

# The **Kadney** Citizen

Issue number 15

A publication of Dialysis Patient Citizens (DPC) Education Center



**To Change or  
Not to Change?**

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**How to Move  
out of Loneliness**

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# President's Message

**S**pring is a time for change and new beginnings. Living through the COVID-19 pandemic may have more people focused on both their physical and mental health with the motivation needed to make changes. Many of us are experiencing life changes. I personally go through a thoughtful renewing of life and reconfirming what is important to me every year. Join me and take advantage of this Spring to make a difference in your own mental health, physical health, and personal awareness.

A change that I made in my life was to join Dialysis Patient Citizens (DPC) after I researched ways to become more educated and empowered as a person living with kidney disease. DPC is a patient-led organization working to improve the quality of life for dialysis patients through education and advocacy. With the information I learned on the DPC website I was able to make better informed decisions on the matters of my health. I was also able to better understand the policies that could affect the kidney community and then decide if I wanted to support these policies.

After joining DPC, I became more aware of the effort and the fight that is made to bring awareness to kidney health and kidney disease. As a DPC Patient Advocate in my home state of New York, I was able to meet and work with physicians, health-care providers, health policy experts, dialysis technicians, and patients like myself, who join in the cause to speak to our government officials and urge them to support and pass bills that put the care of our patients first. Our membership numbers add to our voice within the kidney community and with government officials.

Join us in making a difference for those with kidney disease by becoming a DPC member today. DPC membership is free and is open to patients, their families, and caregivers. Input from our members helps to determine our education and advocacy priorities. Members have the opportunity to attend our annual fly-in and get a heads up on actions needed to pass policies that benefit kidney patients. This newsletter, the patient webinars, the telephone support group, and resources on our two web sites also are available to you. Share our

information with your family and friends to help them become more knowledgeable about your health condition.

We need your help to remind policy makers that we are real people and not just a line-item in their budget. You have the opportunity to make a huge impact by calling, emailing, or writing to share your story with your elected officials. As a DPC member we can supply you with information you can share with your dialysis center and with your health care professional. Having more information at your fingertips will also bridge the gap of awareness when it comes to communicating with your health care team. As a DPC member you can also apply to be a Patient Ambassador, which will give you the opportunity to become a leader, a role model, and a beacon of hope in your community. Join us in making CKD a high priority on the government health agendas.

As you spring into action to reflect, learn, and become an advocate, enjoy the rest of this issue, and learn more about topics such as mental health, cystinosis, preventing falls, nutrition through the CKD stages, and self-cannulation. Always keep learning and share information with your caregivers and invite them to watch/listen to our webinars. This will strengthen your support system to help you learn about and achieve better outcomes for your health. Be empowered, tell your story, and ask politicians to adopt policies that will improve the quality of life for all kidney patients.

*Stay safe and well wishes,*



*DPC Education Center Board President*



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# The DPC Support Group is 1 Year Old and Going Strong

## DPC Support Group by Telephone

Connecting with peers and learning from others in the comfort of your home



The DPC Support Group by Telephone is a unique program that offers real time support and education to chronic kidney disease (CKD) patients at all stages of the illness, as well as support for their family and friends. It can be helpful for those adjusting to kidney disease to:

- Have someone to listen to them
- Gain confidence in living with kidney disease
- Feel more in control of their life
- Provide fellowship and community for those on home dialysis
- Gain tips and encouragement from both someone who has personal experience and from a healthcare professional.

This program is a telephone group experience with two facilitators: a person living with CKD and a healthcare professional. The program is open to any person living with kidney disease and their family members who have a telephone. It provides a safe place to discuss aspects of living with kidney disease.

The group meets on the second Tuesday of the month at 3:00 pm Eastern for one hour.

Join the call:  
Dial: 866-230-9002  
Enter Meeting Code: 420 835 078#




Learn more and RSVP at  
[www.dpcedcenter.org](http://www.dpcedcenter.org)

This past March, the DPC Support Group celebrated one year of providing a safe place for kidney patients and their family members to discuss aspects of living with kidney disease and connecting with others. So far, we have had over 90 people join one of the twelve calls, and we are excited to keep growing! As a reminder, we meet on the second Tuesday of each month at 3pm EST. Please join our next call, it's very easy! Just dial 866-230-9002 and enter meeting code 420 835 078#.

To sign up for a monthly reminder email, visit:

[www.dpcedcenter.org/news-events/dpc-support-group/](http://www.dpcedcenter.org/news-events/dpc-support-group/)

**The "How To's" to Building a Top-Notch Immune System With Lifestyle Changes**  
Presented by Collette Flowers, MA, RD, LDN, ACSM EP  
February 23, 2021  
2:00 pm Eastern  
Webinar Recording



**Illness, Isolation, Dog Poop, and...Joy?**  
Presented by Judy L. Jones, Ph.D.  
May 27th, 2021  
2:00 pm Eastern  
Webinar Recording




**Resilience and Self-Care During Stressful Times**  
Presented by Housen O'Reilly-Landry, Ph.D.  
January 27, 2022  
2:00 pm Eastern  
Webinar Recording



**Fistulas and Grafts: The Basics**  
Presented by David Mahoney, MD  
February 24, 2022  
2:00 pm Eastern  
Webinar Recording



**Effective Communication with Your Health Care Team**  
Presented by Stacy Cyluska, PhD, ASPE, CSOWM, Board-Certified Clinical Health Psychologist, UT Health San Antonio  
March 24, 2022  
2:00 pm Eastern  
Webinar Recording



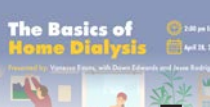
**Getting a Good Night's Sleep**  
Presented by Felicia Speed, LMSW and Tricia McCarthy, RN, MN, ACP  
August 19, 2021  
2:00 pm Eastern  
Webinar Recording



**Medigap Is It For Me?**  
Presented by Heidi Prosser, J.D., LL.M., Insurance Broker, Insurance Officer  
April 19, 2022  
2:00 pm Eastern  
Webinar Recording



**The Basics of Home Dialysis**  
Presented by Vanessa Fong, with David Edwards and Anna Rodriguez  
April 19, 2022  
2:00 pm Eastern  
Webinar Recording



**The Empowered Patient: Taking Steps to Manage Diabetes and Chronic Kidney Disease**  
Presented by  
Webinar Recording



# Be Sure to Check Our Library of Webinars!

The DPC Education Center provides resources to help people living with all stages of CKD to improve their quality of life. Here is a selection of recordings that you can watch anytime:

**Resilience and Self-Care During Difficult Times:** Learn how stress affects our emotions, bodies, and relationships as well as how to increase resilience and self-care.

**The Empowered Patient: Taking Steps to Manage Diabetes and Chronic Kidney Disease:** Learn about the patient empowerment model, change, self-compassion, and how most of the chronic disease care is provided by the patient.

**Illness, Isolation, Dog Poop, and ...Joy?** Learn about the emotional responses to illness, how to find joy, and increase it in our lives, despite the challenges in our lives.

**The How to's to Building a Top-Notch Immune System with Lifestyle Changes:** Learn about your immune system and how nutrition, physical activity and stress affect it.

**Getting a Good Night's Sleep:** Learn more about the sleep issues that kidney patients have, how they can be addressed, and the importance of getting a good night's sleep.

**Effective Communication with Your Health Care Team:** Learn how to effectively communicate with your health care team, even with the communication barriers that may be present.

We are always trying to improve on the quality of our content and how we bring it to you. That is why our Education Webinar have moved to a new platform. Starting in April, you can join the webinar online [www.dpcedcenter.org/joinwebinar/](http://www.dpcedcenter.org/joinwebinar/) and by telephone at 866-230-9002, meeting code 300 513 346#.

