a few hours off per testing day • Surgery & recovery: 6–8 weeks (scheduled) • MD visits: 2–3 hours a month, less later 	Plan surgery with donor and employer around work demands, make MD appointments to reduce lost work time
Cadaver kidney transplant	<ul style="list-style-type: none"> • Evaluation: a few hours off for each testing day • Surgery & recovery: 6–8 weeks (unscheduled) • MD visits: 2–3 hours a month, less later 	Tell your employer when called for transplant, make MD appointments to reduce lost work time

work” law you should be paid the same as anyone else who has the same skills, duties, and works under the same conditions as you.

Dealing with Job Discrimination

According to the U.S. Equal Employment Opportunity Commission (EEOC), the ADA, ADEA, and Civil Rights Act forbid your employer from treating you differently because of your age, race, color, religion, national origin, sex, or disability in any of the following areas:

- Hiring and firing
- Pay, assignment, or classification of employees
- Transfer, promotion, layoff, or recall
- Job advertisements
- Recruitment and testing
- Use of company facilities
- Training and apprenticeship programs
- Fringe benefits and retirement plans
- Disability leave
- Other terms and conditions of employment

Discrimination: What to Do

1. If you believe that you are being discriminated against at work, first try to work things out through your employer’s human resources (HR) department. FindLaw™ (http://public.findlaw.com/employment_employee/) suggests that you:

- Control your emotions.
- Know your rights.

- Write down exactly what happened.
- Make a list of possible solutions.
- Work with the employer on next steps and timelines.
- Check back with the employer about progress regularly.
- If things aren’t better, take notes about events (who, what, when, where), and copy any papers you can copy legally. If co-workers were present, ask them to write what they saw or heard.
- Know the deadline to file specific complaints.

2. Complain to the U.S. EEOC. Call (800) 669-4000 or look up their number in the federal government section of your phone book. If you have the Internet, see www.eeoc.gov.
3. Contact your state human rights or civil rights agency for help. You can find these numbers in the state government section of your phone book.
4. Talk with a lawyer to learn if you have a case. Your state or local Bar Association may have a list of lawyers who charge less for a brief visit or even offer free legal help for people with low income. You can find a list of Bar Associations at www.bg.org/bar.html.
5. Consider going to the press. Your local TV station may have a consumer help-line, or your local newspaper may be willing to do a story that could help you keep your job—or find a new one.

CHAPTER 5 — UNDERSTANDING DISABILITY PROGRAMS

You may qualify for Social Security benefits through one of two federal programs if your health keeps you from working. These programs are intended for people who have a disability that is expected to last at least 1 year.

Disability payments can help take care of you and your family while you learn new job skills or recover enough to go back to work, or if you are permanently disabled. If you get disability, you may qualify for work incentive programs to help you go back to work when you are ready.

Anyone who gets Social Security benefits must report changes to Social Security that could affect benefits. You or your family should call (800) 772-1213 to report:

- Change of address
- Change in your condition
- Change in your work status and any impairment-related work expenses (see page 66)
- Plans to leave the U.S. for 30 days or more
- Other benefits you get, such as worker's compensation, other government disability, or company disability
- Change in marital status
- If you're not able to manage your funds, who can manage these for you

- If you're convicted of a crime
- If the beneficiary dies

If you give Social Security false information and don't correct it, your benefits could stop and you might not get future benefits for up to 2 years.

As of 2003, if you earn at Social Security's limit before your disability claim is approved or in your first 12 months on disability, you can lose your disability benefits. You could also lose the chance to have a trial work period, or other work incentives that we will describe in Chapter 7.

Supplemental Security Income (SSI)

SSI, also called Title 16, is a program that gives money to live on for people who are 65 or older, blind, or disabled. You do not need a work history to get SSI.

To get SSI due to disability, all of the following must be true:

- Your health problem is severe enough to limit any kind of work.
- Your health problem is expected to last a year or result in death.
- You have less than \$2,000 in countable assets (\$3,000 as a couple).
- Your income is below the dollar amount that the Social Security Administration (Social Security)

allows for SSI (call 800-772-1213 for current year amounts or see www.socialsecurity.gov under “benefit/tax changes”).

How much money SSI will pay depends on your other income and your housing. Gifts, pensions, other disability, Social Security, VA benefits, etc. reduce your SSI check. If you live with others and do not pay for rent or food, your SSI check will be 1/3 less. Tell Social Security what you pay for housing and food if you live with other people.

If you are under 18 years old, your parents’ or other family member’s income and assets will affect your SSI benefit. Once you turn 18, Social Security will only count your income and assets to decide how much SSI to pay you.

You can find the federal benefit rate for SSI under “benefits/tax changes” on www.socialsecurity.gov or call (800) 772-1213. Most states supplement SSI payments. Arkansas, Georgia, Kansas, Mississippi, Tennessee, and West Virginia did not supplement SSI in 2003, and with tight budgets in every state, more states may follow suit. When you apply for Social Security disability benefits, the claims representative will check to see if you qualify for SSI.

Social Security Disability Income (SSDI)

Social Security is a disability or retirement insurance plan that you pay

into through a payroll tax. SSDI is the disability insurance program for people with a work history. To qualify for SSDI, all of the following must be true:

- Your health problem is severe enough to limit any kind of work.
- Your health problem is expected to last a year or result in death.
- You earn less than the “substantial gainful activity” (SGA) amount that Social Security allows people to earn and still get SSDI. To find the current SGA, call (800) 772-1213, or see “benefits/tax changes” on www.socialsecurity.gov.
- You have enough work credits. (See page 18 for a chart.)

Social Security will tell you how many work credits you have and how much money you would get each month if you are disabled or retire. Call (800) 772-1213 or visit www.socialsecurity.gov/online-services and ask for Form SSA-7004 to see your Social Security record. Private companies will charge you a fee to find this information, but it is free when you do it yourself.

If you are 18 or older and became disabled before you turned 22, you may get SSDI benefits if all of the following are true:

- Your parent worked and earned enough credits.
- Your parent died or is getting Social Security retirement or disability.

- You are single or married to someone who is 18 or older, not a student, and who gets Social Security.
- You are not working or, if you are working, you are earning less than the Social Security limit.

Your family's income and family savings do not affect how much SSDI you get. Instead, your SSDI amount depends on how much you paid in Social Security taxes and whether you have a family to take care of. In 2003, the average SSDI check for one person was \$833 a month. The average SSDI check for a disabled person, spouse, and children was \$1,395 a month.

You can qualify for SSDI alone or for SSDI *and* SSI, depending on your finances.

To apply for SSDI, call Social Security. You can apply on-line at www.socialsecurity.gov, by calling (800) 772-1213, or by visiting your local Social Security office. The form you need is called *Disability Report* (SSA-3368).

Filling Out a Disability Application

Give good, clear details when you apply. Describe how kidney disease has changed your life:

- How do symptoms or other health problems affect things you have to do every day: bathing, dressing, cooking, walking, standing, balancing your checkbook, using the phone, etc.?
- How many good days do you have compared to the not-so-good days?
- What activities have you had to cut back or stop due to your illness?

Any change you report may help Social Security decide whether you are disabled. Ask family or friends if you need help.

Determining Disability

After you fill out and mail in the form, your local Social Security office will review it. Social Security sends disability applications to your state's Disability Determination Service (DDS). DDS uses a five-step test to decide if you are disabled:

1. Are you working at the **Substantial Gainful Activity (SGA)** level? The SGA is the Social Security income limit. The amount changes each year. Income from pensions, rent, interest, or dividends does not count.
 - If you work for someone else, Social Security looks at how much money you make. If you make more money than the SGA, you will probably not get disability.
 - If you are self-employed, Social Security looks at how many hours you work in a month. If you work more than about half-time for yourself, you will probably not get disability.

NOTE: If you work and earn more than the SGA level, you may still be able to get disability if

you have expenses due to your health problems. If Social Security approves these expenses, they can be subtracted from your income and may bring it below the SGA level.

2. Is your health problem severe enough to interfere with basic tasks in any job? Most people with kidney failure meet Steps #1 and #2.
3. Is your health problem listed in the Social Security's Disability Evaluation Under Social Security (www.socialsecurity.gov/disability/professionals/bluebook/)? Social Security lists lab test results and symptoms of severe kidney damage, as well as hemodialysis, peritoneal dialysis, and kidney transplant under Section 6.00. If your health keeps you from working, you may qualify for SSI or SSDI benefits. If your kidney damage does not meet the level required in the listing, the DDS will apply the fourth and fifth step.
4. Can you do work you've done before?
5. Can you do *any* work, considering your age, education, work skills, experience, and job demands?

It can take 3 or 4 months to decide if you are disabled. The process may be faster if you are on dialysis or have had a transplant for less than a year. It can take longer if your kidneys are failing for the first time or if your

kidney transplant is rejecting after more than a year.

If your application is approved, you will get an award letter. **Keep this in a safe place.** You will get your first check in the 6th month *after* Social Security finds you disabled. *You will not get any money for the 5-month waiting period.* If you have questions, a claims representative can explain how much you will get and what you must report.

Appealing a Disability Decision

If Social Security denies your claim, you can appeal—if you do so *within 60 days*. The 60-day clock starts 5 days after the date on your denial letter. At each step, you have another 60 days plus 5 days, to respond. Your appeal steps include:

1. Ask for **reconsideration** and someone in Social Security who did not review your case the first time will review it.
2. Ask for a **hearing** before an administrative law judge, give medical reports, and ask witnesses to speak for you. The judge can ask any doctor who has treated you to provide medical reports, or ask you to get a physical from a Social Security doctor. You don't need to hire a lawyer, but 80% of the people whose cases are heard by judges have legal help.

3. Write a request for an **Appeals Council Review**. The Council will review what the judge decides. In many cases, the Appeals Council finds that there wasn't enough evidence to deny you disability.

4. Appeal through the **federal court system**, starting with the U.S. District Court. You need a lawyer for this step.

Disability Review

Don't be surprised when you get a survey to fill out asking about your disability. This is part of a **continuing disability review**. Social Security asks everyone with SSI and SSDI to do this. Depending on how likely your condition is to improve, you could have to do this anywhere from every 6 months to every 7 years.

Self-esteem and Disability

If you think that because you are disabled and not working that you are not doing your part, think again. There are many ways you may be helping your family, friends, church, or community. Some of the many things you might be doing:

- Keeping up your home and yard
- Taking care of children or grandchildren so a parent can work
- Helping a student with homework so he or she can finish school
- Staying in touch with friends and boosting someone's mood

- Making handmade crafts or gifts
- Teaching someone a hobby or skill
- Doing things for your church
- Volunteering to help people who are in the hospital, in nursing homes, or homebound

Social Security has a number of work incentive programs if you are on SSI or SSDI that can help you start or ease back into work. We'll cover those in the next chapter.

CHAPTER 6 — FINDING A NEW JOB

Whether you are seeking a first job or have a long work history, getting ready to work and looking for a job can be a full-time job in itself. In this chapter, we'll talk about steps you can take to find a new job. In the next chapter, we'll cover how vocational rehabilitation can help you—and what safety net programs are in place if you get SSI or SSDI disability checks and are worried about losing them if you work.

Getting Strong Enough to Work

If you have been sick for a while, you may have stopped doing anything active and your muscles may be weak. Build up your strength and endurance through exercise. Start slowly and work up until you are doing 45 minutes of exercise most days. You don't have to do all 45 minutes at once. You can do a few minutes at a time.

Life Options has free information to help you stay active. Call (800) 468-7777, or visit www.lifeoptions.org/exercise/ or the “Staying Active with Kidney Disease” module of Life Options Kidney School™ at www.kidneyschool.org. Talk to your doctor before starting a new exercise program.

Selling Yourself, Your Skills, and Your Abilities

Some people think an employer may be afraid to hire them because of their health. The National Organization on Disability published these *Top 10 Reasons to Hire People with Disabilities*:

1. Disabled workers can ease concerns about the labor supply.
2. Disabled people have equal or higher job ratings, lower turnover, and miss fewer days of work.
3. Disabled workers can relate better to disabled customers, who spend \$1 trillion per year.
4. Diverse work groups can create better solutions to business challenges.
5. Disabled people are better educated than ever, and are proven to have met and/or exceeded challenges.
6. Disabled people motivate work groups and raise productivity.
7. Companies that hire and accommodate disabled people in their workplaces can get tax benefits.
8. Employing disabled people is good for the worker, the business, and society. This is a “win-win-win” strategy.
9. Disabled people are motivated by the desire to give something back, and chances for personal growth, job flexibility, and social inclusion.
10. It's *ability*, not disability, that counts.

This should help you feel more confident about yourself and your ability to find a good job despite kidney disease.

Employer Tax Credits for Hiring Disabled Workers

Something else that may help you feel more confident are programs that offer tax credits to companies that hire certain disabled workers. The IRS (www.irs.gov) or a tax advisor can tell an employer more about tax credits for removing barriers and hiring disabled people, long-term welfare recipients, Native Americans, and others.

Your new employer may be able to get a Work Opportunities tax credit worth \$2,400 for the first \$6,000 you are paid if:

- You are disabled.
- You get SSI or you have worked with vocational rehabilitation.
- You work at least 400 hours in your first year.
- You and your employer fill out IRS Form 8850.

Your new employer may be able to get a Disabled Access tax credit worth up to \$5,000 per year. This credit is meant to help small businesses remove workplace barriers so disabled people can work. A company that hires you may qualify if:

- It is a small company that makes less than \$1 million/year.
- The company has less than 30 full-time employees.

- Your employer reports this on IRS Form 8846.

Aiming for the Job You Want

Before you can find a job, you need to have some idea of what you are looking for—and the more clear your idea is, the easier it may be to figure out the steps that will help you to get there.

