



National
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kidney living®

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Issue 12

**HOW I
CHANGED
FOR THE BETTER!**

**WHY WE
LOVE
OUR KIDNEY
CARE PARTNERS**

**DIABETES
& DIALYSIS
WHAT YOU NEED TO KNOW**



PATIENT EDITORS
Meg Banks
Poughkeepsie, NY

Dorothy Davis
Birmingham, AL

Sheldon Francis
Bronx, NY

Celeste Castillo Lee
Ann Arbor, MI

PROFESSIONAL EDITORS
Dawn Berry, RD
West Des Moines, IA

Eileen Boyte, MSW
Los Angeles, CA

Mark Conard, PhD
Darien, IL

Denise Eilers, BSN, RN
Davenport, IA

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Indianapolis, IN

Mandy Trolinger, MS, RD, PA-C
Highlands Ranch, CO

Roberta Wager, RN, MSN
San Antonio, TX

IN-HOUSE STAFF
Jennifer Martin
Executive Editor

Kelli Collins, LICSW
Editorial Director

Bernard Rittersporn
Managing Editor

Staci McKeown
Design Director

National Kidney Foundation
30 East 33rd Street
New York, NY 10016
800.622.9010 | 212.889.2210
Email: kidneyliving@kidney.org
www.kidney.org/kidneyliving

kidney living®
A MAGAZINE FOR PEOPLE ON DIALYSIS

The Future is Bright!

As a former in-center hemodialysis patient and 2-time transplant recipient, I was reminded while reading this issue that we kidney patients are so lucky! We have options that we are able to choose from so that we can continue to live well. With tips on diet, preparing for emergencies, and one man’s journey towards learning to accept dialysis, this issue is packed with helpful information to help you thrive.

I am alive today because of the treatment options available, but also due to kidney patients who came before and participated in clinical trials. We need more clinical trials in the kidney community, not only to improve dialysis and transplant treatment options available today, but to also give us more options in the near future. I am so looking forward to the results of the pilot studies of the implantable kidney and the wearable dialysis machine.

Our future as patients living with kidney disease is bright—the sky is the limit!



Bobbi Wager

Bobbi Wager

Professional Editor
Kidney Patient

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Football season is here!
Root for your favorite team with
healthy game-time snacks.

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DIALYSIS HELPS MY BODY AND CHANGED my MIND

by Bill Appel

I had been told a decade earlier that
I would one day need dialysis three times
weekly for the rest of my life.

Now, as my wife and I came within sight of the dialysis center building, I knew that day had arrived. The shriek of a passing ambulance made my entire body flinch.

I lost whatever small amount of courage I had managed to build upon seeing other patients arrive in medical transport vans or in wheelchairs pushed by aides. Others moved haltingly behind walkers.

My wife, Denise, pressed my hand in support.

“You’re not as sick as they are,” she said. Not yet, I thought. Inside the building we were met by Tricia, the social worker. I’ve been fortunate to have known a few rare people like her. Although we were total strangers, I instantly knew that I was in the company of a genuine, caring person.

Tricia introduced us to Marissa, the nurse manager, a lovely young woman who appeared to me to barely be out of puberty (I’m 76 years old). Marissa eased my mind by answering my questions about what would happen if I needed to use the bathroom during treatment, whether or not my wife could stay with me, and if I could eat during treatment.

“Don’t worry,” Marissa said. “You’re going to feel a lot better, Bill. Your anemia is making you tired. We’re going to give you shots for your hemoglobin—red blood cells—to multiply. You’ll have more energy. You won’t have that metallic taste in your mouth. No more queasiness, or edema, that swelling of your ankles and hands. We’ll get your phosphorous to the point where you won’t be itching.” I took out a pad and made notes.

After two weeks on dialysis, my skin color was beginning to improve. My appetite was much better. I had more energy. I took a two and a half-hour ride to visit my granddaughters. My ankles were no longer swollen. The metallic taste in my mouth and the queasiness were gone.