To sign up for upcoming webinars and receive reminder emails, please visit:

[www.dpcedcenter.org/news-events/education-webinars/signup/](http://www.dpcedcenter.org/news-events/education-webinars/signup/)



OLD  
HABITS

CHANGE



# To Change or Not to Change?



**By Dr. Stacy Ogbeide,**  
Board Certified Clinical  
Health Psychologist  
[www.stacyogbeide.com](http://www.stacyogbeide.com)

**“W**hy is change  
so hard?”  
I hear

this statement often from the patients I see in primary care. From taking a medication as prescribed to starting an exercise program – change is hard. Having a chronic health condition like Chronic Kidney Disease (CKD) can

be difficult because, like many other chronic health conditions, CKD is heavily influenced by lifestyle and behavior modifications. What is a person to do? “I just need to do it.” “I will change when I want to change.” “I will start next week.” “I want to start that walking plan, but it hurts when I move so I stopped walking.” Have you heard any of these statements? Many people have said these statements, or statements similar to these, when thinking about making a behavior change. This is something called ambivalence. Ambivalence is



your internal conflict regarding the pros and cons of behavior change. In order to move forward, ambivalence needs to be addressed and resolved. The bad news? Chances are, if you have said this statement recently, you have not made any changes yet. The good news? If you are willing to have conversations with your loved ones or health care team about making changes, you are moving in the right direction!

What about failure? What about unsuccessful behavior change? What happens when you stop smoking cigarettes but return to smoking six months later? How about when you were taking your medications regularly but now, you are not anymore? What if you have missed your last three appointments with your kidney specialist? What does this mean? There are many things that can go wrong when making behavior changes. The important point to remember is that failure is critical in the behavior change process – you cannot have behavior change without failure!

We are human. Change is complex. We might be unrealistic with our goals. We might feel discouraged or ashamed that we are having a difficult time making changes that we know would help better manage CKD. We sometimes underestimate what is needed to make a behavior change. We do not realize that we may need other team members to help us along the way – a loved one, your kidney specialist, your dietitian, your social worker, a health psychologist, a health educator. It can take some time to figure out what works best for you and that means, many attempts at change that may be unsuccessful!

The key? Learning from your failures and making changes to your plan as you go. This process can be seen as “good” failures. Behavior change is complex and impacted by many factors like beliefs, biases, feelings, thoughts, planning, commitment, and your values. So, if your



change plan does not go according to plan, ask yourself, “What went wrong and how can I do things differently?” Remember, if you are willing to stay in the change process and move towards your health goals, “good” failures are in your future!

Let’s all make this shift towards behavior change together. It is great to feel empowered to make important changes in your life for your health so you can do the things in life that are important to you. Imagine how communities would be impacted by you starting the conversation towards change! Or sharing your own journey on making important changes for managing your CKD. The conversation is similar to a chain being linked – one person starts the conversation but someone else may pick up where you left off – or YOU may be that person!

Healthy people make healthy communities. So, let’s become partners along this journey called *change*.

#### References:

DiClemente, C. (2021). *Relapse and recycling: The function of failure in successful behavior change*. Presentation at the National Practice Conference, Washington, DC.



A close-up photograph of a person's arm with a dialysis catheter inserted into their forearm. The catheter is secured with white tape and has red and blue tubes connected to it. The person is wearing a green sleeve. The background is blurred, showing a hospital setting.

THE COURAGE TO SELF-CANNULATE

# **Taking Control Means Less Pain, More Independence**





**By Michelle Carver,**  
Vice President Clinical  
Service Initiatives at  
Fresenius Kidney Care

If the idea of self-cannulating every time you dialyze seems impossible, you are not alone. Many people fear needles, especially the large ones used for dialysis. But trust me, when you learn to do it, you'll wonder why you ever doubted yourself. It gives you control, may make your access site last longer and, believe it or not, hurt less.

One of my dialysis patients compared it to putting a cotton-tipped swab in your ear – would you rather do it yourself or have someone else do it? Only you – not your care provider – can feel both ends of the needle, so you know when and where to stop, which means fewer complications and missed sticks.

If you don't believe you'll ever be comfortable with self-cannulating, let me tell you about one of my patients. He planned to do home dialysis, so he needed to learn to self-cannulate, because there was no one at home who could do it for him. But he wouldn't even look at me when I put the needle in. He said he'd do it the next day, but again, he wouldn't look. I told him he would have to do it if he wanted to dialyze at home, so finally he gave it a go. He put one needle in, had no problem, and from that day forward never let another professional cannulate him. Previously he had stayed close to home, but after learning to self-cannulate, he traveled all over the world. Overcoming the fear was the key to his freedom and independence. It can be yours, too.

Here's how it works:

- **We teach you.** You'll come into the center for four weeks and we'll teach you how to cannulate step by step. We offer lots of tools and have a number of teaching methods. Because putting the needle in the first time is scary, you may start by

doing it in reverse -- by removing the needle after a treatment. The tandem hand technique involves putting your hand on the care team member's hand and following it as the needle is placed. Then you'll switch, and the provider will put his or her hand on yours and guide you as you place the needle. After a few times you'll wonder why you were so stressed out about it. Our social worker can also work with you on ways to relax and de-stress, as well as, teach you some relaxation exercises.

- **We give you tips.** Using numbing cream can help with the pain, although most patients find they don't need to use it after a while. Using reading glasses helps, even if you don't normally wear them, because it magnifies everything and makes it easier to see the beveled part of the needle. A head lamp frees up your hands and using a one-handed tourniquet helps you see and hit the mark more easily. Pillows help you position your arm, so the access is just right. After you've placed the needles, we'll show you how to secure them by taping them and using pantyhose to keep the lines and needles in place so you can focus on computer work, crocheting, reading, or whatever you need to do during treatment.
- **We support you.** We give you lots of practice and make sure you are 100% comfortable before you self-cannulate. If you dialyze at home and have questions or concerns, a nurse is available 24/7 and you can call anytime you need help or have questions.
- **Options for access.** There are two methods for cannulation:
  - **Site rotation** is the traditional method and most common method, in which you place your needle in a different place every single time. It is the only option if you have a graft.
  - **Buttonhole<sup>®</sup>, or constant site cannulation,** in which you put

the needle in the exact same spot multiple times. After about two weeks a track is formed and you can switch from sharp needles to blunt or dull needles, which prevents you from placing a needle outside the blood vessel. Patients say it's easier because you don't have to find a new spot every time – it's like putting an earring in a pierced ear. Eventually the track is almost painless. A small scab forms over the access and is removed before the needles are placed for the next treatment. It doesn't hurt to remove the scab, but you need to be sure you have excellent infection control techniques to reduce the risk of infection. The buttonhole technique is primarily reserved for patients who are dialyzing at home and can only be used with a fistula.

Self-cannulation gives you control. Because you become so proficient and get to know your body and the process so well, you will very quickly notice even slight changes or issues earlier than others might, so you can quickly address them with your provider. Although you can self-cannulate at the center, it opens the door for home dialysis, which gives you more freedom.

Sound intriguing? Talk to your care team about learning how to self-cannulate.

*Michelle Carver, BSN, RN, CNN, is the Vice President Clinical Services Initiatives at Fresenius Kidney Care. Michelle has over 20 years of experience in dialysis nursing care specifically in peritoneal and home hemodialysis training and support. She currently focuses on developing and implementing standardized processes for improving clinical outcomes for dialysis patients.*



# COVID-19 and Patients with Kidney Disease on Dialysis



By Alan Kliger, MD

I am writing this mid-March 2022, as the last peak of COVID infection with the Omicron variant has rapidly fallen in every US state, but wastewater analysis has shown places in the US where virus infection in some communities is rising again. A new sub-variant, BA.2 is making up about 23% of cases. Abroad, the United Kingdom is seeing increasing hospitalizations with COVID infection, and many locations in the far east have raging infections. The effects of the surge in Omicron cases around the world this past winter have deeply affected patients on dialysis ... effects likely to last well into the spring of 2022, even if we see no further surges or new variants of this wily virus. The pandemic's effect on our healthcare system and on the dialysis industry are widespread, causing supply shortages, supply chain disruptions, and personnel challenges, including the "Great Resignation" where roughly 33 million Americans have quit their jobs since the spring of 2021. Remaining workers have experienced stress, overwork, and burnout. Disagreements about use of face masks, vaccines, and government mandates fracture the country and engender mistrust and anger. Dialysis facilities reflect many of these stressors and have made adjustments to try to keep patients safe. Here is a partial list of these effects of this two-year pandemic:

## The Great Resignation

1. Nursing and dialysis technician staff shortages have occurred across the

country. As many as 1 in 4 or 1 in 5 staff have left their jobs, part of the "Great Resignation." Retention bonuses have had limited utility in keeping many professional caretakers at their jobs. Attracting new staff to work in the vacancies has proven very difficult, even when monetary incentives are offered such as signing bonuses. These staffing shortages have in some areas resulted in shift closures, and even facility closures. Other facilities have considered reducing dialysis time, to allow reduced staff caregivers to deliver dialysis to all patients.

