
FINANCIAL HELP RESOURCES

Dialysis Means Changes in our Lifestyle

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Dialysis Means Changes in our Lifestyle

When we are newly diagnosed with End Stage Renal Disease (ESRD) and begin dialysis, we are given a great deal of information on the changes in our health. This is important information covering the lifestyle changes we need to make such as fluid and food restrictions. These lifestyle changes will help us stay strong and feel better. However, there are other lifestyle changes that we should be making to protect our Financial Health.

To be perfectly honest, many of us have had to accept some financial losses. Some of us have not continued to work and have had a sharp decrease in **Income**. Some of us have struggled with an increase in **Expenses** to cover both medical and non-medical costs that we were not anticipating. As a result, we may have lost assets - cars, homes, savings, college funds, etc.

These changes in both Income and Expenses have become our “new normal” but we are not prepared to make the decisions we need to make. Failure to plan, failure to budget, can be devastating to our lifestyles and our families. However, if we know what to expect and where to find help, some of these losses can be avoided. If nothing else, we are better prepared to make some of the hard decisions we are faced with.

The Need to Adapt

Our first instinct is often to hold on tightly to everything we have. This is understandable. None of us wants to lose anything. But if we are faced with a decrease in income and/or an increase in bills, some changes are necessary. It may become necessary to let go of some of the things that have payments tied to them. Some of us have found that two cars are no longer necessary for our family. Others have found that while we love our houses, an apartment is easier to take care of and a more practical lifestyle.

“ I wish I had a time machine. It would have been great to get a head-start on budgeting and planning. Unfortunately, it’s taken me almost five years to learn things the hard way.”

*- Jeff N., Phoenix, AZ
In-Center HemoDialysis patient*

It is important to look at what money we have and where it is going. At first, it is a good idea to cut down on non-essential expenses until we figure out what our “new normal” is going to be. We can always add a luxury back in if we find that we are in better financial shape that we anticipated.

Even with the best plans in place, though, we may find that we need help. The Resource List on the following pages will hopefully lead you to groups and agencies that can help you gain control over your financial health while you are dealing with the challenges of your physical health.



*Where do I go for help with my **Medical Bills**?*

Financial help is available from the **Federal Government** and other sources. In 1972 the U.S. Congress passed a law that allows most people with kidney failure coverage by Medicare. There are also State and private sources that can help.

Quick Medicare Questions

• **When does Medicare start for people with Kidney Failure?**

- Home Dialysis - Medicare can start the First Month of dialysis **ONLY** if a person trains for home dialysis from the beginning/onset of kidney failure.
- In-Center Dialysis - Medicare will not start until the Fourth Month of in-center dialysis.
- Transplant - Medicare can start the same month as the transplant.

• **When does Medicare end for people with kidney failure?**

- Medicare continues for as long as a person is on dialysis and pays a premium.
- Medicare continues for three years following a transplant. It will end after three years **IF** kidney failure was the only reason you have Medicare.
- Medicare will end if your kidneys get better, and you no longer need dialysis.
- If you are already on Medicare due to age or disability prior to starting dialysis, Medicare will continue.

• **Where do I get more information on Medicare?**

- Your unit Social Worker - This should always be your first resource. Social workers have access to a lot of information that can help you.
- The Medicare booklet explains the basics of Medicare, how Medicare helps pay for kidney dialysis and kidney transplants, and where to get additional help. It can be downloaded at www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf.

What **State Programs** can help?

Since Medicare only covers 80% of the cost of dialysis, you may need additional help. Private insurance, if you have it, should cover the remaining 20%. If not, you may qualify for State or private assistance.

1. **Medicaid** is a state program for those with low income and few assets. Medicaid may pay for things that Medicare does not.
2. **Medigap** (also known as Medicare Supplement) – Medigap can help pay what original Medicare does not. Insurance companies sell Medigap coverage.
3. **Medicare Savings Programs** – some states may pay Medicare premiums, deductibles, and coinsurance if a person has low income and few assets.
4. **State Health Insurance Assistance Programs** – *SHIPs* get money from the Federal Government to give free health insurance advice to those with Medicare.

Where can I get more information on State Programs?

1. Your unit **Social Worker** is always your first resource for State Programs that can help.
2. The **Medicaid** website provides more information about Medicaid including Frequently Asked Questions and instructions for applying for Medicaid in your State. (www.medicaid.gov)
3. **National Association of Insurance Commissioners**. Search by State to find your State Commissioner who can explain the Medicare Savings Program plans available in your State. (www.naic.org/index_members.htm)
4. **State Health Insurance Assistance Program** (SHIP) has information on one-on-one counseling and assistance. Use the SHIP Locator button to your State contact information. (www.shiptacenter.org/)

What Programs can help Special Populations?

1. U.S. Veterans - www.va.gov/healthbenefits
2. Military Service Members, Retirees, and Families (TRICARE) - www.tricare.mil
3. American Indians and Alaska Natives - www.IHS.gov
4. Children - www.insurekidsnow.gov
5. People with Disabilities - www.dol.gov/odep/topics/disability.htm

What Private Organizations can help?

1. The **American Kidney Fund** has grants to help pay health plan premiums. Talk to your Social Worker to see who the appropriate person is in your unit for help in filling out the application. The American Kidney Fund depends on donations, so there may be times when funds are low. More information can be found at www.kidneyfund.org or call 866-300-2900.
2. The **National Living Donor Assistance Center** can help cover the expenses related to living organ donation. They operate a nationwide system that provides reimbursement of travel and living expenses to people being evaluated for and/or undergoing living organ donation. Priority is given to those who could not otherwise afford to donate. More information can be found at www.livingdonorassistance.org/Home/default.aspx or call 703-414-1600.