Today I wished a patient
good morning.
She said, “I HATE THIS PLACE.”

This brings me to the most important part of what I’d like to share with you. A dialysis center contains many things that can drag one down: the sight of sick and aged bodies, faces that are starkly depressed, machines sounding warning or danger signals, and the otherworldly look of nurses and technicians wearing their Plexiglass blood shields.

Kidney failure used to be a death sentence, but dialysis extends our life and enhances its quality. It gave me back energy and increased my appetite. For me, it profoundly cut down on incessant urination, cured my edema, and stopped the maddening itching.

Of course there are days when TV, music, and books don’t immunize us against the mind-numbing boredom that can sometimes happen while we have to sit in the same chair in the same room for twelve hours a week for the rest of our lives.

But what’s our alternative?

I’d like to emulate my friend Grace’s attitude about dialysis. The other day Grace said she looked at the clock every few minutes when she started dialysis. That made time pass more slowly. Now she tries to think of time spent on dialysis as ‘down time’ during which she can escape the distraction of everyday life and concentrate on what she’s grateful for. She’s grateful there’s such a thing as dialysis, and she’s grateful for the people in the clinic including patients, nurses, technicians, dietitians, social workers, and her doctor.

She’s grateful she’s still on the planet and able to watch her grandchildren grow up. She was eating foods that were making her sicker and not exercising. She was having a pity party for herself. Now she eats well, and goes to the gym several times a week.

One day when her granddaughter was visiting her at home, she asked Grace what she did when she was at dialysis. Grace didn’t want a nine-year-old worrying about her

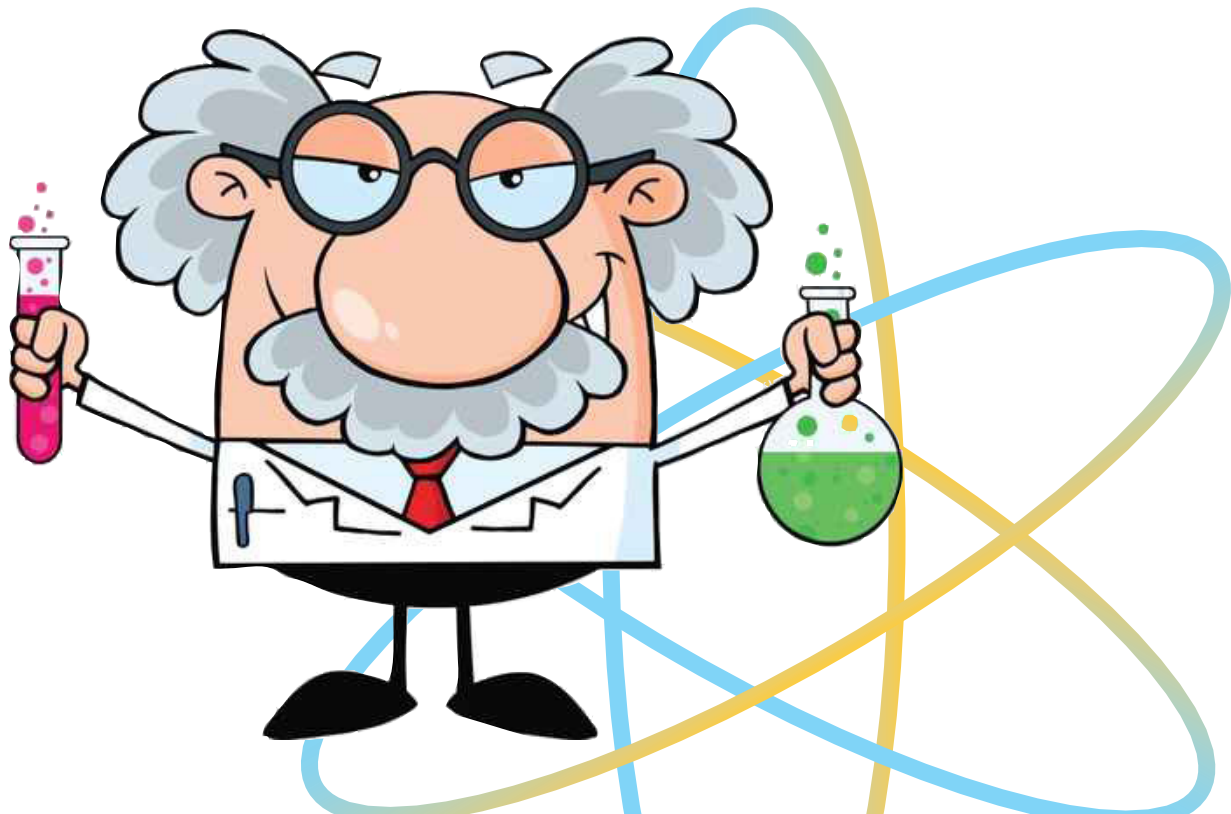
She sort of
surrendered
to the
situation,
and stopped
looking for
negatives.