2. Fewer staff caring for more patients (in those shifts that remain open) are spending all of their time in direct patient care, leaving little or no time for activities such as quality improvement, patient-centered projects, or data collection and reporting. At such stressful times, it is difficult for facilities to compile government-mandated data and report these data, which in turn will make it difficult to use data to understand our quality and safety challenges.
3. Disruptions in manufacturing and supply chain have caused shortage of some dialysate solutions. Even when manufacturers are able to produce these essential solutions, truck drivers and delivery personnel shortages reduce the numbers of these supplies that are delivered on time, as needed to dialysis facilities across the US. The result is that many dialysis facilities have reduced the volume of dialysate for each dialysis. For example, in facilities where a standard dialysate flow rate is 800ml/min., these rates have been reduced to 600 or 500 ml/min to preserve available dialysate solution

and assure the supply for all patients. While studies have shown that the effectiveness of dialysis at these slower dialysate flow rates is not reduced very much, these slower dialysate flow rates are somewhat less than ideal. Manufacturers have had reduced plant inventory of some varieties of dialysate solution, so the solution used by some patients have needed to change. Dialysis staff have carefully monitored patient blood tests and measured the effectiveness of dialysis as measured by Kt/V measurements, to assure that these changes do not result in meaningful changes in patient care.

## Vaccination

Dialysis patients and staff have been strongly encouraged to get COVID-19 immunization and boosters when eligible, and these populations are among the highest percent immunized in most communities. While some have been skeptical and reluctant, many more have sought to get fully immunized and boosted as soon as possible. Some studies have shown that patients who are immune-compromised, such as kidney transplant



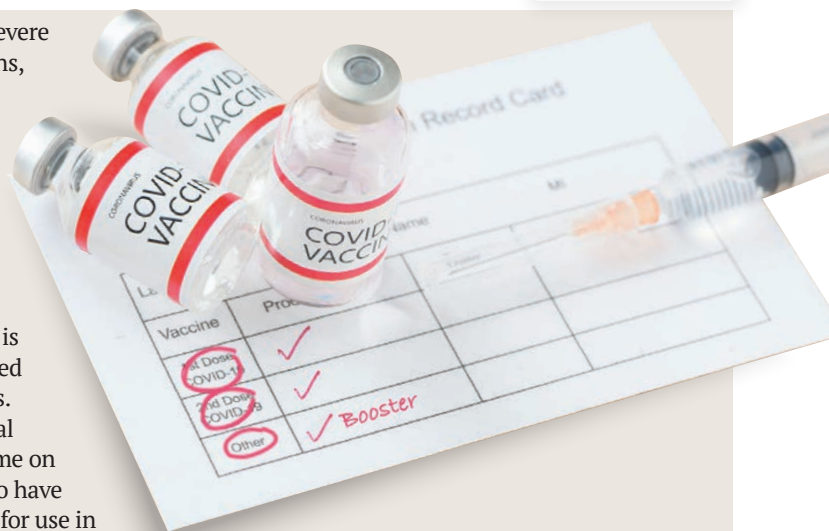


patients taking immunosuppressive medicines, have a much lower response to COVID-19 vaccine than the normal population. The lower levels of antibody that these patients develop in response to immunization makes these patients more susceptible to COVID-19 infection and its complications. Some studies have shown that patients with chronic kidney disease on dialysis, many of whom have other system diseases such as diabetes, hypertension, heart, and vascular disease, also have reduced antibody production after vaccination. It is difficult to identify which dialysis patients are immune-compromised and which are not. For this reason, many nephrologists believe it is prudent to identify all dialysis patients as immune-compromised, and to offer them the same protection as the CDC recommends for moderately or severely immune-compromised individuals. That includes an extra dose of mRNA or vector vaccine to be considered fully vaccinated, and then booster doses after 3 – 6 months.

## Treating COVID-19 Infection

Until recently, there was little that patients with mild or moderate COVID-19 infection could do other than rest, isolate, take pain medicine as needed, and stay well-hydrated. There were no effective anti-viral medicines similar to antibiotics that treat bacterial infections like staph. In recent months, FDA has given emergency use authorization to several drugs and drug combinations that effectively reduce the viral load and decrease the symptoms and possible complications of COVID-19. Remdesivir, which has been used in

hospitals to treat severe COVID-19 infections, now is available for outpatients and works well against this virus. However, it has not been studied adequately in patients with kidney disease and is not currently advised for dialysis patients. Other new anti-viral medicines have come on the market, but also have not been approved for use in dialysis patients. Paxlovid is a combination medication that works well to treat Omicron but has several drug interactions that limits its use. It has not been approved for use in patient with advanced kidney disease or dialysis. These and other anti-viral medicines need to be studied more carefully in patients with advanced kidney disease before they can be widely used. Another category of medicine, monoclonal antibodies, have been used to reduce disease complications and even can be used prophylactically to prevent infection in patients at risk. Sotrovimab is an engineered neutralizing monoclonal antibody that unlike earlier developed monoclonal antibodies, shows strong evidence of stopping spread of the Omicron variant. Evushield, a combination of 2 long-acting human monoclonal antibodies, has been authorized for COVID-19 prophylaxis in patients at high risk for this infection.



Dialysis patients, considered by many nephrologists as immune-compromised and at high risk of infection, are therefore candidates for this therapy. In summary, while the Omicron Variant of COVID-19 is rapidly receding, new waves of infection remain possible. The effect of a two-year pandemic on the workforce, including dialysis personnel, has had profound effects on our ability to provide routine dialysis across the US. Fewer nurses and technicians, fewer drivers and supply delivery personnel have together reduced the number of dialysis stations operating across the country and have limited availability of dialysis solutions. While safety remains the top priority of dialysis providers, these limitations have substantially stressed the dialysis industry. COVID vaccination and boosters have proven very successful in reducing illness and death in the dialysis population: before these therapies were available, dialysis patients infected with COVID-19 often had a 20% or higher death rate. Since most patients have been immunized, the mortality and hospitalization rate for COVID-19 sufferers on dialysis is far lower. New anti-viral medications and monoclonal antibodies are effective in treating non-hospitalized COVID-19 patients, and we need more study on the safety and efficacy of these medications in dialysis patients. A long-acting monoclonal antibody combination Evushield has been useful to prevent infection in high-risk patients with immune-deficiency and may prove valuable for the dialysis population.



*Alan S. Klinger, MD, Clinical Professor of Medicine, Yale School of Medicine, and Chair, Excellence in Patient Care Advisory Committee, American Society of Nephrology*

# Falling by the Wayside?

## Falls Prevention in Dialysis



By **Laura Plantinga, PhD,**  
**Bernard Jaar, MD, MPH,** and  
**C. Barrett Bowling, MD, MSPH**

### Why are dialysis patients at particular risk for falls?

**S**tudies show that approximately one-quarter of dialysis patients fall every year, meaning that they are about three times more likely to fall in any given year, compared to the general population. While older age certainly plays a role, there are several other factors that put dialysis patients — regardless of age — at higher risk for falls. In fact, most falls probably result from a combination of factors, usually a combination of long-term “predisposing” risk factors and short-term “precipitating” factors. For dialysis patients, predisposing factors include health conditions like nerve damage from diabetes, weakness from heart failure, or poor circulation in the legs and feet due to peripheral arterial disease; reduced vision; long-term medication use; and reduced physical functioning and/or frailty. Precipitating factors include environmental factors in your home or neighborhood (or even in the dialysis clinic); slippery and/or dark conditions; and low blood pressure and dizziness after dialysis or in response to starting a new medication (see Table).

### What are the consequences of falling?

Falls can damage more than just your ego! Of course, not all falls result in injury, but a pattern of even minor falls suggests that there are underlying issues that should be addressed to prevent future falls. Additionally, even minor falls can create a vicious circle, in which frequent falls result in a fear of falling, which can then reduce physical activity and functioning, which then makes future falls — and associated injuries — even more likely. For dialysis patients, falls are more likely to result in broken

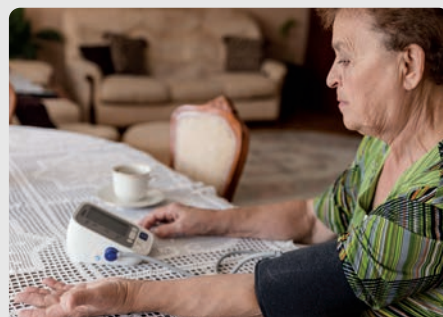
bones (fractures), since end-stage renal disease is associated with bone mineral metabolism problems that can result in bone softening (osteopenia). Additionally, fractures that do occur may take longer to heal. Falls are also associated with increased risk of other unwanted outcomes, such as emergency room visits, hospital admissions, nursing home admissions, and even death. Therefore, it is critical to address falls and their underlying causes as soon as possible.

