

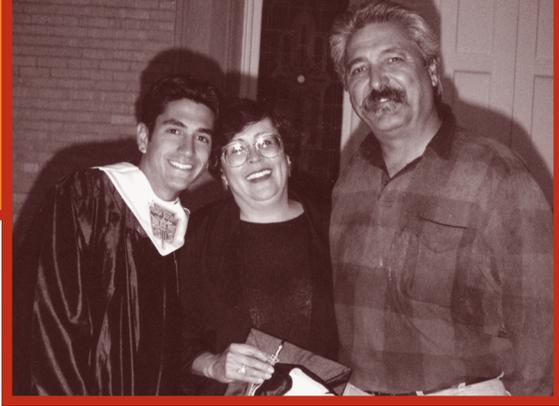
Definitely Yes! Going to School, Working, and Traveling

Having chronic kidney disease (CKD) has forced you to make many changes in your life...some of which have been harder than others. You may have wondered if you could ever return to a “normal” life. The answer for many people is “Definitely yes!” As dialysis becomes routine or as you recover from your transplant, and as your strength and health improve, you can return to the important things in your life, including going to school, working, and traveling for business and pleasure. If you do dialysis, choosing to learn to do it at home will make it easier to schedule your dialysis around other activities.

Definitely yes!— Go to school

Education develops the mind and social skills. It challenges and inspires. It also is a key factor in how much money an individual will earn over his or her lifetime. People with CKD, of all ages, can definitely go to school—from kindergarten through college and graduate school.





Kindergarten through high school

Going to school can be as important to children as going to work is for adults. Yet disabled children are twice as likely to drop out of school as healthy children. They miss getting the education they need for success as an adult, and they miss the socialization of being with other children, making friends, and taking part in after-school activities. All public schools (and many private schools) are not allowed to discriminate against a child who has a disability, including kidney disease. They are required to set up individualized educational programs (IEPs) for these children. IEPs may include fewer hours in school so the child can go to dialysis, or regular breaks to visit the school nurse for medications or to perform peritoneal dialysis.

Paying for college

In addition to traditional sources of information on financial aid for college students, some kidney organizations offer scholarships and grants to help people of all ages with kidney disease pay tuition and other expenses. Check with these organizations for more information:

- National Kidney Foundation affiliates: www.kidney.org, click NKF Affiliates
- American Kidney Fund: www.kidneyfund.org

Health insurance for college students with CKD

If you are the parent of a college-age child with CKD and have a health-insurance plan at work, ask how long that plan will insure your child. Many plans provide coverage for children up to their early to mid-20s (the specific age is set by state or plan) if they are full-time college students. Part-time students may be covered, too, because employer plans often will insure dependent children as long as they are disabled. Your child also may be able to get a student health plan through his or her college or university.

- Kidney and Urology Foundation of America: www.kidneyurology.org, click Patients Resources, then Scholarships
- Transplant Recipients International: www.trioweb.org, click Resources, then TRIO Scholarships

Talk with financial aid officers at state and community colleges in your area. You, or your child, may be able to attend one of these schools for free or at reduced cost. If you are working on a rehabilitation plan through your state Vocational Rehabilitation office, you may be able to get help with tuition payments. Finally, the federal government offers grants and low interest loans to help people pay for college. To learn more about these programs, go online to www.studentaid.ed.gov and click on Funding.

Definitely yes!— Go to work

Working and being independent are strong values for Americans. Work brings in the money we need to support ourselves and our families, gives us a chance to be with other people, and fosters a more positive outlook on life. People with kidney disease can definitely go back to full- or part-time work, pursue different work, or get their first job. Several programs can help you get

to work—and provide income as you move toward independence in the workplace.

Where to start

If you receive income from Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), and you're uncertain about the kind of work you'd like to do, contact your local Vocational Rehabilitation (VR) agency. These agencies help people return to a job or retrain for a new one. They can help you decide what work interests you and provide money for retraining for that work. They may pay your transportation to retraining programs. You will continue to receive SSDI or SSI while you're in an approved VR program even if your health improves and you are no longer disabled. State Vocational Rehabilitation offices are listed at www.jan.wvu.edu, click The Small Business and Self-Employment Service (SBSES), then Resources for Small Business and Self-Employment, then State Vocational Rehabilitation Offices. You also can go to www.socialsecurity.gov/work, and click Service Providers, or call Social Security at 1-800-772-1213 and ask how to contact your state VR agency.

If you received a "Ticket to Work" (sent to people ages 18 through 64 who receive SSDI or SSI payments), you can use it to get free job training or help



finding a job from a public or private employment network (EN). If you are on dialysis and work you can keep Medicare indefinitely. As long as you are disabled, you can keep Medicare Part A for free and Medicare Part B if you pay the premium for eight and one-half years. Find state employment networks online at www.yourtickettowork.com. Click Directory of ENs. For information on Ticket to Work, call your local Social Security office or visit www.socialsecurity.gov/work and click Ticket to Work.