Grammy so she said: ‘I watch my shows on my own TV or I read. Your daddy put together lots of old songs I love on an iPod so I can listen to them with headphones.’ While she was assuring her granddaughter, she began assuring herself that at dialysis she was pretty much doing what she chose to do at home. From that moment on she sort of surrendered to the situation, and stopped looking for negatives. “In a strange kind of a way my kidneys giving out saved my life,” Grace says.

I’m starting to feel that way too.



Bill Appel has a new attitude after going through dialysis. How about you?



Clinical Trials

How research works for you

A clinical trial is a type of research that only happens after many studies of a treatment have been done in a lab. Clinical trials are done to see how actual patients can be helped by new drugs or devices. They have been successful in finding medical advances and even cures. Clinical trials look at new ways to prevent, detect, or treat diseases. You do not need to be 100% healthy to be in a clinical trial. Often, clinical trials seek patients with certain medical conditions, so that they can study those conditions further and test new treatments or drugs. For kidney patients, there is much promise in clinical trials (and research in general) to advance medical knowledge, enhance safety, and improve treatment and quality of life.

Patients in clinical trials may be given new drugs or new combinations of drugs to see their effect. Clinical trials may also use new surgical procedures or devices, or use existing treatments in new ways.

Clinical trial participation may have risks, but it offers patients a chance to improve their own care by exposing them to new treatments that they would not otherwise have access to. A successful clinical trial can also help other patients with kidney problems in the future. The goal of clinical trials is to see if a new test or treatment works, and if it is safe. If the drug or procedure is found to be unsafe during the clinical trial, the trial will be stopped either for the affected individual or for all participants, depending on the issue.

Find out more
information about joining
a clinical trial at
**[www.kidney.org/
kidneyliving](http://www.kidney.org/kidneyliving)**.

Also, talk with your healthcare
provider about participating in a
research study. They may be
aware of opportunities
in your area.



Are You Prepared?

Natural disasters happen — lessons learned

10th
Anniversary
of Hurricane
Katrina

The 2005 Atlantic hurricane season was the most active one ever recorded. The Gulf Coast of the United States experienced devastating effects.

During Hurricane Katrina in August 2005, many dialysis patients and staff had to evacuate their homes. Homes, dialysis centers, and roads were damaged, which made it a challenge for patients to find care and dialysis treatment. Ninety-four Gulf Coast dialysis centers were closed for one week or more, affecting approximately 5,800 dialysis patients. In addition, power lines and phone service were impacted, making communication difficult.

Hurricane Katrina showed us that better emergency response preparation was desperately needed at both national and local levels. Many

state, federal, patient, provider, and local emergency response organizations joined together to create what is now known as the KCER (Kidney Community Emergency Response) Program. KCER has been successful in taking lessons learned from

the storm to make broad changes in the kidney community's emergency response plans.

KCER's goal is to ensure that even in a disaster patients can still find the life-saving dialysis services they need.

The key to achieving this goal is preparing before a disaster occurs!