### What can you do to decrease your risk of falling?

The most important thing you can do to reduce your risk is to report any falls, “near-misses,” or risk factors for falls to your nephrologist, primary care physician, and/or other providers, as appropriate (see Table). While your doctors are likely

aware of any major underlying medical conditions, it is unlikely that they will know about gradual changes in vision, physical performance (strength, balance, walking ability), or environmental conditions. Remember that they most often see dialysis patients in the clinic and sitting still, making it hard to distinguish the patient who easily walked unassisted into the dialysis clinic from the patient who needed help getting in and out of the chair. In some cases, it might be helpful to ask the dialysis clinic nurses, social workers, or dietitians if they can help you access services, rather than wait for doctors, whom you may see less frequently. Note that most of the sources of help listed are at least partially covered by Medicare; your social worker can also help navigate these issues.

While falls assessment is common in geriatric medicine, it is rarely done by busy dialysis clinic providers, who have many competing demands on their time. Thus, advocating for personalized, effective falls prevention for yourself or loved one is important. Preventing falls will help you or your loved one maintain and maximize quality of life and independence.





**Table. Common risk factors for falls in dialysis patients and sources of help**

Risk factor	What you can do	Who can help
<b>Predisposing (long-term) factors</b>		
Diabetes	Control blood glucose as much as possible; get recommended screenings (especially foot/vision checks)	Nephrologist, primary care physician, endocrinologist, dietitian
Peripheral arterial disease	Address diabetes/stop smoking, get recommended screenings (including foot checks)	Nephrologist, primary care physician, cardiologist
Heart failure	Control fluid intake, take diuretics as prescribed	Nephrologist, primary care physician, cardiologist
Vision loss (general or night-time)	Get regular eye exams, identify and address underlying issues	Ophthalmologist, optometrist
Frailty/loss of muscle mass	Follow recommended physical activity plans, ensure healthy diet	Nephrologist, physical therapist, dietitian
Problems with balance, walking, etc.	Rule out and/or treat medical causes, follow recommended physical activity plans, obtain and use walking aids	Primary care physician, physical therapist, occupational therapist, social worker
Cognitive and/or psychiatric issues	Rule out and/or treat medical causes, learn workarounds (e.g., using technology)	Neurologist, psychologist/psychiatrist
Taking unnecessary or harmful medications long-term	Ask for a medication reconciliation (to ensure no duplicate medications and stop or taper any medications that are no longer needed, including any over-the-counter medications or supplements)	Nephrologist, primary care physician, pharmacist
<b>Precipitating (short-term) factors</b>		
Starting a new medication (including those given during dialysis treatment)	Immediately report any new issues with dizziness, vision, balance, etc., if you recently started or were administered a medication, particularly those commonly used for itching (Benadryl, or diphenhydramine), sleep (temazepam, zolpidem), anxiety (lorazepam) or high blood pressure (clonidine)	Nephrologist, nurse, primary care physician, pharmacist
Large volume shifts during dialysis (leading to very low blood pressure/dizziness)	Ask for longer dialysis duration; reduce fluid intake	Dialysis nurses, nephrologists, dietitians
Dialysis clinic factors (examples: blocked walkways, insufficient time to transition from dialysis to walking)	Ask that wheelchairs, IV stands, etc., be moved out of the way during shift changes and request recovery seating areas	Dialysis medical directors, clinic administrators, nurses, social workers
Home factors (examples: low lighting, unsecured rugs/furniture, lack of handrails, pets)	Get a home evaluation and make necessary changes	Occupational therapist, social worker, family members/friends
Neighborhood factors (examples: cracked or blocked sidewalks, insufficient time to navigate crosswalks)	Contact local services (e.g., Department of Transportation), politicians, and/or consumer advocates	Social worker, family members/friends
Rushing	Plan ahead so that you have adequate time to catch public transportation, go to appointments, and complete errands	Family/friends, social worker
Weather (icy or rainy conditions)	Take extra time and wear appropriate footwear; ensure sidewalks are cleared of snow/ice before going out	Family/friends
Footwear	Wear only closed-toe shoes with sufficient support (no flip-flops); obtain neuropathy shoes if needed	Orthopedist
Eyewear	Ensure you are wearing a current prescription; be especially careful when transitioning to bifocals or progressives	Optometrist

**About the Authors:**

*Laura Plantinga is an epidemiologist and health services researcher at Emory University in Atlanta, Georgia, whose work primarily focuses on improving the equity, quality, and patient-centeredness of U.S. dialysis care. Bernard Jaar is a nephrologist and clinical researcher at Johns Hopkins University in Baltimore, Maryland. He serves as the medical director of a dialysis clinic and his research interests include epidemiologic studies of chronic*

*kidney disease and end-stage renal disease and their related complications. C. Barrett Bowling is a geriatrician at the Durham Veterans Affairs Geriatric Research Education and Clinical Center, Durham Veterans Affairs Medical Center (VAMC), and Duke University, Durham, North Carolina, whose research focuses on patient-centered care that optimizes function and quality of life over traditional disease-based approaches, particularly in patients with chronic kidney disease.*

# Living with Chronic Illness and Bipolar: A Story of Resilience



**By Ashley Abedini**

I opened my eyes to find myself lying on a hospital bed. This was not exactly a new experience for me; I have a chronic illness called Cystinosis, a metabolic disorder that has led to health issues, most notably kidney failure. As a result of this, I had to go on dialysis for about a year, leading to frequent hospital stays.

I was diagnosed at just six months, so it is something that has been a pivotal part of my life. The hospital bed, cold blank walls, and countless nurses were a familiar sight. This hospitalization was quite different though. I signed myself in that night for what I would later learn was a manic episode, and I left the facility with a diagnosis of bipolar type 1. That hospitalization was more than 10 years ago. My psychosis from bipolar came extremely suddenly and unexpectedly. I had never shown any behavior or mental health problems