What help is available for Prescription Coverage?

1. **State Pharmaceutical Assistance Programs** are available in 22 states. More information is available at www.medicare.gov/pharmaceutical-assistance-program/state-programs.aspx

2. **Medicine Assistance Tool** (MAT) lists over 200 programs that help pay for medications. More information is available at www.MedicineAssistanceTool.org or www.MAT.org or call 1-888-477-2669.
3. **NeedyMeds** is a nonprofit group that helps people find programs that help pay for medications. www.needymeds.org/newuser or call 1-800-503-6897.
4. **RxAssist** provides information about drug company programs, state programs, discount drug cards, copay help, and more. This is an easy site to search. www.RxAssist.org/patients
5. **National Kidney Foundation** (NKF) - Many drug companies offer prescription assistance programs for their medications to those who qualify. NKF offers a list of phone numbers for some common medications and companies for dialysis patients and transplant recipients. [www.kidney.org/patients/resources Prescription](http://www.kidney.org/patients/resources_Prescription)
6. **Social Security** provides limited Income Subsidy/Extra Help. There are financial guidelines, so not everyone qualifies, but those who do are able to get their medications for a much lower copay. www.ssa.gov/benefits/medicare/prescriptionhelp/

*Where do I go for help with **Employment?***

Having kidney disease has changed our lives, but there are things we can do to reduce the impact on our lifestyle and income. We need to work with our dialysis team to feel well enough to gain employment. We should be able to do most of the job tasks we did before starting dialysis. If an employer requires hard labor, we may even be able to do that job with an assist device or labor-saving equipment. You may, however, choose to look for another job opportunity.

Help with Job Seeking and Training

Vocational Rehabilitation (VR) Agencies furnish a wide variety of services to help people with disabilities return to work. These services are designed to provide the client with the training and other services that are needed to return to work, to enter a new line of work, or to enter the workforce for the first time. VR counselors help to evaluate strengths, resources, priorities, concerns, abilities, and career interests. They help clients get the education or job training they need to get a good job, help with job seeking, and with education-related expenses. They can also assist with understanding how work will impact Social Security Benefits.

1. Talk to your unit **social worker** about Vocational Rehabilitation (VR) and how your treatment plan, dialysis type, and schedule can fit into your work or school goals. The social worker can help you find a VR office or Employment Network (EN).
2. Use the internet to find a **service provider in your area**. www.choosework.ssa.gov/findhelp or call 866-968-7842.
3. Sometimes rehabilitation means continuing education or **returning to school** to learn a new profession. *Some scholarship programs exist for dialysis patients, transplant recipients and their families.* Network 5 has a website list available to help in your search for available programs and resources. www.qirn5.org/Patients-Families/Education-Resources/Vocational-Rehabilitation/Schooling.aspx

4. Social Security's **Ticket to Work** program supports career development for Social Security disability beneficiaries age 18 through 64 who want to work. The *Ticket* program is free and voluntary and helps people with disabilities progress toward financial independence. www.choosework.ssa.gov/index.html
5. The Social Security Administration hosts monthly **Work Incentive Seminar Event** (WISE) webinars to provide education about the Ticket to Work program and work incentives for people who are age 18 through 64 and receive Social Security Disability benefits. WISE webinars are typically held on the fourth Wednesday of each month. You can register for the next WISE seminar by going to www.choosework.ssa.gov/wise/
6. **WISE on Demand**. Many past WISE webinars have been archived and are still available to view. www.choosework.ssa.gov/webinars-tutorials/webinar-archives/index.html

State Agencies

7. Every state has a **Vocational Rehabilitation Agency** that is designed to help individuals with disabilities meet their employment goals. Vocational rehabilitation agencies assist individuals with disabilities to prepare for, obtain, maintain, or regain employment. This site gives a list of all State agencies and their phone numbers and contact information. www.askearn.org/state-vocational-rehabilitation-agencies/

Other Organizations

8. The **Job Accommodation Network** (JAN) has consultants that offer one-on-one guidance on workplace accommodations, the Americans with Disabilities Act (ADA) and related legislation, and self-employment and entrepreneurship options for people with disabilities. Assistance is available both over the phone and online. www.askjan.org/info-by-role.cfm#for-individuals and www.askjan.org/disabilities/Renal-Kidney-Disease.cfm or call 800-526-7234.

9. **DCI Clinics** - Working While on Dialysis www.dciinc.org/working-while-on-dialysis-its-possible/

10. **DaVita** Kidney Care - Keeping Your Job When You Have Chronic Kidney Disease www.davita.com/education/ckd-life/employment/keeping-your-job-when-you-have-chronic-kidney-disease

11. **Fresenius** Kidney Care - Staying Employed While on Dialysis www.freseniuskidneycare.com/thriving-on-dialysis/staying-active/staying-employed

*Where can I get **other financial assistance?***

1. Your local **electricity company** may offer discounted rates for residential customers with powered medical devices such as home hemodialysis machines, Peritoneal Dialysis cyclers, and other devices including CPAP machines.

In California, for example, Pacific Gas and Electric (PGE) offers a Medical Baseline Program which includes

- a lower rate on your monthly energy bill
- extra notifications in advance of a Public Safety Power Shutoff

Check with your local energy provider for more information.

Notes

A large area for taking notes, featuring a vertical margin line on the left and horizontal dashed lines for writing.

This resource was created for
Dialysis Patients, Caregivers and Families
by



KIDNEY PATIENT ADVISORY COUNCIL (KPAC)

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This and other patient resources can be downloaded at
<https://esrdnetworks.org/resources/toolkits/patient-toolkits>

The Forum of ESRD Networks
P.O. Box 203 Birchwood, Wisconsin 54817
Phone (715) 354-3735 Fax (888) 571-2065