These preparations take the form of developing efficient disaster preparedness resources to help save lives, improve

outcomes, empower patients and families, educate healthcare workers, and promote readiness in the kidney community.



Do you feel prepared for a disaster? In honor of the 10th anniversary of Katrina, we encourage you to take time to review your disaster plan with your dialysis care team and create one with your family, if you haven't already. To learn more and to be prepared for any disaster, visit KCER's website: <http://kcercoalition.com>, where you can find tools and resources created especially for dialysis patients.

seeking a treatment for Calciphylaxis (cal-si-fu-lax-is)

By studying the rarest and most terrible diseases, scientists can often uncover solutions for a host of other conditions.

Sagar Nigwekar, MD, MMSc, an Assistant Professor in Medicine at Massachusetts General Hospital and an Instructor in Medicine at Harvard Medical School, is on the front lines of attacking a condition that is rare in most people, but common among people with kidney failure—calciphylaxis.

Calciphylaxis is a type of blood vessel disease. Calcium is usually used by the body to make bones hard and strong, but in calciphylaxis, calcium can build up in other parts of the body such as the skin, blood vessels, and even organs such as the heart and lungs. In kidney failure, high phosphorus levels may play a role in this calcium build up. The process in which calcium builds up in the vessels is called “vascular (vessel) calcification (hardening of calcium).”

Calciphylaxis causes skin sores and severe pain. It can lead to death if not treated. Dr. Nigwekar hopes that solving the mysteries

of this disease will not only save lives, but lead to advances in treating other similar diseases.

With the help of a Young Investigator Grant from the National Kidney Foundation, Dr. Nigwekar is compiling samples from patients with calciphylaxis in order to better understand the disease. The first-ever patient study (clinical trial) with calciphylaxis patients is currently recruiting patients. In this study, Dr. Nigwekar will find out how safe and effective it is to treat calciphylaxis with vitamin K.

Vitamin K has been shown to stop calcium build up in blood vessels and other parts of the body. However, dialysis patients are usually vitamin K deficient, because of dietary restrictions that limit potassium and sodium-rich foods that are also rich sources of vitamin K.

“Once we learn the biology, this information will lead to treatments for other types of vascular calcifications in blood vessels found in the brain, heart, and other parts of the body,” Dr. Nigwekar said. “While those

conditions may not have the same fatality rate as calciphylaxis, by studying this rare disease, we hope to apply what we learn to more common types of vascular calcification.”



“Once we learn the biology, this information will lead to treatments for other types of vascular calcifications in blood vessels”

Sagar Nigwekar
MD, MMSc



I HAVE DIABETES AND AM ON DIALYSIS

What do I need to know to take good care of myself?

Am I eligible to have a transplant?

Having diabetes and kidney failure can be challenging. You are more likely to develop heart disease, stroke, blindness, nerve damage, and foot amputations from diabetes. Not all of these complications will affect whether you can get a kidney transplant, and many people with diabetes are able to receive a transplant. In fact, people with type 1 diabetes may even be able to get a kidney-pancreas transplant. Talk with your doctor about your health conditions and find out if you are a good candidate for a kidney transplant.

The most important thing for you to do to is keep a healthy lifestyle and fight diabetes by controlling your blood sugar. In fact, controlling your blood sugar lowers your risk for all health problems related to diabetes! Talk with your healthcare professional about what you need to do in order to control your blood sugar. You may be able to control it with diet alone, or you may need to also take insulin shots or pills. The dose of insulin may change when you start dialysis or get a kidney transplant.

Work with your healthcare team to develop a treatment plan that helps you manage diabetes:

- Get regular exercise.
- Lose weight, if you need to.
- Eat healthy foods and follow your diabetes and kidney diet.
- Take all your medicines as instructed.
- Get regular eye exams.
- Get regular checkups for your feet. Be sure to wear shoes that fit properly and check your feet every day for injuries, blisters, sores, or redness.
- If you smoke, ask your healthcare professional about a plan to help you quit.



Diabetes 101: The basics

Diabetes is the #1 cause of kidney disease in the U.S. Diabetes happens when your body does not make enough insulin or cannot use insulin properly.