Think about your ideal job. Write down what you are looking for: work conditions, hours, salary, benefits, location, etc. Think about whether you want to work for someone else or for yourself.

Do you want to work part-time, full-time, or in a short-term position? Do you want a job with potential for advancement? What do you value in a job—flexible scheduling, casual dress, working with people, working indoors or outdoors, working at a desk or traveling? Set some goals that you can achieve.

It's easy to blame job search troubles on your kidney disease. But in a tight economy, or when unemployment is high, it can take time to find a good job. Be patient and creative. You may just need to look in different places. Ask your friends for job leads. Talk with others that are also looking for work. Look for a support group or “job club” in your area.

Review Your Skills

List all the skills you have from working and living. You may find that you have skills that you didn't know you had. If you are a stay-at-home mom, you may have experience scheduling, supervising, and settling disputes. If you are a student, you may be able to research topics, write and edit papers, and meet deadlines. Skills like these can be useful in many jobs.

Job-hunting books can help you learn your strengths and skills and can suggest helpful job search tips. We've listed some in the Resources section of this booklet.

Find Your Work Interest

With more than 36,000 careers in North America, it's no wonder many people have a hard time deciding what type of work to do. A career counselor can help you by giving you surveys to help you see how your personality, interests, skills, and values fit with different jobs.

Based on your results, it will be easier to choose a career or know if you need more training for the career that best fits you. A career counselor can help you find more training, if needed. A career counselor can work in a high school, college, employment agency, or private practice. State vocational rehabilitation agencies offer career counseling (see Chapter 7).

There are several websites where you can take tests to find out how your personality and values fit with different careers. Two free ones are:

- www.edonline.com/collegecompass/carhlp2.htm
- <http://career.missouri.edu/holland/>

Look for Job Openings and Resources

Newspaper want ads are only one source of jobs—only about 10% of jobs are listed in the newspaper. There are much better ways to get a new job. Network: tell everyone you know what you are looking for. Employers like to hire people who are referred by someone they trust. Look on the Internet. Check out companies that may be hiring in your field and write to them. Go to job fairs.

The Internet has a wealth of resources that can help you if you are looking for work:

- The **Social Security Office of Employment Support Programs** has fact sheets, booklets, links to other helpful sites, and more for youth and adults with disabilities, employers, and advocates at www.socialsecurity.gov/work.
- The **Office of Disability Employment Policy** website, www.dol.gov/odep/, has fact sheets on topics for disabled people and employers. It also has links to other state offices.

- The **National Center on Workforce and Disability for Adults**, www.onestops.info, covers job search, accommodations, resources for workers and employers, and even work transportation.
- The **National Collaborative on Workforce and Disability for Youth**, www.ncwd-youth.info, has information to help youth with disabilities live productively. A section of the website is devoted to information for youth and their families.
- **WorkWORLD**®, www.workWORLD.org, is a computer program you can download. This program can answer many questions you might have about working and how it will affect your other benefits. Check dates when dollar amounts are quoted because these change every year.
- In addition to well-known sites like **Monster Board**, www.monster.com, there are websites that link you with companies or federal agencies that hire disabled people, such as:
 - **RecruitAbility**, www.disabledperson.com/recruitability.asp
 - **Job Links**, www.dol.gov/odep/joblinks/joblinks.htm
 - **DisabilityInfo**, www.disabilityinfo.gov/Employment

Gaining New Work Skills

If you have been out of the work force for a while, or you can no longer do

the kind of work you did before, there are a number of ways that you can improve your job skills.

Volunteer

Volunteering helps you keep old skills, learn new skills, try out all kinds of work, and get references you can use when you apply for your next job.

You may be surprised at the number of places where you can volunteer. Schools, hospitals, non-profit organizations, churches, and many other places need volunteers. There may even be a “volunteer center” in your community to link volunteers with places they’re needed. For instance, VolunteerMatch (www.volunteermatch.org/) helps to match volunteers, like you, with those nearby who need help.

Take a Temporary Job

Temporary job agencies can give you experience that can help you find a permanent job. They have full-time and part-time jobs that can meet most people’s schedules. Some agencies offer training. Some offer benefits, including health insurance. And some part-time jobs can lead to full-time work.

Kelly Services® (www.kellyservices.com), Olsten™ Staffing Services (www.olsten.com), and Manpower® (www.manpower.com) have all hired people with disabilities, including those with kidney failure.

Go to School

Take classes at a technical school, learn a new trade, or go back to school for that degree you always wanted. Adult students are often good learners and do well.

Find out about scholarships, loans, veteran's benefits, or sponsorship from your local department of vocational rehabilitation to pay for school. Most schools have a financial aid office to help current and future students find money for college or vocational training.

Preparing for a Job Search

Write a Resumé

A good resumé gives a potential employer a first look at you and your skills. Getting help to write a resumé is your first step to get ready for a job interview. There are many books with sample resúmes. You may use a different resumé based on the type of job you are seeking.

There are three main types of resúmes:

1. A *reverse chronologic* resumé is the most common type. You list your most recent job first. Use this type when you have worked in a field, can state results you have achieved in past jobs, or you have worked for a well-known company.
2. A *functional* resumé highlights work skills and is useful for older workers, new workers, or people

who have been out of the workforce for a while. Use this if you have little work experience or breaks in your work record.

3. A *combination* resumé uses the best of both. You list employers and state the job skills you needed for each. Use this if you have jobs that needed different job skills or if you have volunteer jobs or internships in your field.

Tips for Writing a Resumé:

- Tell the truth and be brief.
- List the past 10 years of work only.
- Sell yourself and your skills by listing education, internships, and volunteer work. List only hobbies or activities that are related to the job you seek.
- Focus on achievements, but don't use "I."
- Use "action" verbs: accomplished, administered, advised, audited, built, counseled, designed, directed, edited, designed, estimated, implemented, improved, invented, motivated, operated, purchased, researched, scheduled, supervised, trained, etc.
- Review and spell-check your letter and resume. Mistakes count against you.
- Use quality white or cream colored bond paper for the cover letter and a matching envelope.

- Mail multiple page resumes in a large flat envelope.
- Do not include a photograph.
- Do not list the salary. You can reach a deal on this later and you don't want to sell yourself short.
- Do not include references in your resume — give a list to the interviewer.

Get Ready for an Interview

When you are called for an interview, you probably meet the basic skills for the job. But an employer is not just looking at your skills. He or she is also looking at your personality—your motivation, enthusiasm, dedication, and loyalty.

Tips for Interviewing:

- Research the company.
- Dress neatly and appropriately for the job you seek.
- Bring everything the employer has asked you to bring.
- Practice answers to possible interview questions.
- Keep good eye contact with the interviewer.
- Explain how your skills match the job.
- Ask questions.
- Be positive and enthusiastic.

The interview will find out if you meet the basic job requirements. Put your best foot forward. Learn all you can about the company before you go.

Point out your experience, training, and references, and tell the interviewer how you think your skills and personality fit with the company's mission.

Talk about things that would make you a unique and valuable person for the company. If you are asked to list a fault, think about things that can be also seen as positives too, such as "I've been told that I expect a lot from myself." You can find a list of questions that interviewers often ask at www.careercc.com/interv3.shtml#well. Practicing what you will say can help you answer more confidently in interviews.

Brenda

“I do not like to sweat or mess up my hair, and I know I look good for my age!” says 48-year-old Brenda Dyson from Flowood, Mississippi. Brenda is a Southern Belle in many ways... a Southern Belle with kidney disease.

In 1987, just 2 months after her mother’s death, Brenda faced the unexpected news that she had membranous glomerulonephritis—a disease that would force her to begin dialysis. “When I was first told of my kidney disease, I was too numb to be afraid,” she says. “But I also had a great doctor who helped me to keep going.”

So just 2 weeks after starting dialysis, Brenda quit her job to move closer to her family, and began working at a local hospital. One year later she began a new job at ESRD Network 8. At first, Brenda was on in-center hemodialysis while training to do home hemodialysis. “Not every doctor offers home hemo as an option, but I was lucky to have a physician who knew about home hemo,” she recalls.

Like many working people on dialysis, Brenda had some problems to deal with early on in her treatment. “When I started dialysis, it was in the pre-EPO days, so being tired was a problem,” she remembers. “I worked for

2 years or so with a hematocrit of 19—at the most!” However, Brenda believes that she had most of her physical problems when she first began dialysis. “Don’t give in to the sick feeling when you first start dialysis,” she advises. “Once you get to the point of being able to get on with life, and as soon as you have even a bit of energy, start doing and keep going!”

Once trained, Brenda remained on home hemo until 1990, when she received a kidney transplant from her sister Lynda. In July of 2001, that kidney failed. Brenda began in-center hemodialysis, and 5 months later, was the first person in the U.S. to use the NxStage Therapy System—a portable, daily dialysis machine. She stayed on NxStage



Brenda (center), with her sisters Lisa (left) and Lynda (right).

“Don’t give in to the sick feeling when you first start dialysis. Once you get to the point of being able to get on with life, and as soon as you have even a bit of energy, start doing and keep going!”

until she received her current transplant from her sister Lisa.

“I took 2 and a half weeks off for each of my transplants,” says Brenda. “I probably used less sick time than most people—I’m really stubborn, so that’s part of it!” Brenda does have some fear of losing her current transplant, but doesn’t let the fear take over her life. “It’s nothing that keeps me from everyday living,” she says. In addition, Brenda has had to come up with creative ways to help pay some of her medical costs. “It can be difficult when Medicare runs out. You have to sacrifice a bit and plan and budget,” she says. “It’s good if the pharmacist is willing to work with you, for example to pay as you can, or to get your meds on December 1st and again on December 31st, then you can spread out and budget your deductible for your insurance.”

Brenda, who has a college degree in Health Information Management, currently holds the

title of Patient Services Coordinator at ESRD Network 8—a position that has allowed her to give back to patients. “Working at the Network gives me the best chance in the world to help meet patient’s needs,” says Brenda. “It’s a real good way to give back. It’s just a given that you feel better when you help other people.”

Because Brenda is not married and supports herself, she never thought of not working. Brenda does receive Medicare, but doesn’t receive any other monetary support. “I was never out of work long enough to qualify for programs,” she says.

In addition to working and being a doting aunt to her niece Hannah Rose, Brenda serves as President of the Board of Directors of the American Association of Kidney Patients (AAKP). She is also President-Elect of the Mississippi Sports Hall of Fame and Museum, where she volunteers at the museum two Saturdays a month. “Though I have no athletic skills, I am a sports nut!” explains Brenda.

A recipient of numerous awards, including the National Kidney Foundation, Patient and Family Council’s 2002 Wayne Nix Memorial Award, Brenda lives a rich life beyond her kidney disease. “I enjoy working, volunteering, and keeping busy,” she says. “Otherwise I would sit around eating all day and I would be big as a house!”

CHAPTER 7 — VR AND WORK INCENTIVE PROGRAMS

Working with Vocational Rehabilitation (VR)

The mission of your state VR agency is to help you keep your job or find a new one, especially if you get Social Security. If you apply for Social Security disability, Social Security may refer you to your state's VR agency.

The Rehabilitation Services Administration (RSA) in Washington, DC oversees all state VR agencies, which are funded by federal and state tax dollars. These agencies can:

- Assess your work skills, needs, and goals
- Work with you to develop a plan for service
- Help you get training or retraining for a different job if you need it
- Find employers who are willing to hire disabled people
- Help you find and keep a job

A good VR counselor can be a great advisor and advocate. There is a list of state VR agencies in the Resources section or you can find a list on the Internet at www.socialsecurity.gov/work/ServiceProviders/rehabproviders.html. Call and make an appointment yourself. This is the first step to showing a VR counselor that you want to work.

Talk to Your Doctor

Tell your doctor or social worker that you are trying to work. Ask your doctor or clinic to send medical records right away to speed up the process.

Doctors are used to filling out forms for people who want disability, so be sure your doctor's letters to VR say that you *can* work. Your social worker can work with you and your VR counselor to help you succeed.

VR takes time. You probably won't get a job right away. But you may be able to find a better job with VR help, and employers may be more likely to hire you because they can get a tax credit for hiring a VR client.

If your state VR agency denies you services, or you feel you are not getting the help you need from VR, contact your local Client Assistance Program (see "protection & advocacy" services at www.passonline.org/Resources).

If you qualify for services, but the VR agency can't serve you because it does not have enough money, it can refer you to a one-stop career center partner.

What to Expect at Your First VR Visit

If you get a VR referral, the counselor will use your first visit to look at your health history and talk with you about what you need to work, why you can't

find and keep a job on your own, and what services, if any, the agency can use to help you.

Most VR counselors have never worked with anyone who has kidney disease—so they may think you cannot work. Your counselor may believe you are too sick to work if you are on dialysis, or not sick enough to get help from VR if you have a transplant. Be determined! You know better than anyone else what you can and can't do.

You may have to tell the counselor about kidney disease, treatment, how much you want to work, and what you've done on your own to find a job. The key is to explain any reasons why your kidney disease (or other disability) is keeping you from getting or keeping a job.

Kidney Disease Resource for VR Counselors

There is a new training manual for VR counselors that your VR counselor may not have seen. This manual, *Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease*, tells counselors about the steps of working with a client with kidney disease.

Your counselor should ask the state VR agency for a copy or find it on the Internet at www.rcep6.org/IRI27.pdf. It is easier to get VR services when you are getting Social Security benefits because Social Security has found you disabled.

Testing Your Work Abilities

Once you are accepted for services, a counselor will ask you about your interests, past work history and skills, goals, health, strengths, weaknesses, and limits on work. You may be asked to take tests to measure your interests and abilities. This information will be used to help you decide what kind of work you can do.

It will be much easier for a VR counselor to help you if you have a clear goal for the kind of work you want to do. Telling a counselor, "I'll do anything," does not offer any direction. Dream. Imagine. Pick a goal. Then your VR counselor can help you to get there.