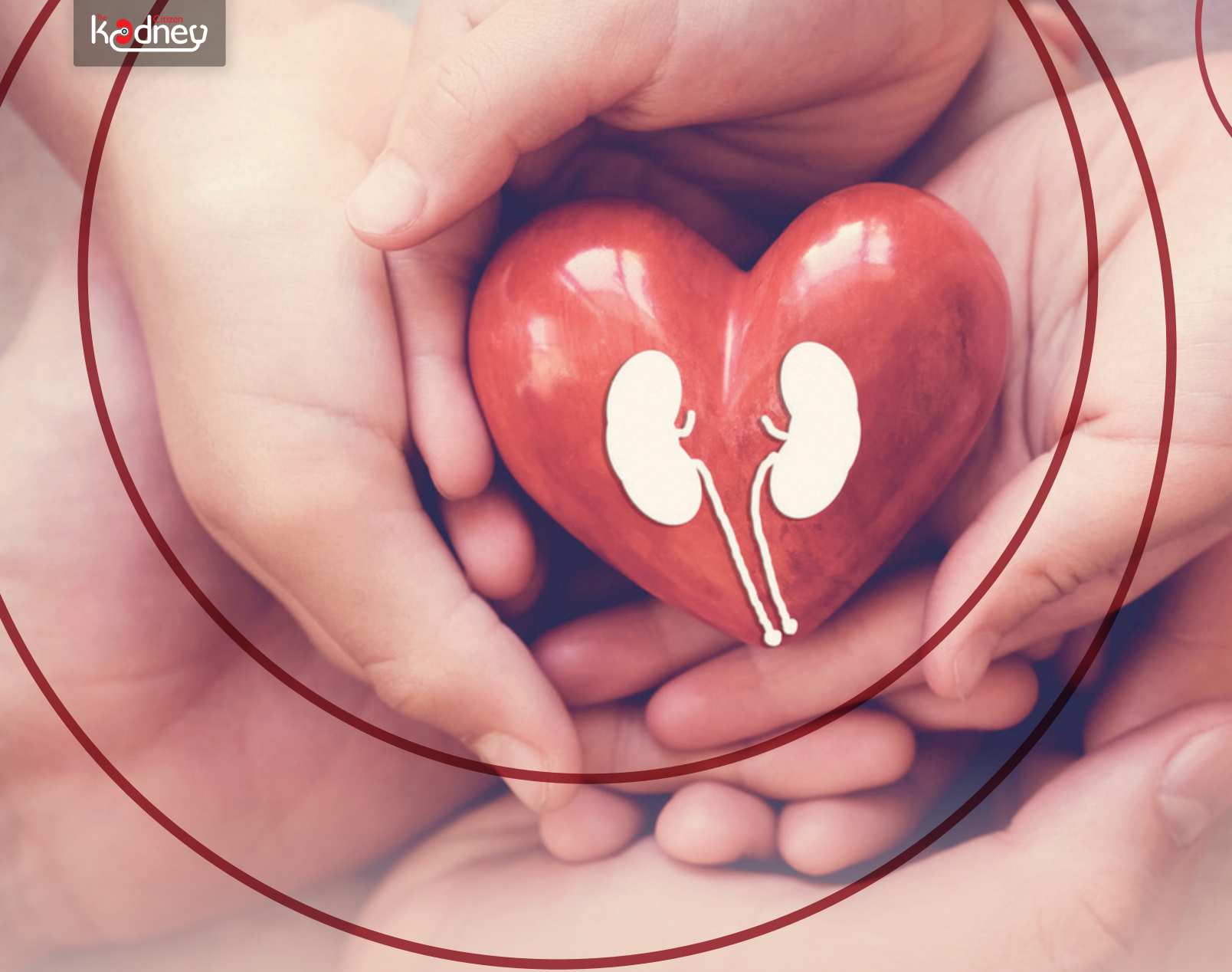


prior, so my family and I needed much convincing. One day I went from living a fairly productive and healthy life, and the next I was having such wild and impulsive thoughts that ultimately led me to getting checked in at the hospital. It was very hard to understand; I wasn't really exposed to bipolar in any way until I got my diagnosis. It took research, many therapy sessions, and enough time to really process my diagnosis and accept it. It has not been easy, but with continued effort, effective medication, intentional planning, and therapy I have been able to effectively manage my illness, despite the eventual challenging times. I have learned it is only when you are vulnerable about your own struggles that others may feel comfortable enough to share theirs. After sharing my story, I discovered many close to me were struggling with their own mental health turmoil, and simply felt embarrassed sharing. Through this I realized that although my experiences might have been unique to me, I was not the only one suffering.

I believe strongly that our purpose is tied to our struggle, and that anyone can bloom, despite growing in the harshest of conditions. Struggle is such a fundamental part of the human experience. If we look hard enough, we can see that everyone is fighting their own distinctive battle. True power is when you are able to transcend your struggle through purpose. As Nietzsche stated: "He who has a why to live for can bear almost any how." True success is overcoming trauma, and not only succeeding, but helping others along the way. Many

people wait to seek treatment out of shame. Although awareness is increasing, and many strides are being made to increase exposure to the mainstream, mental health is still heavily stigmatized. My advice for those with chronic illness is to be aware of their mental health. It can be so easy to overlook how we are feeling since it is invisible and not something we are actively forced to pay attention to for literal survival like our scheduled doctor visits, many medications, and constant checkups. We often have to be in survival mode for much of our life because of our illness that we may not see the need to point out problems if they are not causing an emergency or immediate concern. However, the last thing you want to be doing is being forced to address an issue that has now festered into a big problem. Although it was hard to tell at the time, it would have been great to have a therapist during dialysis. My mind was just trying so hard to survive that at the time I did not realize the amount of trauma I was experiencing. In addition, I think it is important to know trusted loved ones that you can openly communicate with and maintain consistent communication with them. It is often our friends and family that can help point out if we are acting a little "off." I now have a strong support system set up that I feel comfortable going to, but also people that know me well enough to know if I am becoming a bit more maniac. Chronic illness and mental health are so immensely correlated, and it is important to be aware of this to help make the best path possible in your life. Living with chronic illness is hard, but it is a lot easier when I have been able to understand my mental health better.

*Ashley Abedini is the owner of Abedini Social, a social media agency, and currently lives in Wichita, Kansas. A creative marketer, Ashley is known for her innovative approach, direct communication, and skill with executing strategy. Ashley is a devoted foodie and culinary explorer spotlighting Wichita's hole-in-the-wall restaurants on her popular social media account, ICT Broke Girls. Her passion is working with local restaurants to help them use social media to connect with a highly engaged online community. She had her kidney transplant over ten years ago, receiving the life-saving gift from a gracious friend, and has been in good health since, although still dealing with the typical restraints of her rare disease, Cystinosis.*



# **My Experience as a Kidney Patient in CKD, Dialysis, and Transplant**





**By Orlando A. Torres**

**A**fter a 30-year battle with chronic kidney disease (CKD), in 2016 I had Stage Five kidney failure. This was the end of a three-decade battle which took countless hours of treatment. For years, I had been followed medically for CKD, having a special test done monthly and eating a special diet. As a CKD patient, my condition affected other organs in my body. The number of regular activities I could do also declined, but I never quit and refused to accept those limitations. I never let CKD limit what I did. I think it is important to try to work through the potential limitations of CKD to have a strong mental attitude.

Exactly four years ago, when Hurricane Maria had a direct impact and caused devastation to my home island in the Caribbean, Puerto Rico, there were major losses of services and food limitations for months and years after the impact. My medical condition also caused a type of “worst case scenario.” In November 2017, my hemoglobin went down to 8.0 level and my long-term nephrologist told me to go to the hospital. Then, in December, the surgeon created my vascular access and the same day around 11:00 pm I had my first dialysis treatment.

After one week in the hospital, I started outpatient dialysis at a local dialysis facility. The first two weeks on dialysis



*Orlando's first day of dialysis in hospital with friends Roberto Ortiz and Abimael Rodriguez*

were horrible. One day I realized that somehow this experience needed to be transformed into a positive experience and I made a plan to have a level of satisfaction in the dialysis process.

I decided to become more involved in my care and dialysis treatment. I felt that self-management and being actively involved in my treatment were important to me. I was determined to be involved in all treatment decisions and I would have the final say. Although my health care team was concerned that I would oversee all decisions, they came to understand that the care of my health was driven by me, and they were going to be my advisors. The final decision was my responsibility.

My position was unusual for the health care team, but at the end of the day it is my body, my life and I have the legal rights to control my treatment.

After 16 months of incenter dialysis treatment, I decided to do home dialysis using NxStage equipment. It worked perfectly for the next year.

In 2016, one year prior to starting dialysis, I initiated the process to find a transplant center and potential donor. After many trips to centers, interviews, and pre- acceptance medical clearance tests through those years, we found a great, healthy donor who passed all the tests as a donor except one - her blood was not compatible with mine. But she learned about and decided to participate in a new federal program called “EXCHANGE TRANSPLANT”. The program would receive her kidney as an altruist donation to a stranger and

the system also would find an altruistic donor for me.

In November 2020, I received the call from the Methodist Dallas Hospital that a transplant was available. One altruist donor had a kidney compatible with me, and my partner in the program agreed to make her kidney donation to a stranger with the objective that I receive the gift of life. In other words, I thank the person who initially wanted to be my donor but then became part of the Exchange Transplant program when that was not possible. This created the scenario for me to receive my actual kidney from another beautiful donor in the Exchange Program. This person gave me this new opportunity to live and enjoy life with my relatives, especially with my wife and sons and our three grandsons. To both kidney donors, my eternal gratitude.

Today, closing my first year as a transplanted patient, I value the “gift of life” I received and concentrate my time on taking care of my transplant and working with other patients who need my support.

Also, I am involved in work with the American Association for Kidney Patients (AAKP), Dialysis Patient Citizens (DPC) and the American Kidney Fund (AKF), with the objective to expand the scope of the services for my community.

*The author, Orlando Torres, is a DPC Patient Ambassador who lives in Guaynabo, Puerto Rico.*

# How to Move Out of Loneliness and Isolation



By Rebekah Palmer

**O**ftentimes, people whose bodies live with rare diseases and chronic illness are not only separated from their peers and society, but feel separate from their peers and society. This is especially true regarding peers who are considered able-bodied, as well as a society that is inherently ableist.



