UW Medicine
UNIVERSITY OF WASHINGTON
MEDICAL CENTER

Coping and Living with Kidney Disease

Tips, strategies, and resources

Class Goals

1. **Know the common issues and stresses involved in living with kidney disease.**
2. **Understand tips and strategies for coping and living with kidney disease.**
3. **Be able to find and use print and internet resources as needed.**

Overview

It is normal to feel anger, fear, sadness, stress, and frustration when you have a chronic illness. It is normal for your family members to also have these feelings.

There are ways you can think about your situation that will help you to keep or regain control of your life:

- Take responsibility for your health.
- Learn all about your condition.
- Talk openly with your care team, friends, and family.

You are not alone. Others have made it through. You can, too!

Coping with Kidney Disease

How will my life change because of my illness? How will my illness affect my family? Will I be able to return to work and my daily activities?

Do these thoughts sound familiar? They are common for people with chronic health problems. The good news is that you **can** live a good life with kidney disease.

Learn as much as you can about your condition. Talk openly with your care team.

- Nancy Spaeth, a registered nurse who has had kidney disease for over 40 years, said, “I don’t think of myself as a sick person. I think of myself as a healthy person with a kidney problem.”
- Sharon Pahlka, a life coach for people with chronic illness who has had kidney disease for over 30 years, shared with us, “You can handle life in a successful way by redefining what is normal for you. Now that we have kidney disease, things do need to be done a little differently, and that can make us feel sad. But don’t forget, even if we don’t have kidney disease, things happen to everyone’s life. Every single person in the whole world is continually creating his or her new ‘normals.’

  “We kidney patients just have to define our new ‘normal’ to include kidney disease. This is probably a different way of looking at your life than you’ve had before. Let’s define our new normal and expectations.”

With a positive attitude, you can learn to live successfully with kidney disease. It will take some time and effort on your part.

Common Concerns

Most people with kidney failure deal with issues such as:

- Changes in your roles or responsibilities within your family
- Dependence and independence issues
- Changes in sexual function

Chronic kidney disease can also cause changes in your self-image or lifestyle. These are some of the types of stress you may feel:

Psychological Stress

- A loss of sense of well-being
- Uncertainty about the future
- Coping with tests, surgeries, hospitalizations, and dialysis treatments

Social Stress

- Diet and fluid restrictions
- Taking many medicines
- Dialysis treatments
- Less time and energy for family and socializing
- Changes in employment, income, or financial security

Emotional Stress

It is common to have feelings of loss, helplessness, and uncertainty when dealing with a chronic disease. This might result in depression, anxiety, fear, or anger. Sometimes depression can appear as anger, withdrawal, loss of concentration, and problems with sleeping and eating. But remember, these same symptoms might also be signs of uremia.

Every person at one time or another feels cranky, down, sad, or depressed. This is especially true when your life and your health feel out of control. When you are no longer able to do some of the things you used to do, it is normal to feel frustrated.

But, if you begin to withdraw socially or emotionally from others, or if you are starting to doubt your self-worth or lose interest in doing things that you used to, tell your nurse, *nephrologist* (kidney doctor), or social worker. They can talk with you about depression and help provide treatment options and support.

It is very important that you find ways to let go of stressful emotions. Most people get angry from time to time during a long illness. Feeling angry is one of the natural stages of grief. But, staying angry or stressed can drain you of the energy you need to stay healthy.

- Bill Peckham, who loves to travel and has had many hemodialysis treatments in Europe while traveling, said, "When you discover that you're ill, getting depressed is pretty much normal. While there's no way of avoiding it, you don't want to wallow in it because there is a great life ahead of you. You just have to travel a little while to get to it."

Other patients have shared these next suggestions and found them useful in living with chronic kidney disease:

Gather a Support Team

Family and Friends

Getting support from others during any long illness can be a big help, especially when times are hard. Remember, it is important to talk with your family and friends about your thoughts and feelings, and to ask for help when you need it.

Talking with your family will help them, too. Dealing with a chronic illness can be scary for the people who love you. But knowledge is power, and it often provides strength. Everyone benefits when your family feels included in your decision-making process.

- Sharon Pahlka said, "If I had it to do over again, I would acknowledge and empathize much more with my spouse and family who shared my kidney disease with me."

Social Worker

Your social worker can provide support, education, and counseling to you and your family. Also, think about joining a patient support group. Having input from others who are living with chronic kidney disease helps you realize you are not alone in your situation.

Spiritual Support

For many people, their spiritual beliefs are an important part of their life. If this is true for you, spiritual support may give you a lot of comfort during hard times. Your minister, rabbi, priest, or spiritual advisor may be an important member of your support team.