The next step is to write a plan just for you that can help you reach your goals. Your plan might include:

- Talking with an employer about a schedule that meets your needs, but still lets you do your job
- Changing to a less physical job, if necessary
- Helping you get a grant or loan for retraining, college, or other education

Assessing Your Work Site

Most people think of going to VR to help get a new job. But if you are working and your job takes more strength than you have, or you need help to do your job, VR can assess your work site. Your counselor can talk with your employer or supervisor about:

- How to remove workplace barriers
- Tools that can help make your job easier
- Tips to help you change the way you do some job tasks to save your energy
- On-the-job training for a job that is better suited to your needs
- Special equipment, like a computer, wheelchair ramp, or lift

One-stop Career Centers

All states have one-stop career centers (www.onestops.info) to help you understand your rights, write a resume, use a computer to learn about jobs and post a resume, get help, and learn about other resources in your area. One-stop career counselors can tell you about open jobs in your area and around the country.

Most cities, states, counties, and the federal government list civil service (government) jobs. You can find these on the Internet for free, or have them mailed right to your home for a small fee.

Social Security Work Incentives

SSDI and SSI have safety net programs to help disabled people go back to work. The more you know about these work incentive programs, the more you will be able to help use them to your own advantage.

To find whether you will have more money if you work or keep disability

in *your* case, talk with the work incentive liaison or employment support representative in your local Social Security office (see www.passonline.org/resources). You can talk with your area's Benefits Planning, Assistance, and Outreach counselor by calling (800) 772-1213 to find a contact name and number, or visit www.socialsecurity.gov/work/ServiceProviders/BPAODirectory.html.

Social Security pays SSDI because it expects your disability to keep you from working at least 12 months. If you want a trial work period, do not work until after you get your first SSDI check.

Impairment Related Work Expenses (SSI and SSDI)

Social Security can subtract what you pay for doctor visits, dialysis, drugs, tests, supplies, assist devices for your car, a driver for work due to disability, a home dialysis machine and supplies, a home dialysis helper, and more, from your countable earnings. If your earnings minus these costs are less than the SGA level, you keep your *full* SSDI or SSI check. If your earnings are more than the SGA, you may lose your disability check, at least for that month.

Subsidies and Special Conditions (SSI and SSDI)

Social Security does not count pay you get from an employer or VR agency that is over the actual value of your services.

Unincurred Business Expense (SSI and SSDI)

Social Security does not count certain things others give you toward self-employment. Examples: Value of a computer from VR or a friend's donated time.

Unsuccessful Work Attempts (SSI and SSDI)

Social Security does not count earnings if you tried to work above the SGA level but stopped within 6 months due to your disability.

Continued Payments under VR Programs (SSI and SSDI)

If you medically recover (e.g., from a transplant), you can keep disability as long as you are in an approved VR program and working toward a goal of being self-supporting.

Trial Work Period (SSDI only)

You get 9 months (not necessarily in a row) to see if you can work. You keep your full SSDI check no matter how high your income is. If your income is more than the trial work period amount, you use up one month of trial work. Call (800) 772-1213 or see "benefits/tax changes" at www.socialsecurity.gov to find out the current trial work period amount.

Extended Period of Eligibility (SSDI only)

You don't have to file a new application to restart benefits if you are still considered disabled and your income drops below SGA within 37 months after the end of your trial work period.

Continued Medicare Coverage (SSDI only)

People on dialysis can keep Medicare even if they work. Other workers with disabilities can keep Medicare for 8.5 years after they start working at the SGA level.

Medicare for People with Disabilities Who Work (SSDI only)

Even after 8.5 years, you can *buy* Medicare if you are a disabled worker and can't get other insurance. If you or your spouse has worked at least 30 quarters, you can get a discount. If you have low income, your state may pay your Medicare premiums.

Earned Income Exclusion (SSI only)

Social Security does not count the first \$20 of unearned income you get each month. Unearned income includes pensions, rent paid to you, disability payments, interest, etc.). Social Security also does not count the first \$65 of money you earn from work each month. After this \$85, Social Security reduces the amount of SSI it pays you by \$1 for every \$2 you earn from work.

Student Earned Income

Exclusion (SSI only)

If you are a student under 22, single, and not head of a household, you can work and still get your full SSI check. The amount you can earn changes each year. For the current limit, call (800) 772-1213, or see “benefits/tax changes” at www.socialsecurity.gov.

Plan for Achieving Self-Support [PASS, Social Security Form 545] (SSI only)

With a plan that is approved by Social Security, you can set aside income and resources for a work goal—education, training, a business, buying a car for work *if* public transport isn’t available. If you have SSDI, a PASS can also make you eligible for SSI so you can get Medicaid in most states. You can find PASS forms at www.socialsecurity.gov/online/ssa-545.html. A PASS specialist can explain this program (www.passonline.org).

Property Essential to Self Support

Social Security does not count property you use for work or business and it may not count \$6,000 in non-business property or income-producing property.

Tip

A wonderful resource on all aspects of Social Security Work Incentives is the *Red Book on Employment Support* (Social Security Pub. No. 64-030) available on-line at www.socialsecurity.gov/work/ResourcesToolkit/redbook.html.

Special SSI Payments for People Who Work [Section 1619(a)] (SSI only)

You can keep getting SSI if you are a disabled worker and have less than the resource limit. You get the earned income exclusion (above) and Social Security counts only half of what you make from work before deciding how much SSI to pay you. You will get no more SSI cash if you earn over this *break-even point*. To find out this amount, call your local Social Security office or (800) 772-1213.

Continued Medicaid Eligibility [Section 1619(b)] (SSI only)

You can get Medicaid even if you don’t get SSI cash because your work income is too high. You must be disabled, have received at least one month of SSI, meet other eligibility guidelines, need Medicaid to work, and have an income that is not enough to replace SSI, Medicaid, and any personal care you get. For limits, see www.socialsecurity.gov/work/ResourcesToolkit/Health/1619b.html.

Special Benefits for People under Section 1619 (a) or (b)

Who Enter a Medical Treatment Center (SSI only)

Get SSI cash for up to 2 months if you are under Section 1619 and

in a Medicaid facility or public medical or psychiatric center.

Reinstating Eligibility Without a New Application (SSI only)

If you start working and have a health setback due to the illness that caused you to get disability, Social Security can help. You can ask Social Security to reinstate your SSI or SSDI benefits. To qualify, you must ask within 60 months of when your SSI or SSDI cash payments stopped because you went back to work.

Social Security will pay you SSI or SSDI checks for up to 6 months while it decides whether your condition is disabling. You will never have to pay this money back, even if Social Security finds that you're not disabled as long as you *believed* you were disabled. To restart SSI, you must meet the income and resource limits.

Blind Work Expenses (SSI only)

Social Security does not count income used to pay costs of earning income (not necessarily related to blindness)—work transportation, helper animal expenses, translation of materials into Braille, sensory aids, income and Social Security taxes, professional fees, union dues, etc.

SGA Not Applied Under SSI to People Who Are Blind (SSI only)

If you meet the medical definition of blindness, you can get SSI until you get better medically or eligibility ends for a non-disability related reason.

Ticket to Work and Work Incentives Improvement Act

The Ticket to Work and Work Incentives Improvement Act was passed and signed into law in December 1999. By 2004, if you

Ticket to Work Phase-in Year

State	Phase-in Year
Arizona, Colorado, Delaware, Florida, Illinois, Iowa, Massachusetts, New York, Oklahoma, Oregon, South Carolina, Vermont, and Wisconsin	January–June 2002
Alaska, Arkansas, Connecticut, District of Columbia, Georgia, Indiana, Kansas, Kentucky, Louisiana, Michigan, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, South Dakota, Tennessee, Virginia	July–December 2002
Alabama, American Samoa, California, Guam, Hawaii, Idaho, Maine, Maryland, Minnesota, Nebraska, North Carolina, Northern Mariana Islands, Ohio, Pennsylvania, Puerto Rico, Rhode Island, Texas, Utah, Washington, West Virginia, Virgin Islands, Wyoming	January–December 2003

Social Security Administration

Ticket to Work and Self-Sufficiency

Ticket Number
123-45-6789TW

Claim Account Number
987-65-4321 W

Issue Date:

SOCIAL SECURITY ADMINISTRATION

This ticket is issued to you by the Social Security Administration under the Ticket to Work and Self-Sufficiency Program. If you want help in returning to work or going to work for the first time, you may offer this ticket to an Employment Network of your choosing or take it to your State vocational rehabilitation agency for services. If you choose an Employment Network and it agrees to take your ticket, or if you choose your State agency and you qualify for services, these providers can offer you services to help you go to work.

An Employment Network provides the services at no cost to you. The Social Security Administration will pay the Employment Network if you assign your ticket to it, and the Employment Network helps you go to work and complies with other requirements of the Program. An Employment Network serving under the Program has agreed to abide by the rules and regulations of the Program under the terms of its agreement with the Social Security Administration for providing services under the Program. Your State agency can tell you about its rules for getting services.

James B. Bennett
Commissioner of Social Security

receive SSI or SSDI and are between the ages of 18 and 65, you will get a ticket you can use to get free job training or help finding a job from a public or private rehabilitation service called an *employment network*.

If you get a “ticket” in the mail, keep it in a safe place. Read the letter and brochure that come with it. Even if you are not able to work now, you may be able to work later. A sample ticket can be seen above.

Features of the Ticket to Work Program

The new Ticket to Work program has a number of features:

- It gives you a ticket that you can give to any public or private employment network
- People who work in Benefits Planning, Assistance, and Outreach (BPAO) agencies have been trained to advise you on work options and how working affects your other state and federal benefits (www.socialsecurity.gov/work/ServiceProviders/BPAODirectory.html)
- The employment network you choose will be paid for helping you to get and keep a living wage job.
- You can keep Medicare Part A free, and Medicare Part B if you pay the premium, for 8.5 years—as long as you work with a disability.
- You can get back on disability without reapplying if you have to stop working within 5 years because of a change in your health problem.

- You can put your Medigap coverage on hold to take an employer's insurance and get it back later if you have to stop working due to your health problem.
- Social Security disability reviews stop while you are using a ticket to find work.
- You can get Medicaid in some states if the income the state counts is less than 250% of the federal poverty level. You can find the federal poverty level amounts at <http://aspe.hhs.gov/poverty/poverty.shtml>. Remember to multiply by 2.5. If you know your state's income limit for Medicaid for people who are not working, you'll see that the amount you can earn and still keep Medicaid is much higher. You may pay a premium for Medicaid if your work income is higher, but you may also be able to get Medicaid for your family. To see the states that offer Medicaid to working people with disabilities, visit www.socialsecurity.gov/work/ResourcesToolkit/Health/states.html.

You can learn more about Ticket to Work from any Social Security office, one-stop employment center, or online at www.socialsecurity.gov/work.

A company called Maximus manages the ticket program and employment networks. You can call them toll-free at (866) 968-7842 or (866) TDD2WORK if you are deaf. Their website at

www.yourtickettowork.com tells you how to contact your local employment network, services they offer, and if they serve people with kidney problems. Look for "genito-urinary" under disabilities.

This is a new program. Over time, everyone will learn more and make better use of it as more states issue tickets, more employment networks sign up, and more people with disabilities get jobs.

Employment Networks

Social Security is setting up contracts with public and private VR agencies. Disabled people are giving their Ticket to Work tickets to state VR agencies or employment networks. Social Security pays the agency that helps you get job training and keep a job.

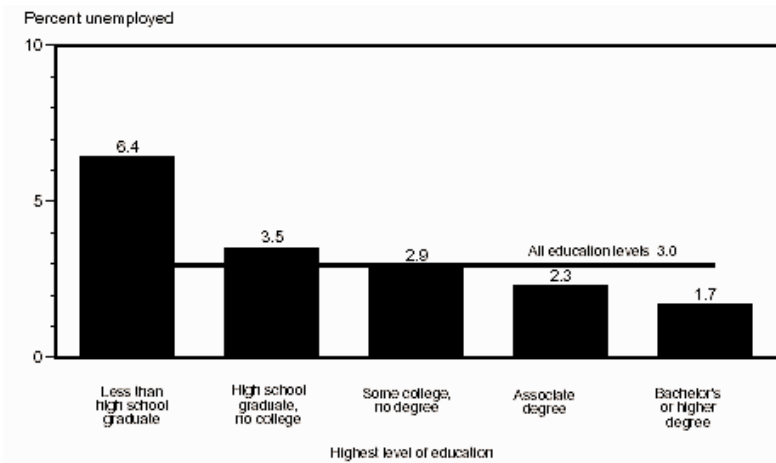
The amount of money the agency can make depends on whether you find and keep a job that lets you stay off of disability. Since the service is free to you, it's a win-win situation. There is a list of employment networks by state at www.yourtickettowork.com/endir

CHAPTER 8 — SCHOOL OPTIONS FOR STUDENTS

Education is the key to opening doors to as many work options as possible. But according to the U.S. Department of Education, children with disabilities are twice as likely as healthy

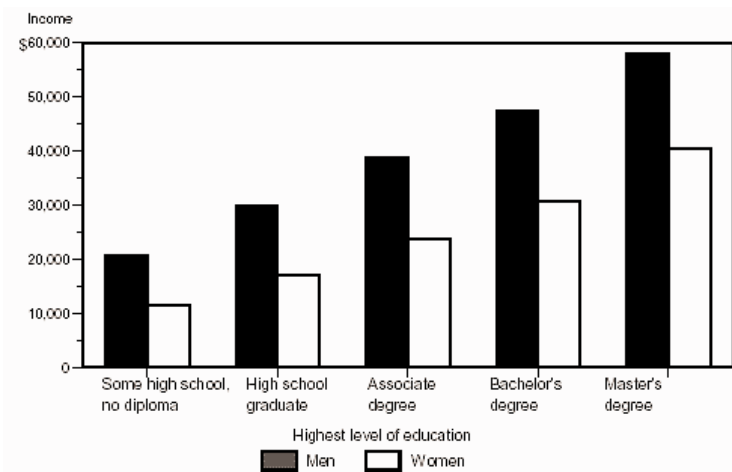
children to drop out of school. The more years a child stays in school, the more likely he or she will be to earn a higher salary and avoid unemployment. (See the charts, below).