Dr. Bessel van Der Kolk, M.D. and author of The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma suggests multiple ways a human can connect to others and themselves (not an exhaustive list):

1. Yoga/mindfulness exercise
2. Theater
3. Neurofeedback
4. Support Groups

People who do not live with chronic illness do not always know the existence that is lived regularly with hospital and clinic visits, and the consumption of treatment and medications. It can be what we see and hear on media and online when it comes to how disabled and rare populations are spoken about by society. It can even be aspects of our lives that don't relate to our illnesses but, because we have an illness, these parts get overlooked.

Those realities of many of us with disability and disease that get overlooked and overshadowed are race and culture, gender, sexuality, religion, class, age, and size. We are whole people who live in these intersections like all other human beings. Kimberlé Crenshaw, an American civil rights advocate and professor, coined the term "intersectionality" to describe how we as human beings exist in this world and to describe where much of the framework wherein people's narrative gets erased.

Loneliness due to lack of shared experiences and continued bodily pain is a human reality and can come from multiple circumstances. When resources for care and resources for connection to other humans is unavailable, this is quite an isolated existence on top of loneliness that could be created by different traumas.

I am speaking pre-pandemic, of course. With the onset of COVID-19, much loneliness and isolation has been compounded. Rare Disease Day Official has reported that two thirds of those with rare disease have experienced more depression since the pandemic and that 83 % have not had the medical care they regularly had before 2020.

Perhaps we can help with the reality of isolation by utilizing video chat for medical appointments. While this may be something a person is already doing for their body, video chats with support groups can assist with feelings of loneliness.

With the exception of live theater in communities and a neurofeedback specialist, yoga can be found online, as well as platforms to speak with support groups who share similar experiences. Doing daily stretches and exercise can assist and support a person with how they are feeling and promote well-being in how to calm one's hyperactivity.

Opening up to peers creates trust and often fosters a sense of belonging. When it is safe to do so in this current pandemic, finding a community center that offers theater or game nights or accessible sports benefits us as people. Check out the following websites to get encouragement to connect with oneself and others:

- [Chronicallysurviving.com](https://chronicallysurviving.com) (Marcelle lives with rare disease and is a yoga and meditation teacher)
- [Facebook.com/wakeuplaughingwellness/](https://facebook.com/wakeuplaughingwellness/) (Tahnie Woodward lives with rare disease and is a Reiki-energy healing-instructor)
- [heypeers.com](https://heypeers.com) is a platform wherein multiple rare and chronic disease

groups chat. A person can connect with their own peer group and trained coach

- CRIP CAMP is a documentary available in Netflix. Check them out at [cripcamp.com](https://cripcamp.com) to learn more about the disability revolution

*Rebekah Palmer is a graduate of UW Stout from Menomonie, Wisconsin. She is a poet and writer and an advocate for adults living with rare disease. She is cofounder of the nonprofit Next Generation of Cystinosis an organization specifically for cystinosis adults. Contact her at [rebekah-palmer@nextgencystinosis.org](mailto:rebekah-palmer@nextgencystinosis.org).*



## EVIDENCE UPDATE

# Treating Depression When You're on Dialysis

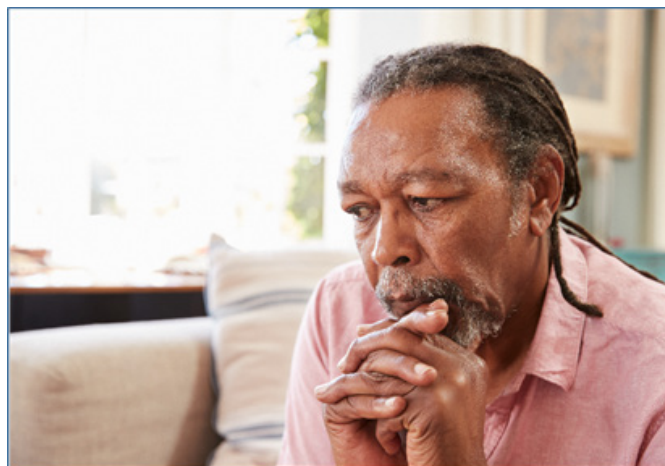
A recent study looked at how well two treatments for depression work for people on dialysis.

**D**epression is common in people who are on dialysis. Depression worsens your quality of life, makes you feel tired, and can affect your kidney health as well as your overall well-being.

There are many ways to treat depression, but not all ways work well for people who are on dialysis. A recent study looked at two ways to treat depression for people who are on dialysis:

- ▶ Cognitive behavioral therapy, or CBT. CBT is a type of talk therapy. In CBT, patients work with a therapist to change patterns in their thinking to improve how they feel. Most people go to several one-hour sessions with a therapist.
- ▶ Sertraline. Sertraline is an antidepressant medicine sold under the brand name Zoloft®. People take this medicine daily as a pill.

Other studies have compared CBT with medicines like sertraline, but this study is unique in looking only at people who are on dialysis.



## Seeking Treatment for Depression While on Dialysis

Many people on dialysis may hesitate to get treatment for depression. Some of the symptoms of depression and kidney failure are similar, such as fatigue, sleep problems, poor appetite, headaches, and lack of focus. As a result, people on dialysis may not realize they have depression. Many people on dialysis also wonder if treatment would improve the symptoms they are feeling.

If you have depression, talk with your kidney care team about any concerns you have about getting treatment. Some people on dialysis have concerns about adding treatment for depression to their care. Weekly therapy sessions can be hard to fit into a schedule that is already busy with clinic visits for dialysis and other kidney care treatment. People on dialysis may also worry about side effects from medicines or about treatment costs. Your kidney care team can help you find answers to these and other questions, and help you get treatment that can improve your health.



### Findings

A PCORI-funded study found that CBT improved depression about as much as sertraline for patients on dialysis with depression. The research team found improvements across all patients in sleep, appetite, mood, energy level, and ability to focus. At the end of the study, about a third of all patients no longer had symptoms of depression.

Compared with patients using CBT, patients taking sertraline had slightly more improvement in symptoms of depression. But patients taking sertraline also had side effects more often than patients using CBT.



## Questions to Ask My Kidney Care Team

Your kidney care team—including your kidney doctor, nurse, and social worker—will talk with you to learn if you have depression. If you do, they can help you choose a treatment that works best for you. Questions to ask your kidney care team include:

- ▶ How do I know if I have depression?
- ▶ What side effects of treatment should I know about?
- ▶ How can I find a therapist and arrange sessions that fit my schedule?
- ▶ Does this dialysis center offer CBT on-site?
- ▶ How can I find out about my out-of-pocket costs for CBT or medicine?
- ▶ What other support for depression is available?

## Resources

There are many resources to help people with depression. Here are a few:

- ▶ A [Dialysis Patient Depression Toolkit](#) is available through the Kidney Patient Advisory Council (KPAC). KPAC is part of the National Forum of ESRD (End Stage Renal Disease) Networks.
- ▶ The Substance Abuse and Mental Health Services Administration's (SAMHSA's) National Helpline at 1-800-662-HELP (4357) is private, free, and available 24 hours a day. It provides help in English and Spanish. You can get information about treatment near you, support groups, and more.

Read more about this study at <http://www.pcori.org/Mehrotra209>

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## About the Study

The research team enrolled 120 patients ages 21 and older with kidney failure who were receiving outpatient dialysis. All patients had depression. The team assigned patients to receive CBT or sertraline by chance and then looked at their health 12 weeks later.

### Notes:

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PCORI® is a nonprofit organization authorized by Congress to fund studies that can help patients and those who care for them make better-informed healthcare decisions

# Wellness and Mental Health While Living with Rare Disease



**By Maya Doyle,**  
MSW, PhD

**C**ystinosis is a rare lysosomal storage disorder (1) that is typically diagnosed in childhood and typically results in kidney failure

and progression to dialysis and/or kidney transplant. In the United States, a disease is considered rare if it affects fewer than 200,000 Americans. According to the National Institutes of Health (NIH), there are approximately 7,000 rare diseases affecting between 25 and 30 million Americans – this means 1 in 10 people may be affected by a rare condition (2). The experience of a rare condition can be very isolating because of the lengthy time to get a diagnosis, the lower number of people with a specific diagnosis, limited access to specialists, and being geographically far apart.