Education

Learn as much as you can about what’s happening to you. You’ve taken a big first step by coming to the KEEP classes and getting information about kidney disease and your treatment options. Meeting with others who are also facing kidney treatment will hopefully give you more emotional support. As you become educated about kidney disease, you increase your sense of control and well-being.

Learn as much as possible so that you can consider all your options and make your best choices. Becoming educated about your disease is an important part of feeling empowered.

Empowerment

Empowerment means taking charge of your body and your life. Do not leave your health up to chance or other’s decisions. Empowered patients ask for and receive what they know is right or best for them.

Being empowered helps you cope with medical issues that come up. When you are told you have a serious medical problem, it is natural to deny there is a problem or to pretend it is not very serious. But, this denial may keep you from learning about your illness so that you can better deal with it.

You are empowered when you take an active role in your care and treatment, while also managing the signs, symptoms, and daily effects of chronic kidney disease.

If you have not started dialysis or have not yet had a transplant, making a treatment choice can be the next step in self-empowerment.

Rehabilitation

If you have anemia and uremia, you may feel tired and be less physically active than usual. Your doctor, nurse, or social worker can help you start an exercise program or can encourage you if you have already started.

Research tells us that exercise can:

- Lessen the emotional stress that comes with chronic health problems
- Increase your energy

- Lessen the risk of coronary artery disease and heart disease caused by high blood pressure
- Improve your quality of life

Employment as Rehabilitation

Many people keep working after they start dialysis. If you need to have your dialysis schedule changed because of work, tell your dialysis unit social worker or nurse so that they can help change your schedule. People who are employed are given priority when scheduling in-center dialysis.

Continuing to work, either full-time or part-time, is often an important part of living fully with kidney disease. If your energy allows you to keep working full-time, that is wonderful. If you still want to work, but find full-time work hard, think about working part-time.

There are federal laws that protect you under the ADA (American with Disabilities Act). Talk with your social worker or staff in the Human Resources Department at work to find out more information and how they may help you.

In Review

Coping with your kidney disease involves taking charge of your life:

- Develop a positive attitude; focus on what you **can** do.
- Learn about your kidney disease.
- Be an active part of your healthcare team.
- Gather a support team.
- Continue the activities you enjoy, be with the people you care about, and continue to plan your life.

Reading List

The books on this reading list may help you deal with your new life and to help you cope with kidney disease. We encourage you to read at least some of these books.

If you need more information, the Patient Library at the Northwest Kidney Center has more books and some videotapes and DVDs.

Chronically Happy: Joyful Living in Spite of Chronic Illness
By Lori Hartwell
Poetic Media Press, San Francisco, 2002

This is an upbeat, motivational book that helps people living with chronic illness create joyful, fulfilling lives. It covers day-to-day issues such as dating and working when you have a chronic illness. It includes the

"Principles of Chronically Happy Living" that the author developed in dealing with her own kidney disease, which she has had since age 2.

Dialysis, An Unanticipated Journey
By David Axtmann
Tucky Paws Publishing, Cottage Grove, MN, 2001

David has been on dialysis for over 30 years. In this book, he shares those first days of doubt and fear of the unknown. He explains how he coped with low blood pressure, inability to sleep, lack of energy, and even changes in his sexual needs and desires. In spite of unexpected changes in his life, he still had much control in deciding the outcomes. This book is compelling, inspiring, and valuable to other patients with chronic illness.

Living a Healthy Life with Chronic Conditions, 2nd Edition
By Kate Lorig, Halsted, and others
Bull Publishing Company, Boulder, Colorado, 2000

This book was written to help people live the best possible life with a long-term health condition. It offers excellent, practical information on managing your condition, nutrition, exercise, and working with healthcare providers. It is based on a 5-year study at Stanford University and input from hundreds of people with long-term health conditions.

Love, Medicine and Miracles
By Bernie Siegel
Harper Perennial, New York, 1988 (also in large print and on audiotape)

This book offers ways of dealing with chronic illness. Although most of the studies in the book deal with cancer patients, the ideas apply to kidney patients as well.

Help, I Need Dialysis! How to have a good future with kidney disease
By Dori Schatell, MS & John Agar, MD
Medical Education Institute, Inc., Madison, Wisconsin, 2012

The non-profit Medical Education Institute helps people with chronic disease learn to manage and improve their health. They hope this book will help those facing kidney disease add years and quality to their lives.