**Unemployment Rates of Persons 25 years old and over,
By Highest Level of Education: 2000**



SOURCE: U.S. Department of Labor, Bureau of Labor Statistics, Office of Employment and Unemployment Statistics, Current Population Survey, 2000.

**Median Annual Income of Persons with Income 25 years old and over,
By Highest Level of Education and Sex: 1999**



SOURCE: U.S. Department of Commerce, Bureau of the Census, Current Population Reports, Series P-60, Money Income in the United States: 1999.

Education Rights for School Children

School for children is as important a task as work is for adults. A number of federal laws address the education and work planning needs of children to ensure that they have access to schooling.

Section 504 of the Rehabilitation Act

A school must set up a 504 Plan for a child with kidney disease. This plan is designed to mainstream children with health needs. The plan may include a shorter day to go to dialysis or breaks for PD exchanges, time to get drugs from the nurse, and so on. Children may not lose credit for missing school due to illness alone. A school that does not comply with this law risks losing federal funds.

Americans with Disabilities Act

Students with disabilities have the same protections under the ADA as under section 504. Day care centers and most schools can't discriminate against them because of their disability. Only religious schools are not covered by this law.

Individuals with Disabilities in Education Act (IDEA)

The IDEA helps children of all ages who have physical, emotional, or learning disabilities get the education they need to live as independently as

they can when they become adults.

The IDEA promotes:

- Including all able children with disabilities in regular classrooms.
- Involving parents more in planning the child's individualized education program (IEP).
- Updating parents on their child's progress.
- Providing a safe learning environment.

You can read a fact sheet about the 1997 amendments to the IDEA at www.ed.gov/offices/OSERS/Policy/IDEA/q_and_a.html.

No Child Left Behind Act

This 2002 law is intended to help disabled and at-risk youth achieve as much in grades K-12 as other youth. Schools are to be more accountable for results, more flexible and open to local control, offer more options for parents, and use proven teaching methods. Read more about this law and find tools and tips at www.nochildleftbehind.gov/.

School to Work Opportunities Act

The School to Work Opportunities Act requires schools to start talking about careers with students in the 7th grade, to help youth choose a career major in the 11th grade, and to give students education and skills training in high school and college to get them ready for their first job. The law applies to all children, not just disabled children.

Finding Help to Pay for College

High school and college counselors can give students information on grants and loans. The federal government has grants and loans to help with college or vocational training. You can find the Free Application for Federal Student Aid on the Internet (www.fafsa.ed.gov) or by calling (800) 4-FED-AID. Some possible grants and loans include:

- Federal Pell Grants
- Federal Stafford Loans
- Federal PLUS Loans
- Campus-Based Programs
- Federal Supplemental Educational
- Opportunity Grants
- Federal Work Study
- Perkins Loans

Every state has a Robert C. Byrd Honors Scholarship Program, which offers an annual \$1,500 a year college scholarship to graduating high school students who have good grades. It can be renewed for up to 4 years. For more information, see www.ed.gov/offices/OPE/HEP/idades/byrd.html.

Students can see options for paying for college on the U.S. Department of Education website (www.ed.gov/studentaid/student.html). The Department of Education has tools for estimating college costs, ways to pay for college and career planning at

www.ed.gov/thinkcollege/highschool/. Social Security also has information for youth with disabilities at www.socialsecurity.gov/work/Youth/youth.html.

Most college scholarships, grants, and loans, are from public agencies or private foundations. But some kidney organizations may offer grants or scholarships to people with kidney disease, including:

- Kidney & Urology Foundation of America – www.kidneyurology.org/Patient_Resources/PaR_Scholarships_Vista.htm
- Transplant Recipients International Organization – www.trioweb.org/resources/scholarships.html
- Some National Kidney Foundation affiliates – www.kidney.org/general/affiliates/nkf_affiliates.cfm.

The George Washington University Health Resource Center (www.heath.gwu.edu/) is a national clearinghouse on college and university education for disabled students. It offers many resources and lists you can order by phone or mail. See the *Resources* section for their contact information.

AmeriCorps National Service Program

AmeriCorps (the domestic Peace Corps) is open to youth 17–24. Students who join AmeriCorps live and work with a team of 15 others in Denver (CO), Charleston (SC), Sacramento (CA), Perry Point (MD), or Washington, DC.

AmeriCorps members develop teamwork and leadership skills working with area non-profit organizations or agencies.

AmeriCorps does such work as cleaning up the environment, repairing park trails, helping with disaster relief, tutoring children, helping at camps for children with disabilities, etc.

They offer health insurance, a living allowance, and sometimes housing.

After the 10-12 month job, students get money they can use for college, graduate school, vocational school, or to pay back student loans if the job was full-time. Some part-time jobs are available that offer less money for education. Learn more about AmeriCorps by calling (800) 942-2677 or TTY (800) 833-3722, or by visiting them on-line at www.americorps.org.

Programs to Help Youth Move from School to Work

Becoming an adult and moving from school to work is both exciting and challenging. A number of resources can help with this transition for students with kidney disease or kidney failure.

National Center on Secondary Education and Transition

The National Center on Secondary Education and Transition (NCSET, www.ncset.org) helps disabled students get education they need in high school and beyond. The goal of the NCSET is to prepare youth to live

independently, have meaningful jobs, and take part in their communities. The program offers booklets, an Internet database of state resources, an e-mail newsletter, and other programs and services.

Parent Advocacy Coalition for Educational Rights (PACER) Center

The Parent Advocacy Coalition for Educational Rights (PACER) Center (www.pacer.org) was started by and is run by parents of disabled children. PACER has several planning tools including a board game called *Transition Trek*.

Social Security Website

A number of government websites help parents and disabled youth. The Social Security website has a special section for youth at www.socialsecurity.gov/work/Youth/youth.html. It links to such sites as federal student jobs, labor laws for youth, and notes about famous disabled people.

Disabilities and Chronic Illness in Girls

The U.S. government wants to help young disabled people to reach their fullest potential. The Disability and Chronic Illness Web Site for Girls (www.4girls.gov) has tips to help girls with talking to their doctors, school, exercise, body image, dating, feelings, and family issues. Games and chat rooms where girls can talk with other disabled girls are also offered.

CHAPTER 9 — HAVING AN ACTIVE RETIREMENT

When you retired, you probably had plans to travel, play golf, spend time with your family, read, join a bridge club or a bowling league, etc. You may have thought your work days were over. However, sometimes the economy, boredom, or a desire to give something back makes people think about other options.

Keep your mind and body as healthy as possible by staying physically and mentally active and being involved with your family, friends, and community. When you feel down about having kidney disease—and most people do sometimes—remember that you can make a big difference in the lives of others.

Working for Pay After Retirement

You may want to think about working full-time or part-time to have extra income after you retire. If you do, your Social Security retirement benefits may change.

You can retire and get Social Security benefits at 62, but your benefits will be lower if you don't wait to retire until your *full retirement age* (see the chart below.) A table at www.socialsecurity.gov/retirechartred.htm tells you how much less your retirement benefits will be if you retire at 62. Talk with Social Security about the pros and cons of taking early retirement.

Full Retirement Age

If You Were Born...	Your Full Retirement Age Is:
1937 or earlier	65
1938	65 + 2 months
1939	65 + 4 months
1940	65 + 6 months
1941	65 + 8 months
1942	65 + 10 months
1943–1954	66
1955	66 + 2 months
1956	66 + 4 months
1957	66 + 6 months
1958	66 + 8 months
1959	66 + 10 months
1960 or later	67

The table below will show you how working can affect your retirement benefit, depending on how close you are to “full retirement age,” as of 2003.

For current amounts, see “benefits/tax changes” at www.socialsecurity.gov or call (800) 772-1213. Social Security does not count pensions, interest, investment income, or annuities, but does count wages (or net profits, if self-employed), bonuses, vacation or sick pay, commissions, etc.

Volunteer Work After Retirement

You may enjoy helping others. Volunteering is one way you can do this on your own time and at your own pace. A number of volunteer coordinating centers can help match you up with a chance to do something you enjoy.

Service Corps of Retired Executives (SCORE®)

SCORE is a partner with the Small Business Administration. SCORE counselors help people who are thinking

about starting a business know what is involved and make better decisions. To contact SCORE, call (800) 634-0245 or visit their website at www.score.org.

Senior Corps

Senior Corps has several programs that are described below. To find out about any of these programs, call (800) 424-8867 or (800) 833-3722 if you are deaf. You can also visit their website at www.seniorcorps.org.

- If you are 55 or older, you may want to volunteer with the **Retired and Senior Volunteer Program (RSVP)**. Trained volunteers work with non-profit organizations doing tasks such as setting up neighborhood watch programs, fixing up homes for low income or elderly people, helping disaster victims, or tutoring and working with at-risk youth. The average commitment is 4 hours a week. Volunteers are not paid, but agencies can help you with meals, travel expenses, and some insurance.

Your Age	How Work Affects Your Retirement Benefit
Under the full retirement age	<ul style="list-style-type: none"> • Earn up to \$11,280 with no effect on benefits • Over \$11,280, you lose \$1 of each \$2 of retirement benefits (2003 amounts)
Before your birthday in the year you reach full retirement age	<ul style="list-style-type: none"> • Earn up to \$30,000 with no effect on benefits • Over \$30,000, you lose \$1 of each \$3 of retirement benefits (2003 amounts)
At full retirement age	No limit on earnings

- If you are 60 or older, have limited income, and like working with youth, the **Foster Grandparent Program** may be right for you. Trained volunteers work about 20 hours a week through hospitals, schools, children's services organizations and faith-based programs. They help at-risk children of all ages, including disabled youth, by doing such things as tutoring, mentoring, and providing care. Volunteers make a small, tax-free hourly wage to cover meals and travel, and get liability and accident insurance while working.
- If you are 60 or older and have limited income you may want to volunteer with the **Senior Companion Program**. Trained volunteers work about 20 hours a week with 2–4 clients to help them stay in their own homes. They do tasks such as paying bills and grocery shopping and they alert doctors and family members when problems arise.
- National Kidney Foundation chapters need people like you to help support new patients, plan events and fundraisers, educate policymakers about your needs, do clerical work, give speeches, and many other activities. See www.kidney.org/general/affiliates/nkf_affiliates.cfm for a list of NKF affiliates' contact information.
- **VolunteerMatch**, at www.volunteermatch.org, helps link volunteers with organizations that need help.

Social Activities and Travel

Sometimes people with kidney disease focus on what they can no longer do. But kidney disease or no kidney disease, *you're still you*. If you look at the list of activities in your life, you may find that there are many things you can still do alone and with others, such as:

- Maintaining your home
- Gardening
- Eating out
- Getting together with friends
- Going to movies or plays
- Playing golf
- Dancing
- Playing cards
- Bowling in a league
- Going to your place of worship
- Working puzzles
- Sewing
- Building models
- Reading
- Using a computer

Travel with Kidney Disease

Many retirees look forward to planning and taking trips. You can travel with kidney disease, even if you are on dialysis. It just takes some extra time to plan. Be sure to find out what your insurance covers when you travel.

- If you are on a transplant list, let your transplant team and your doctor know how to reach you. Think about

getting a cell phone or nation-wide pager. It's important that you get the call if an organ is available.

- If you have a working kidney or kidney-pancreas transplant, you should be able to travel with somewhat less planning—but see the tips below about what to bring with you.
- If you are on hemodialysis, find a center where you want to travel. If you get dialysis in a center that is part of a chain, ask to see the list of the centers. Staying in the same corporation may make travel planning easier.

– **DaVita Guest Services** –
(800) 400-8331

– **Dialysis Clinic Inc.** clinics at
www.dciinc.org/clinics/clinics.htm
or (615) 329-2315

– **Fresenius (FMC) Patient
Travel Service** – (800) 634-6254

– **Gambro At Your Service** –
(877) 842-6276

– **Renal Care Group** clinics at
[www.renalcaregroup.com/html/
patients.htm](http://www.renalcaregroup.com/html/patients.htm) or (615) 345-5500

- Use www.wheredialysis.com, www.dialysisfinder.com, or www.nephron.com to find U.S. dialysis centers. At least a month's advance notice is often needed to find an opening; longer is better. You will need to have medical records with you, and may need certain blood tests or proof of immunization.

- Use *Dialysis and Transplantation's* Listing of Dialysis Centers (www.eneph.com/thelist/index.asp) or Global Dialysis (www.globaldialysis.com) to find centers in other countries. It helps if you make the first contact to find out if the clinic has an opening on your travel dates. Call and ask for an appointment several months ahead and be flexible about dates and times to improve the chances that you can visit your desired travel spot. Give your social worker at least 30 days notice to get medical records to the center unless you must travel for an emergency.

- If you use peritoneal dialysis and plan to drive, you can take your machine and supplies. If you will be gone for a few days, the supplier can ship your supplies to your travel spot. You may need to do manual exchanges if you use a cyclor and can't bring it or have it shipped. Bring along the phone number of a nearby center and carry your records so if you have an emergency, you know who to contact. Otherwise, call your home center if you have questions.

Travel Tips for Kidney Patients

- Take a list of your medications and hand-carry the drugs in their original bottles. Do not pack drugs away in your suitcase if you'll be flying or

taking a bus or train—if your bag goes astray, so will your drugs.