Insulin is a hormone that controls how much sugar is in your blood.

A high level of sugar in your blood can damage the very small blood vessels in your body. Extra sugar “sticks” to your small blood vessels and makes it hard for blood to get to your organs.

Damage to blood vessels occurs most often in the eyes, heart, nerves, feet, and kidneys.



When transplant isn't an option **Dialysis Works**

For some people on dialysis, transplant is not an option. Some may have other conditions that prevent them from being able to undergo surgery, while others may decide that transplant is not the right treatment choice for their lifestyle.

It may be frustrating and disheartening to learn that transplant is not an option for you, especially when many people view transplant as a possible means to end dialysis treatments. However, it's important to remember that even a transplant is not a cure for kidney failure—it is simply another treatment option.

For those without the option of transplant, here are some important things to consider:

Life is not over.

Dialysis is a life-sustaining treatment that was not available even 50 years ago. Dialysis allows you to continue your life outside of treatment. There are many different types of dialysis to meet the needs of your personal lifestyle and health.

Transplant is not a cure;

it's just another treatment option.

You are more than just a number.

Dialysis survival statistics can be scary. However, you are not a statistic, so get involved in your care, and learn about your health conditions and treatment. There are people who have been on dialysis for 30–40+ years. Learn to live well on dialysis.

Choose a dialysis treatment that's right for you.

Consider home dialysis. Peritoneal dialysis and home hemodialysis are great alternatives to in-center hemodialysis treatment. Home dialysis may offer you flexibility and independence to live well on dialysis. Talk with your healthcare team about your options and what's right for you.

Talk to a peer

If you are interested in talking to another patient about their experience with in-center hemodialysis, home hemodialysis, peritoneal dialysis, or a transplant, call NKF Peers today **855.653.7337**.

Football & the Holidays

Kidney-friendly Advice

With holidays around the corner and football season in session, desserts and snacks are everywhere! Here's what to "PASS" on and what to "SCORE" on this holiday season.

PASS on packaged pies, cakes, and cookies that can be loaded with saturated fats.

SCORE! Crustless pumpkin pie, fruit crisps, or angel food cake topped with berries.

PASS on added salt. **SCORE!** Learn to season your food with herbs and spices. Giving up salt does not mean giving up flavor. Be creative and experiment.

PASS on saturated and trans fats. **SCORE!** Use heart-healthy fats when possible. Swap applesauce for oil in baked goods to cut back on the fat and calories.

PASS on processed, prepackaged appetizers and snacks. **SCORE!** On unsalted nuts, cooked seafood, fruits, and raw vegetables with low-fat dips or hummus.



Baked Crab Rangoons

Makes 12 servings (2 rangoons each)

INGREDIENTS

8 ounces nondairy cream cheese, softened

- 3 sticks of imitation crabmeat, diced
- 2 green onions, thinly sliced
- 1 tsp garlic powder
- 24 wonton wrappers

INSTRUCTIONS

1. Preheat oven to 350 degrees.
2. Mix nondairy cream cheese, crabmeat, green onion, and garlic powder in a bowl.
3. Fill each wonton with a tablespoon of filling and fold wonton wrapper lightly over top.
4. Bake on a greased sheet pan for 10-15 minutes or until wrappers are golden brown.

ANALYSIS

Calories 132.5
Protein 3.0 g
Total Fat 8.1 g
Carbohydrates 8.5 g
Sodium 351 mg
Potassium 64 mg
Phosphorus 115 mg



Wonton Quiches

Makes 6 servings (2 wontons each)

INGREDIENTS

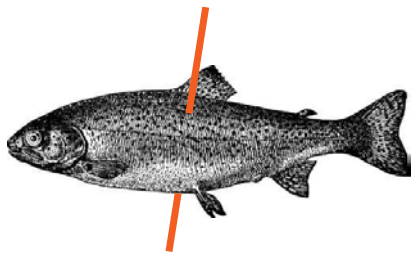
- 24 wonton wrappers
- 1¼ cup of egg beaters
- 1 tbsp nondairy milk
- 2 tsp Italian seasoning
- 1 precooked (non-smoked) Italian sausage link, diced
- 1 tbsp sundried tomatoes (rehydrated in boiling water and diced tiny)
- 1 green onion, chopped