Work incentive programs

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs help you take your first steps into the workplace. The SSDI “trial work period” (TWP) lets you find out if you are able to work without giving up your disability payments. Your SSDI check will keep coming for nine months (which don’t have to be in a row), no matter how much money you earn by working. If a job pays less than \$620 (2006) a month, it doesn’t count against the nine-month trial work period. After you use all nine TWP months, any month you make \$860 (2006) or more (\$1,450 if the recipient is blind) you will not get your SSDI check. Those who get SSI benefits and work can keep some SSI benefits while

working. How much depends on the SSI benefits they get and the amount of income they get from work. Someone with the full SSI 2006 individual benefit (\$603) can keep the first \$185 of earned and unearned income from a job. After this, they lose \$1 of SSI cash benefits for every \$2 they earn until their SSI check is gone. In 2005, this occurs at \$1,243 a month.

Unmarried students who get SSI under age 22 can earn up to \$1,460 a month or \$5,910 a year (2006) without losing benefits.

If you work and are disabled, you may have expenses for work that people without disabilities don’t have. For example, you may need specialized work-related equipment, medical supplies, or a wheelchair, or you might have to take a taxi to work instead of using public transportation. If the cost is related to your disability and is needed so you can work, you may be able to subtract the cost of these things from your monthly earnings before Social Security determines if you are still eligible for disability benefits.

The SSI “Plan for Achieving Self-Support” (PASS) program helps you write a plan for supporting yourself, such as going to school or buying a car for work (if public transportation is not available). Money to put your plan into action can be set aside without lowering your SSI income for up to 48

months. The work incentive specialist at your local Social Security office can tell you more about these and other programs.

If you work, find out if your state offers a Medicaid “buy-in” program. This program might let you pay a premium and get help from Medicaid with your medical costs—even if you earn more than other people with disabilities who don’t work. To find the phone number for your state’s Medicaid office, call 1-800-MEDICARE (1-800-633-4227).

Definitely yes!—Travel

If you have had a transplant or are on dialysis, you don’t have to stay close to home for the rest of your life. You definitely can send your child to camp, take a trip to the Grand Canyon, or go out of town on business. Traveling can lift your spirits and boost your sense of well-being.

You will have to do extra planning before you leave, especially if you are on dialysis. Start by talking with your doctor. You’ll find your doctor supportive as long as your health is stable. Your social worker is a source of valuable information to help you have a healthy and worry-free trip. Check your health-insurance plan to find out if dialysis away from home, called “transient” dialysis, will be paid for. Generally, insurance providers

have the following policies for dialysis away from home:

- Private insurance plans, such as those provided by employers: Many will pay for dialysis in the United States; some will pay for it outside the United States.
- Medicare Original and Medicare Advantage: Will pay 80 percent of dialysis costs in the United States; will not pay for dialysis outside the United States; may pay part of the costs of your dialysis treatments while traveling in the United States if your private health insurance does not pay, except for some non-standard plans in Massachusetts, Minnesota, and Wisconsin. Call the insurance company and ask if your policy covers routine dialysis when you travel inside or outside the United States.
- Medigap: Some policies may not pay for dialysis treatments you get in another state. Call the insurance company to ask if your policy covers routine dialysis when you travel inside or outside the United States. To read the publication, *Choosing a Medigap Policy*, go to www.medicare.gov, click on Find a Medicare Publication, and then type Medigap in the box shown.
- Managed care organizations (MCOs)/Health maintenance organizations (HMOs): Often only pay for dialysis outside their primary



service or geographic area in an emergency; routine dialysis is not considered an emergency. Call your provider and ask what coverage you have.

- **Medicaid:** Most programs will not pay for dialysis outside your state unless the dialysis clinic is a provider with your state Medicaid. Sometimes clinics in states that border one another have these arrangements.
- **State kidney programs:** Most will not pay for dialysis outside your state.

If you are on a kidney transplant waiting list, talk with your transplant coordinator about your travel plans. Let your coordinator know where you can be reached if a kidney becomes available or ask to go “on hold” for the time you will be away.

If you are on hemodialysis

If you receive hemodialysis treatments at a dialysis center (or if you cannot bring your home hemodialysis machine with you), you will need to arrange for dialysis where you will be visiting. Make arrangements at least six weeks before your trip—sooner if you’re going to a popular place or traveling during the holidays.

To locate Medicare-certified dialysis centers in another town, city, or state, go online to www.medicare.gov. Click Compare Dialysis Facilities In Your

Area and then type in the name or ZIP code of the place you will be visiting to see a list of centers in that area. The social worker, nursing director, or other staff member at your center also can help you locate dialysis centers, but it usually will be up to you to contact them and schedule dialysis.