- If you have diabetes, take your pills or insulin and U-100 syringes plus your meter, test strips, and lancets with you. Test your blood sugar as often as you would at home.
- Take written prescriptions for drugs or medical supplies, especially if you'll be going to another country.
- Bring the name and area code and phone number of your doctor and dialysis or transplant center.
- Wear medic alert jewelry and be sure you have information in your wallet or purse about your condition, your treatment, and drugs you take.

You may be surprised that people with kidney disease and kidney failure travel close to home or even around the world. They take cruises (see Dialysis at Sea® Cruises at www.dialysisatsea.com/index.asp?id=1), camp, hike, go to family and class reunions, and take day or longer trips with their church or other group. Don't let kidney disease keep you from doing the things you enjoy.

Part III: Resources

GLOSSARY

Access – An access, or vascular access, is a way to reach the blood vessels for dialysis. For hemodialysis, there are three types of access: a fistula, a graft, or a catheter. A fistula is a surgical connection between a vein and an artery, usually in the arm. This is the best and longest-lasting type of access. A graft connects a vein and an artery with a piece of artificial vein. A catheter is a plastic tube inserted into a central vein in the neck or chest. Catheters have a high risk of infection. A doctor will decide which type of access will work best for his/her patient. For peritoneal dialysis, a catheter is placed in the abdomen in a minor surgery.

Accommodation – A minor change in the workplace to allow a disabled person to work, or help to get or keep a job. Some examples include changes in work hours, time off for doctor's appointments or treatments, a clean room to do CAPD, special equipment to help you lift heavy objects, etc. Some employers are required to make "reasonable accommodations" for known disabilities.

Americans with Disabilities Act (ADA) – A federal law that applies to employers with 15 or more workers. Employers cannot treat a person with a disability differently in several areas, including hiring. A condition is considered "disabling" when it substantially limits your ability to do one or more major life activities. Besides work, the ADA also forbids discrimination in transportation, communications, and public places like schools, stores, libraries, medical offices, and recreation areas.

Anemia – A shortage of oxygen-carrying red blood cells. Anemia occurs in kidney disease because damaged kidneys do not make enough of a hormone called *erythropoietin*. This hormone tells the bone marrow to make red blood cells. Anemia causes fatigue; weakness; feeling cold; confusion; pale skin, lips, and nail beds; and other symptoms. Left untreated, anemia can cause heart damage.

COBRA (Consolidated Omnibus Budget Reconciliation Act) – A federal law that offers health insurance continuation to employees in companies that had at least 20 full or part-time employees on at least half the work days in the past year.

Coinsurance – The amount of a medical bill you must pay after your deductible and your insurance company's payment.

Continuation of Medicaid [Section 1619(b)] – A program to help people with disabilities work by giving them health insurance through Medicaid.

Continuation of Medicare – A program to continue Medicare coverage for 8.5 years if a person with a disability earns too much money to keep SSDI payments.

Coordination of benefits – A method of making sure that two health insurance companies do not both pay for the same medical care.

Co-payment – A set dollar amount that you must pay each time you get certain services, like each prescribed drug, a doctor visit, or a hospital stay. This amount can be billed to another insurance company or to Medicare, but the co-payment may or may not be paid by them.

Deductible – A set fee you must pay during a set period (such as quarterly or annually) for services before your insurance company will begin to pay. After you pay the deductible, you may still have to pay the co-payment or coinsurance.

Employment Network – A public or private service contracted by Social Security to help people with disabilities return to work.

Employment Support Representative – Experts in some Social Security offices who can advise people with disabilities about work incentive programs and options for working.

End Stage Renal Disease (ESRD) – Legal term used by the federal government to define kidney failure: when kidney function is less than 15% of normal and dialysis or a kidney transplant is needed to live.

Expedited Reinstatement of Disability – A program to restart Social Security benefits without a new application if you return to work at the SGA level and have a health setback in the first 5 years.

Extended Period of Eligibility – For 37 months after your last disability check, Social Security can pay disability payments in any month when your income is less than the SGA.

Family and Medical Leave Act (FMLA) – A law that applies to employers with 50 or more employees, working within 50 miles. Your employer must let you take up to 12 weeks per rolling 12-month period for your own or a family member's serious illness. You should still get health insurance but you may have to pay premiums.

Health Insurance Portability and Accountability Act (HIPAA) – A law that allows many people with health problems to get individual or group insurance if they lose their job, change jobs, or lose group health insurance coverage.

Impairment-Related Work Expenses (IRWE) – Medical expenses that you pay for, such as drugs, doctor visits, other health services, or items that allow you to work. Social Security subtracts allowable expenses from your income before it decides how much to pay you.

Medicaid – A joint federal and state health insurance program that helps elderly, blind, disabled, or low-income people to pay for hospital and medical care.

Medicaid Buy-In – State programs that allow working disabled people to get Medicaid for free or with a premium.

Medicare – A federal health insurance program for people who are U.S. citizens or permanent residents, age 65 or disabled, or have kidney failure.

Medicare Savings Program – Programs for people with lower income and little in savings to help them pay all or part of their Medicare premiums, co-payments, and coinsurance. Programs include Qualified Medicare Beneficiary (QMB), Specified Low-Income Medicare Beneficiary (SLMB), and Qualifying Individual.

Medicare Secondary Payer Coordination Period – A period of 30 months during which employer group health plan insurance pays first and Medicare pays second.

Medigap – A health insurance plan from a private company that helps pay the balance left after Medicare pays for covered services. In some cases, Medigap will pay for services that Medicare will not. In some states, only people 65 and older with Medicare can get Medigap plans.

PASS Specialist – A Social Security employee who specializes in helping disabled people understand the Plan for Achieving Self-Support and other work incentives.

Plan for Achieving Self-Support (PASS) – A program under SSI to set aside income and resources toward a goal to become financially independent and off disability. Social Security must approve a PASS.

Pre-existing Condition – A health problem that was diagnosed or treated within 6 months before enrolling in a new health insurance policy.

Premium – The amount of money charged for insurance coverage.

Primary Payer – The first insurance policy that is billed for care you receive and usually pays a larger part of the bill.

Provider – A doctor, nurse, social worker, respiratory therapist, physical therapist, occupational therapist, dietitian, or other person who provides health services; a hospital; or a clinic.

Qualified Medicare Beneficiary (QMB) – A Medicare savings program for people with low income and few resources. QMB helps pay Medicare premiums and coinsurance for Medicare-covered services.

Rehabilitation – A process in which patients, family members, and professionals work together to achieve the outcomes of optimal physical, social, emotional, and role functioning in the presence of a potentially disabling condition.

Secondary Payer – An insurance plan that is billed for your care after another insurance plan has already been billed first.

SGA – *See* Substantial Gainful Activity.

Social Security – A federal program of long-term disability and retirement benefits for people who have paid into the Social Security system through taxes withheld from earnings.

Social Security Administration (Social Security) – The federal agency charged with managing disability, retirement, survivors benefits, and work incentive programs.

Social Security Disability Insurance (SSDI) – A federal program of disability insurance that pays monthly cash benefits, depending on past earnings. A spouse and dependent children may also receive benefits.

Specified Low-Income Medicare Beneficiary (SLMB) – State Medicaid pays the Part B Medicare premium for people who qualify.

Substantial Gainful Activity (SGA) – A Social Security limit on the amount that can be earned by a disabled person before loss of benefits occurs. The SGA amount changes each year.

Supplemental Security Income (SSI) – A federal program of disability insurance that pays monthly cash benefits to eligible low-income people. In most states, people who receive SSI also receive Medicaid.

Ticket to Work – A Social Security program that provides a voucher (ticket) for work training or help finding a job to disabled people aged 18 through 64.

Trial Work Period (TWP) – A period of 9 months during which an SSDI recipient can earn as much as possible without losing benefits. The 9 months do not have to be in a row. Once all TWP months have been used, SSDI checks may stop if earnings are at the SGA level. Reapplying for disability later can start a new TWP.

Work Incentive Liaison – Experts in some Social Security offices that can advise disabled people about work incentive programs.

ORGANIZATIONS FOR PEOPLE WITH KIDNEY DISEASE

American Association of Kidney Patients (AAKP)
3505 E. Frontage Road, Suite 315
Tampa, FL 33607
(800) 749-2257 or (813) 223-7099
www.aakp.org

American Kidney Fund (AKF)
6110 Executive Blvd. #1010
Rockville, MD 20852
(800) 638-8299 or (301) 881-3052
www.akfinc.org

International Center for the Disabled
340 E. 24th Street
New York, NY 10010-4019
(212) 585-6000
www.icdrehab.org

Kidney Transplant/Dialysis Association
P.O. Box 1362 GMF
Boston, MA 02205-1362
(781) 641-4000
www.kdta.org

Life Options Rehabilitation Program
414 D'Onofrio Drive, Suite 200
Madison, WI 53719
(800) 468-7777 or (608) 833-8033
www.lifeoptions.org
www.kidneyschool.org

National Foundation for Transplants
1102 Brookfield, Suite 200
Memphis, TN 38119
(901) 684-1697 or (800) 489-3863
www.transplants.org

National Kidney Foundation, Inc. (NKF)
30 East 33rd Street
New York, NY 10016
(800) 622-9010 or (212) 889-2210
www.kidney.org

National Kidney & Urologic Diseases Information Clearinghouse (NKUDIC)
3 Information Way
Bethesda, MD 20892
(800) 891-5390 or (301) 654-4415
www.niddk.nih.gov/health/kidney/nkudic.htm

National Transplant Assistance Fund
3475 West Chester Pike, Suite 230
Newtown Square, PA 19073
(610) 353-9684 or (800) 642-8399
www.transplantfund.org

Polycystic Kidney Disease (PKD) Foundation
4901 Main Street
Kansas City, MO 64112
(800) PKD-CURE or (816) 931-8655
www.pkdcure.org/

Transplant Recipients International
2117 L Street, NW #353
Washington, DC 20037
(202) 293-0980; (800) TRIO-386

United Network for Organ Sharing
P.O. Box 2484
Richmond, VA 23218
(804) 330-8500 or (888) TX-INFO-1
www.unos.org

ON-LINE SUPPORT GROUPS

For All Kidney Patients: Send an e-mail to: dialysis_support-subscribe@yahoogroups.com

For Transplant Patients: Send an e-mail to: kidney_transplants-subscribe@yahoogroups.com

For Peritoneal Dialysis Patients: Send an e-mail to: capd-ccpd-subscribe@yahoogroups.com

To find other on-line support groups, visit www.yahoogroups.com.

END STAGE RENAL DISEASE NETWORKS

The ESRD Networks are regional non-profit organizations with government contracts to oversee care provided by dialysis centers. You can find your Network on the map at right, or by visiting the Forum of ESRD Networks website.

Forum of ESRD Networks

1527 Huguenot Road
Midlothian, VA 23113
(804) 794-2586
E-mail: forum@forum.esrd.net
www.esrdnetworks.org

Network 1 (CT, ME, MA, NH, RI, VT)

ESRD Network of New England, Inc.
30 Hazel Terrace
Woodbridge, CT 06525
(866) 286-3773 (Patients only)
(203) 387-9332
E-mail: jkitsen@nw1.esrd.net
www.networkofnewengland.org

Network 2 (NY)

ESRD Network of New York, Inc.
1249 Fifth Avenue, A-419
New York, NY 10029
(800) 238-3773 (NY Patients Only)
(212) 289-4524
E-mail: info@nw2.esrd.net
www.esrdnetworks.org/networks/net2/net2.htm

Network 3 (NJ, PR, VI)

Trans-Atlantic Renal Council
Cranbury Gates Office Park
109 S. Main Street #21
Cranbury, NJ 08512-3142
(888) 877-8400 (Patients only)
(609) 490-0310
E-mail: jsolanbick@nw3.esrd.net
www.tarcweb.org



Network 4 (DE, PA)

ESRD Network #4
UPMC Health System
200 Lothrop Street
Pittsburgh, PA 15213-2582
(800) 548-9205 (Patients only)
(412) 647-3428
E-mail: bfreed@nw4.esrd.net
www.esrdnetworks.org/networks/net4/net4.htm

Network 5 (VA, WV, MD, DC)

Mid-Atlantic Renal Coalition
1527 Huguenot Road
Midlothian, VA 23113
(866) 651-6272 (Patients only)
(804) 794-3757
E-mail: marc@nw5.esrd.net
www.esrdnet5.org

Network 6 (GA, NC, SC)

Southeastern Kidney Council, Inc.
1000 St. Albans Drive #270
Raleigh, NC 27609
(800) 524-7139 (Patients only)
(919) 855-0882
E-mail: jkrisber@nw6.esrd.net
www.esrdnetwork6.org

Network 7 (FL)

ESRD Network of Florida, Inc.
600 S. Magnolia Avenue #300
Tampa, FL 33606
(800) 826-3773 (Patients only)
(813) 251-8686
E-mail: info@nw7.esrd.net
www.esrdnetworks.org/networks/net7/net7.htm

Network 8 (AL, MS, TN)

Network 8, Inc.
P.O. Box 55868
Jackson, MS 39296-5868
(877) 936-9260 (Patients only)
(601) 936-9260
E-mail: jfuller@nw8.esrd.net
www.esrdnetworks.org/networks/net8/net8.htm

Network 9/10 (IL, IN, KY, OH)

The Renal Network, Inc.
911 E. 86th Street #202
Indianapolis, IN 46240
(800) 456-6919 (Patients only)
(317) 257-8265
E-mail: sstark@nw10.esrd.net
www.therenalnetwork.org

Network 11 (MN, MI, ND, SD, WI)

The Renal Network of the Upper Midwest, Inc.
970 Raymond Avenue #205
St. Paul, MN 55114
(800) 973-3773 (Patients only)
(651) 644-9877
E-mail: dcarlson@nw11.esrd.net
www.esrdnet11.org