Websites

American Association of Kidney Patients
www.aakp.org
800.749.2257

AAKP Kidney Beginnings: The electronic newsletter is a monthly newsletter for people who have recently been diagnosed with kidney disease and for those approaching kidney failure. You can also download a free book, *Kidney Beginnings: A patient's guide to living with reduced kidney function*.

American Kidney Fund
www.kidneyfund.org
800.638.8299

The American Kidney Fund has a grant program that may help pay some costs related to your treatment. To learn more, please see Chapter 9 of the KEEP notebook, "Financial Information and Resources."

Culinary Kidney Cooks
www.culinarykidneycooks.com

The "Helpful Hints" section of this website offers detailed nutrition information on 91 different food and diet topics.

DaVita Kidney Care
www.davita.com/kidney-disease/kidney-disease-education-center

An educational resource sponsored by DaVita Kidney Care., a division of DaVita HealthCare Partners, Inc. The site includes videos and printed text.

Dialysis from the Sharp End of the Needle
www.billpeckham.com

An informational and supportive blog by a long-term dialysis patient, with links to other patients and other information.

Fresenius Medical Care
www.ultracare-dialysis.com

Fresenius Medical Care North America provides ongoing dialysis treatment for more than 139,000 patients through their network of more than 1,800 facilities nationwide. Fresenius is the largest provider of such renal services in North America.

IKAN (Increasing Kidney Awareness Network)
www.youtube.com/ikankidney

This VA-affiliated project has created 12 short educational videos focusing on African Americans, kidney disease, and treatments.

KEEP Class Online
http://kidneyclass.com

This website provides online copies of this KEEP notebook and links to resources, class schedules, and registration.

Kidney and Urology Foundation of America
www.kidneyurology.org

This website has pages on patient resources, organ and tissue donation, health information, and news and recent events.

Kidney School
www.KidneySchool.org

This site is sponsored by an educational grant by Fresenius Medical Care North America and was developed by the Medical Education Institute. It is an interactive, web-based learning program in 20-minute modules.

Life Options
www.lifeoptions.org
800.468.7777

This research-based program focuses on helping people live long and well with kidney disease. It has information on exercise, employment, and living life to the fullest while on dialysis. It also includes information for caregivers.

My Life, My Dialysis Choice
http://mydialysischoice.org/

This tool will help you choose the right treatment for you, so you can feel your best and live the way you want to.

National Kidney Disease Education Program (NKDEP)
www.nkdep.nih.gov

The mission of the NKDEP is to improve the understanding, detection, and management of kidney disease. Their website has educational materials to help you learn about and live with kidney disease.

National Kidney Foundation
www.kidney.org/patients
800.622.9010
Toll-free patient information health line: 855.653.2273

National Kidney Foundation is a nonprofit health organization. It is dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals and families affected by kidney disease, and increasing the availability of all organs for transplantation. Resources on the website include education about kidney disease, dialysis, transplant, and nutrition.

Northwest Kidney Centers
www.nwkidney.org
206.292.2771

Northwest Kidney Centers provides dialysis for most people who are on dialysis in King and Clallam counties in Washington state. They provide services in 14 dialysis centers and 11 hospitals. They also train and offer support for people who give themselves dialysis at home.

The centers' mission is "to promote health, independence and quality of life for people with kidney disease."

To learn more about the centers' foundation that offers education, transportation, and financial support for treatment, please see Chapter 9, "Financial Information and Resources."

Northwest Renal Network (Network 16)
www.nwrenalnetwork.org
206. 923.0714
Toll-free line for patients only: 800.262.1514

Northwest Renal Network is a private non-profit corporation that promotes optimal dialysis and transplant care for kidney patients in Alaska, Idaho, Montana, Oregon, and Washington. Their website has a "For Patients" section that lists resources. This site is helpful for anyone who has concerns about the quality of dialysis or kidney care in the Pacific Northwest.

Puget Sound Kidney Centers
www.pskc.net
425.259.5195

Puget Sound Kidney Centers (PSKC) provide dialysis and education to patients with kidney disease in Washington state. Their 5 centers are in Anacortes, Arlington, Everett, Monroe, and Oak Harbor.

Renal Info
www.renalinfo.com
877.543.6394

This site is sponsored by Baxter Health Corporation. It is a free program for people with reduced kidney function and their loved ones. It is designed to help you plan your course toward better kidney health.

This site includes information on the topics listed below. Click on the world map to access many non-English translations of this information.

- How do kidneys function?
- What is kidney disease?
- What are the symptoms of kidney disease?
- Treatment options for early-stages kidney disease
- Treatment options for end-stage kidney disease
- Emotional issues linked to kidney disease
- Sports and exercise
- Traveling with kidney disease

Renal Support Network
www.rsnhope.org
800.579.1970 (English) or 800.780.4238 (Spanish)

Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run organization that provides non-medical services to those affected by chronic kidney disease. It includes education, support groups, newsletters, awareness events, and HOPEline.