INSTRUCTIONS

1. Preheat oven to 375 degrees.
2. Grease 12 cup muffin tin.
3. Take 2 wonton wrappers and crisscross them into each muffin tin cup, to form 8 points.
4. Whisk egg beaters, nondairy milk, and Italian seasoning in a bowl.
5. Add sausage, sundried tomato, and green onion to egg mixture.
6. Spoon into wontons, filling each cup ½ to ¾ full.
7. Cook for 20 minutes or until the egg is fully cooked. Serve hot.

ANALYSIS

Calories 115
Protein 8 g
Total fat 1 g
Carbohydrates 17 g
Sodium 246 mg
Potassium 50 mg
Phosphorus 61 mg



Asian Salmon Kabobs

Makes 4 kabobs (1 kabob per serving)

INGREDIENTS

- 7 ounce skinless salmon fillet, cut into 1-inch chunks
- 1 slice fresh pineapple, cut into 1-inch chunks
- 1/4 red onion, cut into chunks
- 1 zucchini, sliced into thick rounds
- 8 1-inch chunks each of red pepper, yellow pepper, and orange pepper
- 2 tbsp chopped fresh cilantro leaves

FOR THE MARINADE

- 2 tbsp reduced sodium soy sauce
- 1 tbsp seasoned rice wine
- 1 tbsp brown sugar, packed
- 3 cloves garlic, minced
- 1 tsp canola oil

INSTRUCTIONS

1. In a small bowl, whisk together soy sauce, rice wine, brown sugar, garlic, and canola oil.
2. Thread peppers, zucchini, salmon, red onion, and pineapple onto skewers. Brush marinade onto the skewers and let sit for 10-15 minutes.
3. Grill kabobs at medium high heat, turning occasionally, until salmon is opaque throughout and vegetables are tender, about 5-7 minutes.
4. Garnish with cilantro. Serve immediately.

ANALYSIS

Calories 184
Protein 12 g
Total fat 8 g
Carbohydrates 17 g
Sodium 330 mg
Potassium 435 mg
Phosphorus 151 mg



Vietnamese Crunchy Spring Rolls

Makes 2 servings

INGREDIENTS

- 4 rice paper wraps
- 1 cup cooked sushi rice
- 6 cooked tiger shrimp, cut in half along the vein
- 6 baby carrots, julienne sliced
- 1 small cucumber, center removed, julienne sliced

Topping

- 2 tbsp mayonnaise
- 1 tsp sweet chili sauce
- 3 tbsp french fried onions

INSTRUCTIONS

1. Mix mayonnaise with chili sauce, set aside.
2. Soak each wrapper individually, for 5-15 seconds (until soft). Make sure to finish each roll, prior to soaking another wrapper.
3. Fill wrapper with ¼ cup rice, 3 shrimp halves, ¼ of the carrots, and cucumber.
4. Roll tightly, and cut into 1-inch slices like sushi.
5. Drizzle with mayonnaise sauce. Top with french fried onions.
6. Serve immediately.

ANALYSIS

Calories 318
Protein 8.6 g
Total fat 7.7 g
Carbohydrates 51 g
Sodium 339 mg
Potassium 374 mg
Phosphorus 92.5 mg

Self Care



What are the best ways to take care of yourself while caring for your loved one on dialysis?

Advice from care partners to care partners!