Network 12 (IA, KS, MO, NE)

ESRD Network #12
7505 NW Tiffany Springs Parkway #230
Kansas City, MO 64153
(800) 444-9965 (Patients only)
(816) 880-9990
E-mail: ltaylor@nw12.esrd.net
www.network12.org

Network 13 (AR, LA, OK)

ESRD Network #13
6600 N. Meridian Avenue #155
Oklahoma City, OK 73116-1411

(800) 472-8664 (Patients only)
(405) 843-8688
E-mail: pPhilliber@nw13.esrd.net
www.network13.org

Network 14 (TX)

ESRD Network of Texas, Inc.
14114 Dallas Parkway #660
Dallas, TX 75240-4349
(877) 886-4435 (Patients only)
(972) 503-3215
E-mail: gbarbert@nw14.esrd.net
www.esrdnetwork.org

Network 15 (AZ, CO, NM, NV, UT, WY)

Intermountain ESRD Network #15
1301 Pennsylvania Street #750
Denver, CO 80203-5012
(800) 783-8818 (Patients only)
(303) 831-8818
E-mail: ssbiles@nw15.esrd.net
www.esrdnet15.org

Network 16 (AK, ID, MT, OR, WA)

Northwest Renal Network
4702 42nd Avenue, SW
Seattle, WA 98116
(800) 262-1514 (Patients only)
(206) 923-0714
E-mail: lLawson@nw16.esrd.net
www.nurenalnetwork.org

Network 17 (Am. Samoa, Guam, HI, Mariana Islands, Northern CA)

TransPacific Renal Network
25 Mitchell Blvd. #7
San Rafael, CA 94903
(800) 232-3773 (Patients only)
(415) 472-8590
E-mail: asukolksy@nw17.esrd.net
www.network17.org

Network 18 (Southern CA)

S CA Renal Disease Council, Inc.
6255 Sunset Blvd. #2211
Los Angeles, CA 90028
(800) 637-4767 (Patients only)
(323) 962-2020
E-mail: dmarsh@nw18.esrd.net
www.esrdnetwork18.org

STATE KIDNEY DISEASE PROGRAMS

If your state is not listed, it probably does not have a state kidney program. Talk with your National Kidney Foundation affiliate to see how you can support funding for a kidney program in your state.

ALABAMA

Alabama Kidney Foundation
2012 University Blvd., Room 164
Birmingham, AL 35201
(205) 934-2111
www.alkidney.org

ARKANSAS

Arkansas Kidney Disease Commission
Program Administrator
1123 S. University #600
Little Rock, AR 72204
(501) 686-2806

DELAWARE

Chronic Renal Disease Program
Department of Health and Social Services
Division of Social Services
Milford State Service Center—CRDP
11-13 N. Church Street
Milford, DE 19963
(302) 422-1393

FLORIDA

Freestanding Dialysis Centers Program
Florida Agency for Healthcare Administration
Medicaid Program Development
2727 Mahan Drive, Fort Knox Complex
Mail Stop 20, Building 3
Tallahassee, FL 32308
(850) 972-7308

ILLINOIS

State Renal Program
Illinois Department of Public Aid
P.O. Box 19129
Springfield, IL 62794-9129
(217) 524-7195
www.state.il.us/dpa

INDIANA

Indiana State Dept of Health-Renal Program
2 N. Meridian
Indianapolis, IN 46204
(317) 233-7816
www.in.gov/isdb

IOWA

Chronic Renal Disease Program
Iowa Dept. of Public Health-Chronic Renal
Lucas State Building
321 E. 12th Street
Des Moines, IA 50319-0075
(515) 281-4960

MARYLAND

Kidney Disease Program of Maryland
Department of Health and Mental Hygiene
Medical Care Programs
Beneficiary Services Administration
201 W. Preston Street, Room 314A
Baltimore, MD 21201
(410) 767-5000

MISSOURI

Missouri Kidney Program
AP Green Building #111
201 Business Loop, 70 West
Columbia, MO 65211-8180
(800) 733-7345 or (573) 882-2506
www.bsc.missouri.edu/~mokp

MONTANA

Montana ESRD Program
Department of Health and Human Services
Box 202951
Helena, MT 59620-2951
(406) 444-7018

NEBRASKA

Nebraska Chronic Renal Disease Program
Nebraska Health and Human Services System
P.O. Box 94817
Lincoln, NE 68509-4817
(402) 471-2638

NEW HAMPSHIRE

Catastrophic Illness Program
New Hampshire Office of
Community and Public Health
6 Hazen Drive
Concord, NH 03301
(603) 271-4529

NEW JERSEY

Chronic Renal Disease Services
Special Child and Adult Health Services
P.O. Box 364
Trenton, NJ 08625-0364
(609) 984-6137

NORTH CAROLINA

State Kidney Program
Department of Health and Human Services
Division of Public Health
1915 Mail Service Center
Raleigh, NC 27699-1915
(919) 715-3113

PENNSYLVANIA

Chronic Renal Disease Program
P.O. Box 90
Harrisburg, PA 17108
(717) 783-5436

PUERTO RICO

Consejo Renal De Puerto Rico, Inc.
Reparto Metropolitano Shopping Center #208C
Rio Piedras, PR 00921
(787) 764-2254 or (787) 764-8689
www.consejorenal.com

SOUTH DAKOTA

South Dakota Chronic Renal Disease Program
South Dakota Department of Social Services
700 Governor's Drive
Pierre, SD 57501-2291
(605) 773-3495
www.state.sd.us/social/medical/

TENNESSEE

Tennessee Renal Disease Program
Tennessee Department of Health
Cordell Hull Building, 6th Floor
425 5th Avenue N
Nashville, TN 37247
(615) 741-5259

TEXAS

Bureau of Kidney Health Care
Texas Department of Health
1100 W. 49th Street (Y-950)
Austin, TX 78756-3184
(512) 794-5185
www.tdh.state.tx.us/kidney/kbcmain.htm

WASHINGTON (State)

Washington State Kidney Disease Program
Department of Social and Health Services
P.O. Box 45530
Olympia, WA 98504-5530
(360) 753-1659

WISCONSIN

Wisconsin Chronic Renal Disease Program
Department of Health and Family Services
P.O. Box 1508
Madison, WI 53703
(608) 266-2469

WYOMING

Wyoming End Stage Renal Disease Program
Department of Health
Hathaway Building, 4th Floor
Cheyenne, WY 82002
(307) 777-3527

FEDERAL AGENCIES AND REHABILITATION

Centers for Medicare and Medicaid Services

7500 Security Blvd.

Baltimore, MD 21244-1850

(877) 267-2323 or (410) 786-3000

TTY: (866) 226-181

Call (800) 633-4227 or (877) 487-2048 (TDD) to order print publications by name and number or read on-line at www.medicare.gov/Publications/home.asp.

- *Coverage of Kidney Dialysis and Kidney Transplant Services*, Pub. No. 10128 (10/02)
- *Dialysis Keeps People with Kidney Failure Alive: Are You Getting Adequate Hemodialysis*, Pub. No. 10924 (2/02)
- *Don't Miss Out on Your Turn for Medicare Savings*, Pub. No. 10126-A (10/02)
- *Health Care Coverage Directory for People with Medicare*, Pub. No. 02231 (7/01)
- *Medicare Appeals and Grievances*, Pub. No. 10119 (5/00)
- *Medicare and Home Health Care*, Pub. No. 10969 (11/01)
- *Medicare Hospice Benefits*, Pub. No. 02154 (7/02)
- *Medigap Policies: The Basics*, Pub. No. 10209 (8/01)
- *Medicare Preventive Services to Keep You Healthy*, Pub. No. 10110 (5/01)
- *Medicare & You 2003*, Pub. No. 10050 (1/03)
- *Preparing for Emergencies: A Guide for People on Dialysis*, Pub. No. 10150 (11/02)
- *Supplemental Health Insurance Policies*, Pub. No. 10115
- *You Can Live: Your Guide to Living with Kidney Failure*, Pub. No. 02119 (1/02)
- *Your Medicare Benefits*, Pub. No. 10116 (9/02)
- *Your Medicare Rights and Protections*, Pub. No. 10112 (8/02)
- *Where to Get Your Medicare Questions Answered*, Pub. No. 02246

Social Security (Selected Resources)

Most booklets are available in English and Spanish. To order Social Security benefit publications, call Social Security's call center (800) 772-1213, or visit www.socialsecurity.gov/pubs/.

Disability

- *The Appeals Process*, Pub. No. 05-10041 (10/99)
- *Definition of Disability for Children*, Pub. No. 05-11053 (7/97)
- *Disability Benefits*, Pub. No. 05-10029 (2/02)
- *How We Decide If You Are Still Disabled*, Pub. No. 05-10053 (7/00)
- *How Worker's Compensation And Other Disability Payments May Affect Your Benefits*, Pub. No. 05-10018 (6/97)

- *Reviewing Your Disability*, Pub. No. 05-10068 (6/97)
- *Social Security: Benefits for Children with Disabilities*, Pub. No. 05-10026 (8/02)
- *Social Security Disability Programs Can Help*, Pub. No. 05-10057 (8/01)
- *Social Security: If You Are Blind or Have Low Vision – How We Can Help*, Pub. No. 05-10052 (4/02)
- *Social Security: What You Need to Know When You Get Disability Benefits*, Pub. No. 10153 (2/02)
- *Ticket to Work and Self-Sufficiency Program*, Pub. No. 05-10061 (4/01)
- *Ticket to Work and Work Incentives Improvement Act of 1999*, Pub. No. 05-10060 (6/01)
- *Working While Disabled...How We Can Help*, Pub. No. 05-10095 (5/02)
- *Work Incentives for People With Disabilities (Redbook)*, Pub. No. 64-030 (1/02)
- *Your Right to Question the Decision Made on Your Claim*, Pub. No. 05-10058 (4/99)
- *Your Right to Question the Decision Made on Your SSI Claim*, Pub. No. 051108 (3/99)
- *Your Right to Question the Decision to Stop Your Disability Benefits*, Pub. No. 05-10090 (5/98)
- *Your Right to Representation*, Pub. No. 05-10075 (2/02)
- *Your Ticket to Work – What You Need to Know to Keep It Working For You*, Pub. No. 05-10062 (9/02)

Supplemental Security Income Program (SSI)

- *Food Stamp Facts*, Pub. No. 05-10101 (5/02)
- *Food Stamps and Other Nutrition Programs*, Pub. No. 05-10100 (3/02)
- *How Worker's Compensation and Other Disability Payments May Affect Your Benefits*, Pub. No. 05-10018 (6/97)
- *Reviewing Your Disability*, Pub. No. 05-10068 (6/97)
- *Social Security: What You Need to Know When You Get SSI*, Pub. No. 05-11011 (3/02)
- *Social Security: Working While Disabled...A Guide to Plans for Achieving Self-Support (PASS)*, Pub. No. 05-11017 (3/99)
- *Social Security: You May Be Able to Get SSI*, Pub. No. 05-11069 (2/02)
- SSI State Supplement Factsheets on-line at www.socialsecurity.gov/pubs/statessi.html
- *Supplemental Security Income for Noncitizens*, Pub. No. 05-11051 (3/02)

Work and Earnings

- *Government Pension Offset*, Pub. No. 05-10007 (1/03)
- *A Guide For Farmers, Growers, and Crew Leaders*, Pub No. 05-10025 (5/97)
- *Household Workers*, Pub. No. 10021 (2/02)
- *How State and Local Government Employees Are Covered by Social Security and Medicare*, Pub. No. 05-10051 (10/02)
- *How Work Affects Your Benefits*, Pub. No. 05-10069 (3/02)
- *If You Are Self-Employed*, Pub. No. 05-10022 (1/03)
- *If You Work for a Nonprofit Organization*, Pub. No. 05-10027 1/03)
- *Military Service and Social Security*, Pub. No. 05-10017 (1/03)
- *Social Security: How You Earn Credits*, Pub. No. 05-10072 (1/03)

U.S. Department of Justice

The Americans With Disabilities Act (1990), available from:

U.S. Department of Justice
Coordination and Review Section
Civil Rights Division
P.O. Box 66118
Washington, DC 20035-6118
(202) 514-0301 or (202) 514-0381

U.S. Office of Personnel Management

1900 E Street, NW
Washington, DC 20415-0001

People with Disabilities in the Federal Government: An Employment Guide, available at:
www.opm.gov/disability/text_files/Employment_Guide.PDF.

BOOKS ABOUT WORK

Below is a list of books that may be helpful for you. Life Options does not recommend or endorse any particular book.

Best Answers to the 201 Most Frequently Asked Interview Questions

Deluca, Matthew J.

McGraw-Hill Trade, New York, 1996

Price: Approximately \$11.95

Chronically Happy: Joyful Living in Spite of Chronic Illness

Hartwell, Lori

Poetic Media Press, 2002

Price: Approximately \$12.95

www.chronicallyhappy.com

The Complete Q&A Job Interview Book

Allen, Jeffrey G.

John Wiley and Sons, Inc., New York, 2000

Price: Approximately \$14.95

Continuing Employment Series for Employer, Physician, and Individuals on Renal Replacement Therapy

International Center for the Disabled

340 E. 24th Street

New York, NY 10010-4019

(212) 585-6072

Price: Single copies are free

The Job Club: A Guide to Job Search, Interviewing, Resumés and Cover Letters for Transplant & Dialysis Patients (1995)

Rager, Dennis & Rager, Kris

Available from Dennis & Kris Rager

P.O. Box 2817

Vancouver, WA 98668-2817

(360) 699-6165

E-mail: RagerDK@aol.com.