Cystinosis causes an abnormal accumulation of the amino acid cystine in various organs and tissues of the body such as the kidneys, eyes, muscles, pancreas and brain (1). The disease affects almost every organ of the body over time. Advances in treatment have improved the quality and length of life for people with cystinosis and extended the timeframe of kidney failure often from childhood into adolescence and young adulthood (3). This change has made the health challenges of the disease later in life more evident. Likewise, the mental health challenges that accompany living with a rare,

chronic, and progressive disease have become clearer to patients, family members, and healthcare professionals. Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make choices (4). In my role as a social worker in pediatric nephrology over the last two decades, I have watched a generation of kidney patients grow up, many pursuing their educations and careers, and starting relationships and families. The burdens of kidney disease are many:

- staying healthy and well while living with illness
- maintaining adherence with often-unpleasant treatments
- accepting the unexpected events that accompany illness
- keeping up with peers, friends, and colleagues
- changes to the body, and having differences in physical growth, appearance, and development
- educational and vocational challenges
- navigating social and romantic relationships

It is not surprising that these things result in strong emotions of sadness, worry, loss, or anger for both the individuals affected and the people who care about them, or that people with kidney disease experience higher rates of anxiety and depression (5, 6). Both talk therapy and medication





can be helpful to manage anxiety and depression and reduce symptoms (5). There are of course clinical definitions of anxiety and depression; in helping patients understand why a team might be recommending “getting help,” I find it helpful to understand and explain those words this way:

- Anxiety is fear and worry for what the future – be it, the next day, the next year, or the indistinct future – will bring.
- Depression is sadness and loss, a sense of being stuck, within what has already occurred in the past, and feeling that things will never improve, or will only worsen.

These are very real aspects of living with rare or chronic disease, and it is important to remember that health and mental health are intertwined. Put simply, how we feel affects how we feel! I find it helpful to remind patients and families that the feeling of being “stressed” is our body’s alarm clock, a way of telling us that change is needed. They can envision a filling bucket that can either be filled and overflowing with stress or can have a valve to help release that stress. There are many strategies that patients and families use that allow them to regain and maintain a sense of calm or control (7). There is no single or quick “fix”, and no one approach that fits everyone, when it comes to mental health. There are three levels of support

(often used in combination) that are helpful to explore:

- Professional help
- Peer support
- Wellness and self-care practices

### Using Professional Help

People with kidney disease may be referred for “professional help” by their medical team, or may self-refer, to support their coping, relationships, or well-being; for concerns about anxiety, depression, self-harm or thoughts of suicide; or other behaviors that are creating risk. For kidney patients, this can include not participating in needed medical treatments (a complex topic but often one with a mental health component). There are many trained and licensed professionals, including social workers, psychologists, couples or family therapists, substance abuse counselors, psychiatrists, and others who can provide appropriate services. Every dialysis and transplant team are mandated to have social workers as part of their team and may include other mental health-oriented professionals as well, so this can be a good place to start to either get support directly or get a referral to a provider focused on mental health. You may also want to contact the behavioral health component of your health insurance to get a referral for an “in network” provider. It is helpful to recognize that different types of therapy



have different goals – from helping patients to manage their thoughts and feelings; coping with their illness or other life stressors; making changes to reduce unhealthy or risky behaviors; and addressing emotions and conflict within family or partner relationships. As with many other types of healthcare providers, it is likely that a therapist will not be deeply familiar with your particular rare diagnosis; sharing accurate information may be helpful but does not have to be the focus of your work together unless that is one of your goals.

Especially in the wake of COVID, many of us have had experiences of fear, anxiety, sadness, or frustration. We may have lost loved ones, seen others ill, or been ill ourselves. Being locked down or socially distant takes away some crucial support. Return to school and community life has been difficult for many and those who are immunosuppressed or compromised may have ongoing concerns. Increased awareness of mental health and increasing access to mental health services online and via telehealth may make access to treatment faster and easier.

Whatever type of therapy or type of therapist one works with, it is helpful to inquire about the training and background of the person you are working with and collaborate to decide on the goals of therapy and a treatment plan. Many mindfulness practices (see below) can be learned or used as part of the therapy process, particularly in EMDR or cognitive-behavioral therapy (CBT) to help manage anxiety and develop new ways of coping. You should not feel shame or embarrassment to asking for help, or for having it suggested to you. Asking for help, going for an assessment, or logging on for that first virtual visit can be hard – it is scary to show our vulnerabilities. Building an open and trusting relationship with a therapist can be a key element in coping and making needed changes.

## Peer Support

Peer support from others who share parts of your experience can take many forms – whether in-person, by phone or text, or in forums on social media. The ability to access resources and connect online has been a boon to those with rare conditions, who might otherwise not meet other people who share, recognize, or understand their diagnosis. Peer support can provide both

If you or a loved one are having thoughts of suicide or self-harm, a call to a national or state hotline can get you immediate contact with someone who can listen, direct you to a local source of support, or get crisis services to you.

Call the National Suicide Prevention Lifeline at 1-800-273-TALK (8255), or text the Crisis Text Line (text HELLO to 741741). Both services are free and available 24 hours a day, seven days a week.

You can also text “care” to 202-596-6520 to contact the Chronic Illness hotline and get in touch with a volunteer Compassion Counselor.

informational and emotional support. It is so valuable to learn that you are not the only person experiencing something, and that others have walked this path before. Many patient organizations have in-person (and now virtual) conferences; patients and parents have told me about being overwhelmed and tearful the first time they walked into a room “where everybody gets it.” Some organizations offer mentoring programs that connect newly diagnosed patients and families with those who have lived the experience of illness for a number of years. Patients and families who share your experience may give you a greater sense of “comfortability” in talking about the impact of the illness in your life (8).

They may have resources and knowledge that can be helpful for you in navigating daily life, the healthcare system, or the trajectory of that particular illness. When I was running a group for parents of children with cystinosis several years ago, one mom shared how her family used to find fun and relaxation in camping, an activity made harder by her son’s diagnosis and medical needs. Other families instantly chimed in with empathy and ideas, things they had done to get back to life in the great outdoors, but with some modifications. In other groups, I have seen cystinosis patients share laughter with each other over medical issues that others might not understand or find funny. For those with rare conditions like cystinosis, disease-





## Examples of advocacy groups focused on rare kidney diseases

- Alport's Syndrome - [www.alportsyndrome.org](http://www.alportsyndrome.org)
- Atypical Hemolytic-Uremic Syndrome - [www.ahusallianceaction.org](http://www.ahusallianceaction.org)
- Cystinuria - [www.cystinuria.org](http://www.cystinuria.org)
- Cystinosis - [www.cystinosis.org](http://www.cystinosis.org)
- Fabry disease - [www.fabry.org](http://www.fabry.org)
- FSGS/nephroticsyndrome - [www.nephcure.org](http://www.nephcure.org)
- IgA Nephropathy - [www.igan.org](http://www.igan.org)
- Joubert syndrome
- Lupus - [www.lupus.org](http://www.lupus.org)
- Oxalosis/hyperoxaluria - [www.ohf.org](http://www.ohf.org)
- Polycystic Kidney Disease - [www.pkdcure.org](http://www.pkdcure.org)
- Prune Belly - [www.prunebelly.org](http://www.prunebelly.org)

specific advocacy groups (see examples below) or umbrella groups like National Organization for Rare Disorders (NORD), Global Genes or the National Kidney Foundation (NKF) can be a good place to start making connections. Later on, you may be able to “pay it forward” by offering similar resources and support to someone else; for some people helping others is an important part of their own self-care.

## Wellness and self-care practices

For many patients and family members, resilience, hope, faith, humor, and mindfulness can be key ingredients to

maintaining wellness, even while living with illness. Wellness encompasses many elements of healthy living, self-help, self-care, fitness, nutrition, diet, and spiritual practices. Whether you are a kidney patient yourself or a caregiver for someone who is, there are many things you can do to regain or sustain a sense of wellness. Making small, incremental changes – dropping one food from your diet, using a water bottle to track your fluids, exercising just 5 minutes a day, giving yourself a positive message instead of criticizing yourself - may make a difference in your lab values and your overall health, as well as your outlook. Each person needs to find a balance between self-care and support from peers and professionals. It

is important to remember that despite the best intentions of our family or our healthcare team to encourage changes in our routines, cultivating a sense of acceptance and gratitude for things just as they are is as important as making needed changes.