Be flexible about travel dates because space in dialysis centers can be limited. Ask your dialysis center to send a copy of your medical records to the out-of-town center and take another copy with you. Confirm your appointment as soon as you arrive at your destination. Ask the chosen center to explain all charges and how they can be billed. You may have to pay a fee for the doctor. Ask what will be billed to Medicare and/or other insurance providers and what portion, if any, you will have to pay yourself.

If you are on peritoneal dialysis

With peritoneal dialysis (PD), you have more freedom to travel because you do treatments yourself or with a partner. You’ll want to make sure you have the supplies you need on your trip. You can take what you need with you on short trips. For longer trips, arrange for supplies to be delivered to you. PD supplies are shipped worldwide every day, so it should not be hard to schedule a delivery at your destination. Carry your supply company’s phone number with you in case you need to contact them.

Vacations on dialysis

Easter Seals Project ACTION has a list of accessible transportation services in the United States serving people with disabilities. The list includes tours and tour companies, airport and other private shuttles, taxi companies, and public transit services. Go to www.projectaction.org, click Free Resources, then National Accessible Travelers Database, and then Search. Type in the name of the place you want to visit, and a list of available transportation services will appear.

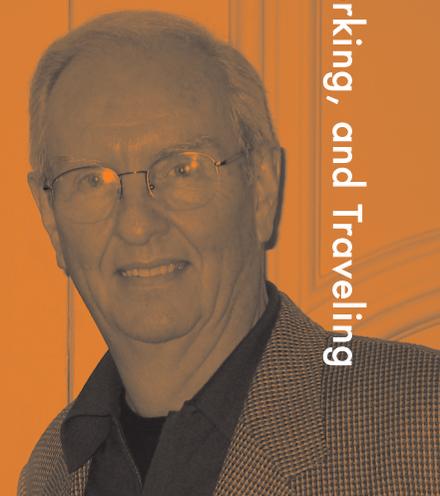
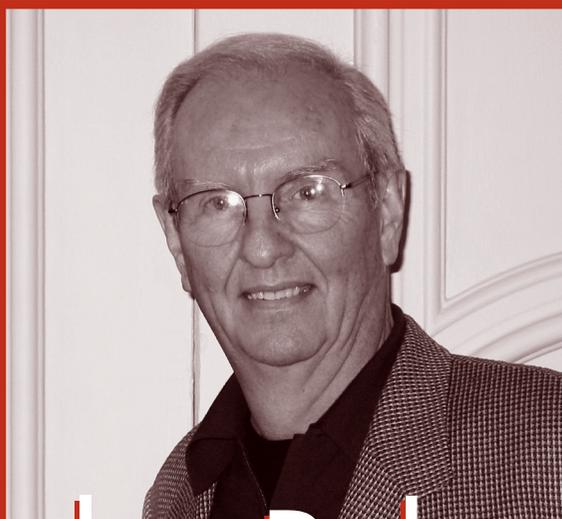
You also can find travel agencies specializing in planning for people with disabilities. Several companies specialize in vacation and travel planning specifically for people on dialysis, including cruises, international travel, and wilderness trips. Camps are available for adults and children who are on dialysis. Contact your local National Kidney Foundation affiliate for information and a directory of camps. To locate your local affiliate, go to www.kidney.org, click Who We Are, then Affiliate Offices. A U.S. map will appear on the screen. Click your state. Check with your health insurance plan about payment for the cost of dialysis on these trips. Generally, Medicare does not pay for treatments outside the United States. Also, check with your health insurance plan to see if it will pay for dialysis outside the United States.

Just to be safe, get a copy of your medical records to take on the trip and ask your doctor or social worker to help you locate a center that offers PD in the area you'll be visiting. Call that center and ask if you can use them, if needed, while you're in the area. You can then rest easy, knowing who to contact if you run short of supplies or have an emergency.

Traveling for family emergencies

If you have to travel because of a sudden illness or death in your family, you won't have a lot of time to schedule dialysis or supply deliveries. But don't let that stop you from going. You may have to drive farther to a center, or go at a less desirable time, but you probably can get the treatments you need. Many centers make every effort to treat patients visiting because of an emergency. Your social worker can help you locate dialysis centers, secure a copy of your medical records, and schedule treatments on short notice. The National Kidney Foundation can help patients and families in a variety of emergency situations. These services and programs vary across the country. Contact the National Kidney Foundation for information at 1-800-622-9010 or www.kidney.org or refer to p.xx for a list of NKF affiliates.

"If you travel and need dialysis treatments, ask the social worker at your dialysis facility to send your Medicare and insurance information to the dialysis unit you will use on your trip before your arrival. "



Douglas Robertson