Price: \$8.50 a copy

Job Hunting for the So-Called Handicapped

Bolles, Richard N. & Brown, Dale Susan

Ten Speed Press, 2001

Price: Approximately \$12.95

Kidney Disease and Rehabilitation: The Role of the Rehabilitation Counselor

National Kidney Foundation, Inc.

(800) 622-9010

Living Well With a Hidden Disability: Transcending Doubt and Shame and Reclaiming Your Life

Taylor, Stacy & Epstein, Robert

New Harbinger Publications, 1999

Price: Approximately \$15.95

No More Job Interviews!: Self-Employment Strategies for People with Disabilities

Doyel, Alice Weiss

Training Resource Network, 2000

Price: Approximately \$29.95

The Rehabilitation Series: Financial Resources for Kidney Patients

National Kidney Foundation

30 East 33rd St.

New York, NY 10016

(800) 622-9010

Price: Single copies are free

The Resumé Makeover (2nd Edition)

Allen, Jeffrey G.

John Wiley and Sons, Inc., New York, 2001

Price: Approximately \$27.90 (print)

or also available as an eBook

What Color Is Your Parachute 2003: A Practical Manual for Job-Hunters and Career-Changers

Bolles, Richard Nelson

Ten Speed Press, 2002

Price: Approximately \$18.00

What Every Patient Needs to Know (2001)

United Network for Organ Sharing (UNOS)

Professional Services

P.O. Box 2484

Richmond, VA 23218

(888) TX-INFO1 or (804) 782-4841

Price: Up to 100 copies free

DISABILITY AND HEALTH ORGANIZATIONS

American Association of People with Disabilities

1819 H Street NW, Suite 330
Washington, DC 20006
(800) 840-8844 or (202) 457-8168
www.aapd.com

FedWorld (government jobs)

www.fedworld.gov

Goodwill Industries International, Inc.

9200 Rockville Pike
Bethesda, MD 20814
(240) 333-5200
www.goodwill.org

Heath Resource Center

George Washington University
2121 K Street, NW, Suite 220
Washington, DC 20037
(800) 544-3284 or (202) 973-0904
www.heath.gwu.edu/

Indian Health Service

The Reyes Building
801 Thompson Avenue, Suite 400
Rockville, MD 20852-1627
(301) 443-3024
www.ihb.gov/GeneralWeb/HelpCenter/CustomerServices/elig.asp

International Center for the Disabled (ICD)

340 E. 24th Street
New York, NY 10010-4019
(212) 585-6072
www.icdrehab.org/prog12.htm

Job Accommodation Network

P.O. Box 6080
Morgantown, WV 26506
(800) 526-7734 or (304) 293-7186
www.jan.wvu.edu

Mainstream Inc.

Project Link
6930 Carroll Avenue, Suite 240
Takoma Park, MD 20912
(301) 891-8777

National Center on Workforce and Disability/Adult

Institute for Community Inclusion
University of Massachusetts-Boston
100 Morrissey Blvd.
Boston, MA 02125
(888) 886-9898
www.onestops.info

National Collaborative on Workforce and Disability for Youth

c/o Institute for Educational Leadership
1001 Connecticut Avenue NW, Suite 310
Washington, DC 20036
(877) 871-0744

National Council on Disability

1331 F Street, NW, Suite 850
Washington, DC 20004
(202) 272-2004
TTY: (202) 272-2074
www.ncd.gov

National Federation of the Blind

Jobline®
1800 Johnson Street
Baltimore, MD 21230
(800) 414-5718 or (410) 659-9314
www.nfb.org

Office of Disability Employment Policy

U.S. Department of Labor
Frances Perkins Building
200 Constitution Avenue NW
Washington, DC 20210
(202) 693-7880
TTY: (202) 693-7881
www.dol.gov/odep/welcome.html

Office of Special Education Programs (OSEP)

U.S. Department of Education
400 Maryland Avenue SW
Washington, DC 20202
(202) 205-5507
www.ed.gov/offices/OSERS/OSEP

RecruitABILITY

www.disabledperson.com/recruitability.asp

Rehabilitation Services Administration

U.S. Department of Education
Mary E. Switzer Building, Room 3329
400 Maryland Avenue SW
Washington, DC 20202-2551
(202) 205-5482
www.ed.gov/offices/OSERS/RSA/

Social Security Administration

Office of Employment Support Programs
6401 Security Boulevard
Baltimore, MD 21235
(800) 772-1213 (Public Inquiries)
TTY: (800) 325-0778
www.socialsecurity.gov/work

**StudentJobs (student jobs
in federal employment)**

www.studentjobs.gov/

USAJobs (federal employment)

www.usajobs.opm.gov/

U.S. Department of Justice

Disability Rights Section
950 Pennsylvania Avenue NW
Washington, DC 20530-0001
(800) 514-0301
TTY: (800) 514-0383
www.usdoj.gov/crt/drs/drsbhome.htm

U.S. Department of Labor

Frances Perkins Building
200 Constitution Avenue NW
Washington, DC 20210.
(866) 4-USA-DOL
TTY: (877) 889-5627
www.dol.gov

**U.S. Department of Veterans Affairs
Vocational Rehabilitation and
Employment Service**

www.vba.va.gov/bln/vre/index.htm

**U.S. Equal Employment
Opportunity Commission**

1801 L Street NW
Washington, DC 20507
(800)669-4000 or (202) 663-4900
TTY: (202) 663-4494
www.eeoc.gov

U.S. Small Business Administration

6302 Fairview Road, Suite 300
Charlotte, NC 28210
(800) UASK-SBA
www.sba.gov

**Veteran's Administration Health
Administration Center**

CHAMPVA
P.O. Box 65023
Denver, CO 80206-9023
(800) 733-8387

STATE VOCATIONAL REHABILITATION AGENCIES

This list of state vocational rehabilitation agencies is taken from the Council on State Administrators of Vocational Rehabilitation and the Social Security Administration website at www.socialsecurity.gov/work.

ALABAMA

Alabama Dept. of Rehabilitation Services
2129 E South Blvd.
Montgomery, AL 36116
(800) 441-7607 (AL) or (334) 281-8780
TTY: (334) 617-2249
www.rehab.state.al.us

ALASKA

Division of Vocational Rehabilitation
801 W. 10th Street, Suite A
Juneau, AK 99801-1894
(800) 478-2815 (AK) or (907) 465-2814
www.labor.state.ak.us/dvr/home.htm

AMERICAN SAMOA

Vocational Rehabilitation
ASG Mail 3492
Pago Pago, AS 96799
(684) 699-2336

ARIZONA

Arizona Rehabilitation Services Admin.
1789 W. Jefferson NW, 2nd Floor
Phoenix, AZ 85007
(800) 563-1221 (AZ) or (602) 542-3332
www.de.state.az.us/rsa/

ARKANSAS

Arkansas Rehabilitation Services
1616 Brookwood Drive
Little Rock, AR 72203
(800) 330-0632 (AR) or (501) 296-1600
TTY: (501) 296-1669
www.arsinfo.org

Arkansas State Services for the Blind
Department of Human Services
522 Main Street, Suite 100
Little Rock, AR 72203
(501) 682-0360

CALIFORNIA

California Health and Human Services
Department of Rehabilitation
2000 Evergreen Street
Sacramento, CA 95815
(916) 263-8981
TTY: (916) 263-7477
www.rehab.cabwnet.gov

COLORADO

Division of Vocational Rehabilitation
2211 W. Evans, Building B
Denver, CO 80223
V/TDD: (303) 866-4150
www.cdbs.state.co.us/ods/dvr/index.html

CONNECTICUT

Department of Social Services
Bureau of Rehabilitation Services
25 Sigourney Street
Hartford, CT 06106
(800) 842-1508 (CT)
TDD/TTY: (800) 842-4524
www.dss.state.ct.us/divs/brs.htm

Board of Education and Services
for the Blind
170 Ridge Road
Wethersfield, CT 06109
(860) 602-4000 or (800) 842-4510 (CT)
TDD: (860) 602-4002
www.besb.state.ct.us

DELAWARE

Division of Vocational Rehabilitation
4425 N. Market Street
Wilmington, DE 19809-0969
(302) 761-8275
TTY: (302) 761-8296
www.delawareworks.com/divisions/dvr/welcome.htm

Delaware Division for the Visually Impaired
1901 N. Dupont Highway, Biggs Building
New Castle, DE 19720
(302) 255-9800
www.state.de.us/dbss/dvi/dvibome.htm

DISTRICT OF COLUMBIA

DC Rehabilitation Services Administration
Department of Human Services
810 First Street NE
Washington, DC 20002
(202) 442-8663

Council of State Administrators
of Vocational Rehabilitation
4733 Bethesda Avenue, Suite 330
Bethesda, Maryland 20814
(301) 654-8414
www.rehabnetwork.org

National Association of Protection
and Advocacy Systems (NAPAS)
900 2nd Street NE #211
Washington, DC 20002
(202) 408-9514
www.napas.org

FLORIDA

Florida Division of Vocational Rehabilitation
Dept. of Labor and Employment Security
2002 Old St. Augustine Road, Building A
Tallahassee, FL 32399
(904) 488-6210
TTY: (800) 451-4327

Florida Division of Blind Services
2551 Executive Center Circle W
Tallahassee, FL 32399
(800) 342-1330 (FL) or (850) 488-1330
(850) 487-1260
www.state.fl.us/dbs

GEORGIA

Department of Labor, Rehabilitation Services
148 Andrew Young International Blvd. #510
Atlanta, GA 30303-1751
(404) 657-3000

GUAM

Department of Vocational Rehabilitation
1313 Central Avenue
Tiyán, Guam 96910
(671) 475-4640

HAWAII

Hawaii Voc. Rehab. and Services for the Blind
The State Kakuhihewa Building
601 Kamokila Boulevard, Room 515
Kapolei, HI 96707
(808) 692-7722

IDAHO

Division of Vocational Rehabilitation
Len B. Jordon Building, Room 150
650 W. State, P.O. Box 83720
Boise, ID 83720-0096
(800) 856-2720 (ID) or (208) 334-3390
www.state.id.us/idvr

Commission for the Blind
and Visually Impaired
341 W. Washington Street
Boise, ID 83720
(208) 334-3220

ILLINOIS

Office of Rehabilitation Services
100 S. Grand Avenue East
Springfield, IL 62762
(800) 843-6154 or (217) 785-0234
www.dbs.state.il.us/ors/

INDIANA

Division of Disability, Aging,
and Rehabilitative Services
402 W. Washington Street
P.O. Box 7083
Indianapolis, IN 46207
(800) 545-7763
www.in.gov/fssa/servicedisabl/vr/

IOWA

Division of Vocational Rehab. Services
510 E. 12th Street
Des Moines, IA 50319-0240
(515) 281-4211
www.dvrs.state.ia.us

Department for the Blind
524 Fourth Street
Des Moines, IA 50309-2364
(515) 281-1333
TTY: (515) 281-1355
www.blind.state.ia.us

KANSAS

Department of Social and Rehab. Services
3640 S. Topeka Blvd. #150
Topeka, KS 66611-2373
(785) 267-5301
www.srskansas.org/rehab/

KENTUCKY

Kentucky Department of Vocational Rehab.
209 St. Clair Street
Frankfort, KY 40601
(800) 372-7172 (KY) or (502) 564-4440
TDD: (800) 420-9865 (KY)
<http://kydvr.state.ky.us>

Kentucky Department for the Blind
209 St. Clair Street, P.O. Box 757
Frankfort, KY 40602
(877) 592-5463 (KY) or (502) 564-4754
<http://kyblind.state.ky.us>

LOUISIANA

Louisiana Rehabilitation Services
Department of Social Services
8225 Florida Blvd.
Baton Rouge, LA 70806-4834
(800) 737-2958 (LA) or (225) 925-4131
www.dss.state.la.us/offhrs/index.htm

MAINE

Bureau of Rehabilitation Services
150 State House Station
Augusta, ME 04333-0150
(800) 698-4440 (ME) or (207) 624-5950
TTY: (888) 755-0023
www.state.me.us/rehab

MARYLAND

Division of Rehabilitation Services
2301 Argonne Drive
Baltimore, MD 21218-1696
(888) 554-0334 (MD) or (410) 554-9388
TDD: (800) 735-2258 (MD)
www.dors.state.md.us

MASSACHUSETTS

Massachusetts Rehabilitation Commission
Fort Point Place
27-43 Wormwood Street
Boston, MA 02210-1606
(800) 245-6543 (MA) or (617) 204-3600
TTY: (617) 204-3868
www.state.ma.us/mrc/

Massachusetts Commission for the Blind
88 Kingston Street
Boston, MA 02111-2227
(800) 392-6450 (MA) or (617) 727-5550
TDD: (800) 392-6556 (MA)
www.state.ma.us/mcb

MICHIGAN

Department of Career Development
Disability and Rehabilitation Section
608 W. Allegan, 45th Floor
P.O. Box 30010
Lansing, MI 48909
(517) 373-3390
www.michigan.gov/mdcd/0,1607,7-122-1681---,00.html

Michigan Commission for the Blind
Family Independence Agency
201 N. Washington, 2nd Floor
Lansing, MI 48909
(517) 373-2062
TTY: (517) 373-4025
www.michigan.gov/fia/0,1607,7-124-5460_7258---,00.html

MINNESOTA

WorkForce Center
Vocational Rehabilitation Services
390 N. Robert Street, 5th Floor
St. Paul, MN 55101
(800) 328-9095 (MN) *or* (651) 296-9981
TTY: (800) 657-3973 (MN) *or*
TTY: (651) 282-5909
www.mnwfc.org/rehab/vr/main_vr.htm

State Services for the Blind
and Visually Impaired
2200 University Avenue W #240
St. Paul, MN 55114-1840
(800) 652-9000 (MN) *or* (651) 642-0508
www.mnssb.org/index.html