One way in which we can better understand and manage chronic illness and maintain wellness is through mindfulness, defined by Jon Kabat-Zinn as “awareness that arises through paying attention, on purpose, in the present moment, non-judgmentally.” There are many mindfulness practices that individuals can try – from deep breathing for just a few minutes to longer meditation or yoga practices. It is important to realize that self-care and mindfulness can take many forms – exercise, hobbies, a daily ritual, drawing or coloring, journaling, cooking, reading, the practice of one’s faith, spending time with others, or even that first cup of morning coffee! (Truth be told, that’s mine!). While some people will find it helpful to try something new to reduce stress, you can also draw on the things you already enjoy or that you enjoyed in the past. Particularly because illness can make planning challenging and life unpredictable, many rare patients and caregivers have shared with me the ways that they “live in the now” – building in fun and playful activities, quiet moments, and valued time with friends and family – whenever they have the chance (including during dialysis or during hospital stays). There are also many free and low-cost apps that provide suggestions, timers, and step-by-step guides for mindfulness and self-care activities. Simply taking time to notice the world around you with each of your five senses for a few minutes, and to be attentive to your own breathing and heartbeat, may be enough to bring you a sense of calm.

Over time, different ways of accepting (and giving) support may work for you as a patient or caregiver. Notice when the “stress bucket” is overflowing – or if thoughts and feelings are getting in the



way of how you function every day – how you interact with others; work or study or take care of things at home; or take care of yourself or your health. It may be a time to find additional support beyond self-care and friends, family, or your online community.

*Maya Doyle is an MSW and PhD who is now an associate professor of social work at Quinnipiac University. She was a hospital social worker for many years, serving as the senior social worker at the Children's Hospital at Montefiore since 2000, where she met her first patient with cystinosis. She is a professional advisor to the Cystinosis Research Network and a mentor to CRN's Adult Leadership Advisory Board (ALAB). She is also the coordinator of the Ruth Gottscho Dialysis and Children's Kidney Program at Frost Valley YMCA ([www.frostvalley.org/kidney](http://www.frostvalley.org/kidney)). She has lived with Type I diabetes since age 8 and is the mom of a 14-year-old.*

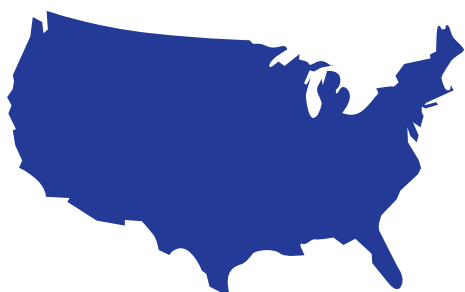
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# Education and support for patients and their families



## RARE

About 500 to 600 people in the United States have cystinosis.



## GENETIC

Cystinosis is passed down in a person's genes.

Learn more, get tips, and find resources at **CystinosisUnited.com**, and follow us on **Facebook** to join the conversation. ***Scan the QR code!***



# DPC's State Advocacy Efforts Flourish with

## Elevated Voice of DPC Patient Ambassadors



**By Kelly Goss, J.D., LL.M.,**  
Western Region Advocacy Director and  
**Elizabeth Lively,** Eastern Region Advocacy  
Director, Dialysis Patient Citizens (DPC)

**I**t's been a busy start in 2022 for DPC's state advocacy efforts. Many states are holding shorter legislative sessions due to the upcoming primary elections, and several bills impacting dialysis patients have been introduced and are moving quickly through the legislative process.

Legislation to expand Medigap access has been introduced in Arizona, Kentucky, Louisiana, Maryland, Nebraska, New Jersey, Rhode Island, Vermont, and Wisconsin. Improving access to affordable Medicare Supplement (Medigap) plans is a top policy priority for DPC, and we are pleased that multiple states are considering how they can help patients achieve greater financial security and achieve access to kidney transplantation, particularly in states that have limited or no access to Medigap for the under-age 65 ESRD population. Kentucky, Nebraska, and Rhode Island legislatures have already held committee hearings on Medigap expansion bills that would require insurers to allow Medicare enrollees under-age 65 the same access



*Medigap champion Kentucky State Rep. Tom Burch and Elizabeth Lively, DPC Eastern Region Advocacy Director*



to Medigap plans offered to those age 65 and older. In addition to building strong support among an array of advocacy groups, actuarial premium rate research DPC commissioned shows only a small increase in the overall Medigap premium pool when adding access for under-age 65 ESRD patients. This important data has strongly supported our efforts to educate legislators and gain their support. In Nebraska, there was broad support for Senator Steve Lathrop's bill (LB 1190) at the hearing from numerous patient advocacy organizations, healthcare professionals and patients to require greater access to affordable Medigap coverage for Medicare-eligible disability and ESRD patients under age 65. Committee members, including Chair Matt Williams, expressed their commitment to working with interested parties to craft a bill that can be passed next year. A post-hearing article in the Nebraska Examiner articulates the severity of the problem that patients under age 65 and their families experience because they are not able to access Medicare supplemental insurance. In Rhode Island, a similar bill (H7244) sponsored by Representative Brian Patrick Kennedy was unanimously approved by the House Committee on Health & Human Services and reported for passage to the House floor. The bill is supported by numerous legislators, the Rhode Island Health Insurance Commissioner, and the Rhode Island Governor's Commission on Disability, among others. A recent House Health & Family Services Committee hearing in Kentucky on HB 430 also received a lot of support from patient advocacy groups. The bill achieved unanimous approval to move out of committee while continuing to work on bill language with the insurers and is now being considered by the House Banking & Insurance Committee. Sponsored by Chair Kimberly Poore Moser, this legislation has strong bipartisan support, including legislative champions Representatives Burch and Willner. In addition to Medigap legislation, several states have introduced bills to enhance living donor protections through anti-discrimination measures and financial incentives, such as tax credits or reimbursement costs, that will help increase the number of kidneys available for transplant. Bills are being considered by state legislators in California, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky,



*Those testifying in favor of LB 1190 included Kelly Goss, DPC Western Region Advocacy Director, as well as local activists Steve and Jean Kay of North Platte (Courtesy of Sara Kay)*

Massachusetts, Michigan, Ohio, Nebraska, New Jersey, New York, North and South Carolina, Virginia, and West Virginia.

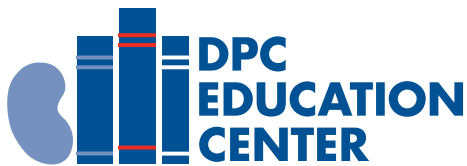
How can you help? We are always looking for DPC Patient Ambassadors to share their stories by writing letters to legislators, testifying at committee hearings, and participating in advocacy meetings and email Action Alerts that are sent to legislators encouraging them to support legislation. A big shout out to DPC Patient Ambassadors Michael Peoples (Colorado), James "Hap" O. Strunk (Kentucky), Tangela Robinson (Georgia), Jim Myers (Indiana), Angela Gaskell (North Carolina), Gwendolyn Snell (Ohio), Gene Blankenship

(Oklahoma), Theodore Chaplin (Rhode Island) and DPC Board Members Maria Robinson (Maryland) and Vanessa Evans (Massachusetts) for their efforts with policy makers or sharing their stories in letters of support for legislation that will help improve the lives of dialysis patients.

Building strong relationships with policy makers through the legislative process is how DPC can achieve success for its members. DPC members play a crucial role in educating policy makers and elevating the patient voice. To learn more about how you can help DPC's state advocacy program, visit DPC's website to find your state's Medigap status and to Get Involved with DPC.

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Find you state's Medigap status: [www.www.dialysispatients.org/medigap](http://www.www.dialysispatients.org/medigap)  
Get Involved with DPC: [www.dialysispatients.org/get-involved/](http://www.dialysispatients.org/get-involved/)



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# Kidney Disease and the Family

All parents desire for their children to be happy and healthy. So, finding out that your child has kidney disease can leave you and your child feeling sad, confused, and scared. This free course, developed in partnership with the American Psychological Association, will help you learn more about how your child's mental health may be impacted by this diagnosis and what parents can do to help them cope. It will also offer tips for siblings and parents.



Check out the course at:

[www.dpcedcenter.org/resources/online-courses/kidney-disease-and-the-family/](http://www.dpcedcenter.org/resources/online-courses/kidney-disease-and-the-family/)