When my husband went on peritoneal dialysis, I was totally overwhelmed. I felt like I had no time to do anything. So I decided to treat all my tasks as a part-time job. I do everything I can first thing in the morning (cleaning, changing his exit site bandage, paper work, phone calls, emails) and then I consider my job done for the day. I try to not do anything dialysis-related until it is time to do setup that night. This has helped me cope with all the tasks. *Ann D.*

Talk about everything: how you both feel. Let your patient know when you are tired, getting down, and need a break. There is no shame in this. You have not failed. And most importantly, never let treatment and the stress affect your feelings for one another. Love is the key! *Bill O.*

Be kind to and make time for yourself. Make it a point to do things that bring you joy. It makes the dialysis road that much easier to travel. *Michelle*

Let family members know about diet. They should also be aware of what the dialysis process is. Few people understand the dialysis process until it becomes part of their lives. Do not be embarrassed to seek help if you need it—either with daily tasks or to have someone to share your fears and concerns with. *Barbara O.*

Have back-up support. I take a day to have a mini-vacation every week. I go to the beach, a concert, a museum, and I'm still a phone call away. There is so much to be thankful for. Because of dialysis, we have had extra years as a family. Priceless! *Rosemarie S.*

Treasure the time after you drop your loved one off at dialysis and use it for yourself. Don't feel guilty. It is your time off from being a caregiver! Plan ahead and do nice things for yourself. Your loved one is in good hands at dialysis, and you should enjoy the "time off" without worry! *Dar*

Exercise! I found that Yoga helps the mind, body, and spirit. Getting the right help is key and will keep you strong, healthier, enlightened, and positive. *Ann Maria L.*

My advice to a caregiver of someone on peritoneal dialysis (PD) would be learn about the treatment and prescription, and help the patient set up and organize PD supplies. Pray together, be patient, give support, and LOVE by doing simple things. *Mary W.*

Be considerate of the person who is on dialysis. Don't assume they're okay, and don't need your help. Remember to always wash your hands to prevent spreading germs. *Michael B.*

Be supportive. Understand that dialysis is difficult, and that they will always need someone to talk to. Even if you don't understand, just listen and learn. *Brittany D.*

Be kind, understanding, and patient. *Tina M.*

Hats off to Care Partners!

Advice to care partners from patients!

I'm a kidney recipient and my husband was my caregiver. My hat is off to anyone who is a caregiver. It's a rewarding, but hard job, and the caregiver needs support too. Our roles were changed in 2012, and I became his caregiver. Having experienced what he went through gave me new perspective on what a caregiver's role is. Again, support from others is a major factor in full recovery for the patient. *Bev*

Have a listening ear. Having the support of the family member or caregiver is highly important in a patient's journey through dialysis. This has helped me so much as a patient! *Jessica H.*

It's wonderful when the people helping you remain positive — always giving you a smile and hope. No matter what. A person needs hope. *Susie*

I was on dialysis for nearly 3 years and received a living donor transplant 7 months ago. My family was so supportive. My suggestion to caregivers is to be patient. Exhaustion comes with the territory, so does moodiness, and irritability. It is challenging dealing with some with so many ups and downs. People on dialysis aren't made of glass. They should be able to enjoy the normal things in life. Let them to enjoy their lives when they are not in dialysis. Going to the movies, dinner, and making short trips to the mall or stores can be extremely uplifting for a dialysis patient. Treating them as normally as possible is so important for their well-being. *Lauren G.*

As a patient, I think we should always be kind to our caregivers. They do what they do because they love us so much. We must remember, they have feelings too! *Tonya M.*

As a dialysis patient, I have talked to my family about the process and procedures involved with peritoneal dialysis. *John G.*

As a dialysis patient for the second time after losing a transplant I had for 14 years, it has been especially important for caregivers to educate themselves on every aspect of kidney disease as it relates to both dialysis and kidney transplant. The support they provide can be as simple as preparing a kidney-friendly meal or knowing the medication a patient takes on a daily basis. From the perspective of a person living with kidney disease, the most important thing is we don't want to feel like a burden to our family, we just want to live as normal a life as possible.

Be patient. Understand that treatment of a chronic medical condition takes lots of time and trips to physician's office appointments, lab tests, as well as treatment. It is always better to err on the side of caution than to ignore symptoms. It takes a team to help fight this. *Toni M.*



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