MISSISSIPPI

Department of Rehabilitation Services
P.O. Box 1698
Jackson, MS 39215-1698
(800) 443-1000 (MS) *or* (601) 853-5100
TTY: (601) 853-5308

MISSOURI

Division of Vocational Rehabilitation
3024 Dupont Circle
Jefferson City, MO 65109
(800) 735-2466 (MO) *or* (573) 751-3901
TTY: (800) 735-2966 (MO) *or*
TTY: (573) 751-0881
www.dss.state.mo.us/dfs/rehab/vr.htm

Rehabilitation Services for the Blind
3418 Knipp, P.O. Box 88
Jefferson City, MO 65103-0088
(800) 592-6004 *or* (573) 751-4249
DSS/TDD: (800) 735-2966
www.dss.state.mo.us/dfs/rehab/index.htm

MONTANA

Department of Public Health
and Disability Services Division
111 Sanders #307, P.O. Box 4210
Helena, MT 59604
(877) 296-1197 (MT)
V/TDD: (406) 444-2590
www.dphbs.state.mt.us/dsd/index.htm

NEBRASKA

Vocational Rehabilitation
Nebraska Department of Education
301 Centennial Mall S, 6th Floor
Lincoln, NE 68509-4987
(800) 637-3422 (NE) *or* (402) 471-3644
TTY: (402) 471-3645
www.vocrehab.state.ne.us/

Rehab. Services for the Visually Impaired
4600 Valley Road #100
Lincoln, NE 68510
(402) 471-2891
TTY: (402) 471-8126

NEVADA

Rehabilitation Division
Department of Employment, Training,
and Rehabilitation
505 E. King Street, Room 502
Carson City, NV 89701
(702) 687-4440
TTY: (702) 684-8400
<http://detr.state.nv.us/rehab/index.htm>

Bureau of the Blind and Visually Impaired
505 E. King Street, Room 505
Carson City, NV 891701
http://detr.state.nv.us/rehab/reb_bvi.htm

NEW HAMPSHIRE

Vocational Rehabilitation
New Hampshire Department of Education
78 Regional Drive
Concord, NH 03301
(800) 299-1647 (NH) *or* (603) 271-3471
www.ed.state.nh.us/VR/

NEW JERSEY

Department of Labor
Vocational Rehabilitation Services
135 E. State Street
P.O. Box 398
Trenton, NJ 08625-0398
(609) 292-5987
TTY: (609) 292-2919
www.state.nj.us/labor/dvrs/vrsindex.html

Commission for the Blind and Visually Impaired
New Jersey Department of Human Services
153 Halsey Street
P.O. Box 47017
Newark, NJ 07102
(973) 648-2324
www.state.nj.us/humanservices/cbvi/

NEW MEXICO

Division of Vocational Rehabilitation
New Mexico Department of Education
435-D Saint Michael's Drive
Santa Fe, NM 87505
(800) 224-7005 (NM) *or* (505) 954-8500
TTY: (877) 475-8226 (NM)
www.dvrgetsjobs.com/

New Mexico Commission for the Blind
PERA Building, Room 553
Santa Fe, NM 87501
(888) 513-7968 (NM) *or* (505) 827-4479
www.state.nm.us/cftb

NEW YORK

Office of Vocational and Educational Services
for Individuals with Disabilities (VESID)
New York State Education Department
1 Commerce Plaza
Albany, NY 12234
(800) 222-JOBS
www.vesid.nysed.gov/

Commission for the Blind
and Visually Handicapped
Office of Children and Family Services
52 Washington Street, Room 201
Rensselaer, NY 12144-2796
(518) 474-5686 *or* (518) 473-1774
TTY: (518) 474-7501
www.ocfs.state.ny.us/main/cbvb/default.htm

NORTH CAROLINA

Department of Health and Human Services
Division of Vocational Rehabilitation
805 Ruggles Drive, 2801 Mail Service Center
Raleigh, NC 27699-2801
(919) 855-3500
<http://dvr.dbhs.state.nc.us/>

Division of Services for the Blind
North Carolina Department of
Health and Human Services
309 Ashe Avenue, 2601 Mail Service Center
Raleigh, NC 27699-2601
(919) 733-9822
www.dbhs.state.nc.us/dsb/

NORTH DAKOTA

Disability Services
North Dakota Department of Human Services
600 S. Second Street #1B
Bismarck, ND 58504-5729
(701) 328-8950
TTY: (701) 328-8968
[http://notes.state.nd.us/dhs/dhsweb.nsf/
ServicePages/DisabilityServices](http://notes.state.nd.us/dhs/dhsweb.nsf/ServicePages/DisabilityServices)

NORTHERN MARIANA ISLANDS

Office of Vocational Rehabilitation
P.O. Box 1521-CK
Saipan, MP 96950
(670) 664-6448
TTY: (670) 322-6449

OHIO

Ohio Rehabilitation Services Commission
400 E. Campus View Blvd.
Columbus, OH 43235-4604
(800) 282-4536 (OH) *or* (614) 438-1200
www.state.oh.us/rsc/index.asp

OKLAHOMA

Department of Rehabilitation Services
3535 NW 58th Street #500
Oklahoma City, OK 73112-4815
(800) 845-8476 (OK) *or* (405) 951-3400
www.okrehab.org/

OREGON

Department of Human Resources
Vocational Rehabilitation
500 Summer Street NE
Salem, OR 97310-1018
(503) 945-6201
TTY: (503) 945-5894
www.dhs.state.or.us/vr/

PENNSYLVANIA

Office of Vocational Rehabilitation
Department of Labor and Industry
1521 N. 6th Street
Harrisburg, PA 17102
(717) 787-5244
TTY: (717) 783-8917

PUERTO RICO

Division de Rehabilitacion Vocacional
Departamento de Sevicios Sociales #1118
Hato Rey, Puerto Rico 00919
(787) 728-3520 or (787) 728-8070

REPUBLIC OF PALAU

Vocational Rehabilitation Services
Republic of Palau
P.O. Box 6027
Koror, Palau 96940
(680) 488-2813

RHODE ISLAND

Office of Rehabilitation Services
Department of Human Services
40 Fountain Street
Providence, RI 02903
(401) 421-7005
TTY: (401) 421-7016
www.ors.state.ri.us

Services for the Blind and Visually Impaired
Department of Human Services
40 Fountain Street
Providence, RI 02093-1898
(800) 752-8088 ext 2300 or (401) 222-2300
TDD: (401) 222-3010
www.ors.state.ri.us/sbvi.htm

SOUTH CAROLINA

South Carolina Vocational
Rehabilitation Department
1410 Boston Avenue, P.O. Box 15
West Columbia, SC 29171-0015
(803) 896-6504
TTY: (803) 896-6636
www.scvrd.net/scvrinfo.htm

South Carolina Commission for the Blind
1430 Confederate Avenue, Box 79
Columbia, SC 29201-0079
(803) 734-7520
TTY: (800) 735-2905 (SC)

SOUTH DAKOTA

Division of Rehabilitation Services
East Hwy. 34
c/o 500 E. Capitol
Pierre, SD 57501-5070
(605) 773-3195
www.state.sd.us/dhs/drs/

TENNESSEE

Tennessee Department of Human Services
Vocational Rehabilitation
Citizens Plaza Building #1100
400 Deaderick Street
Nashville, TN 37248-6100
(615) 313-4902
www.state.tn.us/humanserv/VRServices.html

TEXAS

TX Rehabilitation Commission
4900 N. Lamar Blvd. #7102
Austin, TX 78751
(512) 424-4000; (800) 628-5115 (TX)
www.rehab.state.tx.us

Texas Commission for the Blind
Administration Building
4800 N. Lamar #320
Austin, TX 78756
(800) 252-5204 (TX) or (512) 377-0500
www.tcb.state.tx.us/

UTAH

Utah State Office of Rehabilitation
250 East 500 South
Salt Lake City, UT 84111
(801) 538-7530
www.usor.state.ut.us/

VERMONT

Division of Vocational Rehabilitation
Vermont Department of Aging and Disabilities
Osgood II Building
103 S. Main Street
Waterbury, VT 05671-2303
(802) 241-2186
www.dad.state.vt.us/dvr/

Division for the Blind and Visually Impaired
Department of Aging and Disabilities
Osgood Building, Waterbury Complex
103 S. Main Street
Waterbury, VT 05676-2303
(802) 241-2210
www.dad.state.vt.us/dbvi/

VIRGIN ISLANDS

Division for Disabilities and
Rehabilitation Services
Department of Human Services
Knud Hansen Complex, Building A
1303 Hospital Ground
St. Thomas, VI 00802
(340) 774-0930

VIRGINIA

Department of Rehabilitative Services
8004 Franklin Farms Drive
P.O. Box K300
Richmond, VA 23288-0300
(800) 552-5419 (VA) or (804) 662-7000
www.vadrs.org/

Department for the Blind
and Vision Impaired
397 Azalea Avenue
Richmond, VA 23227
(800) 622-2155 (VA) or (804) 371-3140
www.vdbvi.org/

WASHINGTON

Department of Social and Health Services
Division of Vocational Rehabilitation
P.O. Box 45340
Olympia, WA 98504-5340
(360) 438-8008

Department of Services for the Blind
1400 S. Evergreen Park Drive SW
P.O. Box 40933
Olympia, WA 98504-0933
(800) 552-7103 (WA) or (360) 721-4056
TDD: (360) 721-4056
www.wa.gov/dsb/

WEST VIRGINIA

West Virginia Department of
Education and the Arts
Division of Rehabilitation Services
State Capitol
P.O. Box 50890
Charleston, WV 25305-0890
(800) 642-8207 (WV) or (304) 766-4600
www.wvdrs.org/

WISCONSIN

Vocational Rehabilitation
Department of Workforce Development
201 E. Washington Avenue, Room A100
P.O. Box 7852
Madison, WI 53707-7852
(800) 442-3477 (WI) or (608) 243-5603
TTY: (888) 877-5939 (WI)
www.dwd.state.wi.us/dvr/

WYOMING

Vocational Rehabilitation Services
Department of Workforce Services
1100 Herschler Building
Cheyenne, WY 82002
(307) 777-7389
<http://dwsweb.state.wy.us/vr.asp>

SAMPLE PHYSICIAN LETTERS

Sample Physician Letter to Employer (Peritoneal Dialysis)



1301 Pennsylvania St #750, Denver, CO 80202-5012
tel: 303-831-8818 fax: 303-860-8932 www.esrdnet15.org

Dear _____,

As the physician coordinating the peritoneal dialysis care of _____, one of your employees, I'm writing to you about individuals with kidney failure and their ability to work.

First, let me acquaint you with peritoneal dialysis. Peritoneal dialysis is a medical procedure performed several times daily to remove harmful toxins in the blood when a person's kidneys have failed and can no longer do that vital job on their own. This type of dialysis can be done by the patient in any clean, private environment—even at work. Thus, not only is kidney failure treatable, but this type of treatment, in particular, may be most compatible with the demands and schedule requirements of a job.

It is a myth that once a person starts dialysis he or she categorically cannot work. Certainly, one's age, general health, and other factors may determine physical limitations, but the range of those limitations is a vast one, indeed. Most patients will be restriction-free, and with the exception of heavy physical labor, capable of performing the specific job tasks they did before starting dialysis.

Regarding any concern you may have about the use of sick time, it may be necessary for the employee to take short-term medical leave during times of acute illness, possibly requiring a hospital stay. Those needs, however, are about as predictable as those of all your other employees. For the routine dialysis treatments each day, every attempt can be made to schedule them so as to avoid interfering with the workload. Another option, if necessary, may be to consider a modified work schedule, deemed a reasonable accommodation[®] by the Americans with Disabilities Act, which does recognize kidney failure as a qualifying physical impairment.

In summary, my experience with people on dialysis is that the opportunity to continue working after starting dialysis provides the employee with economic stability, personal satisfaction, and an enhancement to the sense of well-being, as well as giving you, the employer, a willing, highly motivated, experienced member of your team.

Please don't hesitate to call if you have further questions about _____'s physical capabilities in relation to employment.

Sincerely,

_____, MD

Sample Physician Letter to Employer (Hemodialysis)



1301 Pennsylvania St #750, Denver, CO 80202-5012
tel: 303-831-8818 fax: 303-860-8932 www.esrdnet15.org

Dear _____,

As the physician coordinating the dialysis care of _____, one of your employees, I'm writing to you about individuals with kidney failure and their ability to work.

First, let me acquaint you with dialysis. Dialysis is a medical outpatient procedure performed usually three times per week to remove harmful toxins in the blood when a person's kidneys have failed and can no longer do that vital job on their own. Thus, kidney failure is treatable.

It is a myth that once a person starts dialysis he or she categorically cannot work. Certainly, one's age, general health, and other factors may determine physical limitations, but the range of those limitations is a vast one, indeed. Most patients will be restriction-free, and with the exception of heavy physical labor, capable of performing the specific job tasks they did before starting dialysis.

Regarding any concern you may have about the use of sick time, it may be necessary for the employee to take short-term medical leave during times of acute illness, possibly requiring a hospital stay. Those needs, however, are about as predictable as those of all your other employees. For the routine dialysis treatments each week, every attempt will be made to schedule them so as to avoid interfering with the work schedule. Another option, if necessary, may be to consider a modified work schedule, deemed a reasonable accommodation by the Americans with Disabilities Act, which does recognize kidney failure as a qualifying physical impairment.

In summary, my experience with people on dialysis is that the opportunity to continue working after starting dialysis provides the employee with economic stability, personal satisfaction, and an enhancement to the sense of well-being, as well as giving you, the employer, a willing, highly motivated, experienced member of your team.

Please don't hesitate to call if you have further questions about _____'s physical capabilities in relation to employment.

Sincerely,

_____, MD