HOPEline gives individuals and families living with chronic kidney disease a chance to talk with someone who has lived successfully with chronic kidney disease. It is available weekdays, 10 a.m. to 8 p.m.

Road Back to Life: Hope and Help for Kidney Patients
www.theroadbacktolife.com
This blog includes personal stories of people with kidney disease, and includes pages on healthy choices and new advances in kidney care.

10 Tips for Caregiving

This information is adapted with permission from the Crisis Clinic website: www.crisisclinic.org/caregiver2.html. The Caregiver Assistance Program at Crisis Clinic's Community Information Line is an ongoing resource for information and support.

When serious illness or disability occurs, it's hard to know where to turn for help. As a caregiver, you may be a husband or wife, daughter or son, sibling or close friend of someone who needs your help. You may help out from time to time with chores or transportation, or you may arrange for and provide round-the-clock supervision or hands-on care. Whatever your relationship or how much you are involved, it's important to prepare for the future by taking these steps:

- **Plan** for present and future care needs and for legal and financial decision-making.
- **Learn** about the disease or disability and about caregiving.
- **Seek support** for arranging and providing care and for the emotional changes you may have as a caregiver.

Use these 10 tips to help you with your planning.

1. **Make sure you have well-informed and supportive healthcare providers.**
2. **Get your affairs in order by doing legal and financial planning.**
3. **Educate yourself about the specific disease or disability and about caregiving.**
4. **Know what resources are available to help.**

5. **Hold a family meeting to sort out roles and responsibilities.**
6. **Develop a "care book" to keep information in one place.**
7. **Build a strong support system for yourself. Use it regularly.**
8. **Accept and honor your limits. Know that you cannot "do it all."**
9. **Listen to and express your feelings.**
10. **Take time for yourself.**

Tips for Friends and Relatives of the Chronically Ill

There is much you can do to help! This list of tips suggests the kinds of attitudes, words, and acts that are truly helpful. In fact, simply expressing your caring is probably the most important and helpful thing anyone can do. These tips will guide you in communicating with care.

Get in Touch

Call on the phone. Speak either to the person with kidney disease or to someone who is close to them. Ask when you can talk or visit and how you might help. Even if time has passed, it's never too late to express your concern.

Listen

Say little in the first conversations. Just saying a few words of concern and affection may be all that is needed. Listening is more important than any other skill you can offer a chronically ill person. If they say nothing, just being with them is helpful.

Avoid Clichés and Easy Answers

- Don't say the expected, such as, "Things will get better."
- Don't give advice unless asked.
- Don't recommend doctors or relate stories about someone else who is "much worse off."
- Don't compare your illnesses to kidney disease. Your flu or bout with pneumonia (from which you fully recovered) is a very different problem than an illness that will last for the rest of one's life.

Be Yourself

Show your natural concern and sorrow in your own way and in your own words. At the same time, do not be overly sentimental, overly tearful, or force the ill person into comforting or taking care of you. Do **not** try to be a therapist to a friend – your friendship is needed, not analysis.

Keep in Touch

- Be available. Be there. If you are a close friend or relative, your presence might be needed.
- Calling can be helpful anytime. Do not go by whose "turn" it is to call. The chronically ill often don't have the physical or emotional energy to call but appreciate someone who calls them.

Help with Practical Needs

Find out if you are needed to answer the phone, prepare meals, clean the house, care for children or pets, or provide transportation. Cooking a meal or doing the laundry can be more important to a chronically ill person than any other type of help. This kind of help lifts burdens and spirits and can create strong bonds between you.

Encourage Others to Help

People often don't know what to do or say. Encourage other friends and family to call and show their compassion and caring.

Support the chronically ill person's interest in going to appropriate support groups or seeking psychotherapy to deal with the many issues caused by the illness.

Accept Silence

Sometimes the ill person doesn't have the physical or emotional energy to talk, so don't force conversation. Silence is better than filling up space with chatter.

Be sensitive to the person and don't expect him or her to stay on the phone for long periods, or even want to talk about the problems he or she is facing.

The Importance of Attitude

The longer I live, the more I realize the impact of attitude on life. Attitude, to me, is more important than facts. It is more important than the past, than education, than money, than circumstances, than failures, than successes, than what other people think or say or do. It is more important than appearance, giftedness, or skill. It will make or break a company ... a church ... a home.

The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day.

– Charles Swindoll

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

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