

The **Kidney** Citizen

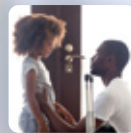
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Dialysis Patients and COVID 19: Should I get the Vaccine?

[Read on page 4](#) →



How to Prepare your Child for a Hospitalization

[Read on page 10](#) →



New Organ Transplant Guideline

[Read on page 9](#) →

President's Message

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I want to thank our Board of Directors, staff, and our Dialysis Patient Community for this opportunity to serve you as the new President of DPC's Education Center. I want to thank Nancy Scott (our founder) for creating a space for our organization to educate and deliver the tools needed to fight this illness. Her shoes will be tough to fill so my goal will be to continue in her footsteps and carry on our mission to empower individuals through education, to improve kidney patients' quality of life and reduce the occurrence of end stage renal disease (ESRD).



As a kidney transplant recipient, who suffered from ESRD, I know firsthand the importance of patient education and the critical role it plays in improving our health. My goal is that we share our experiences with others in various communities, who may be unaware of our fight. That way we can better prepare patients to take the necessary steps to improve their self-care and possibly become transplant recipients.

As the world is in a race to improve the fight against COVID-19, U.S. President Biden signed an executive order that requires our government to take meaningful steps to prevent and reduce the number of patients that contract COVID-19. He also laid out his COVID-19 vaccination plan. As kidney patients, we should take all precautions to follow the CDC guidelines of wearing a mask while receiving treatments in all clinical settings. Patients should follow CDC's guidelines for wearing gloves which will vary by situation. Usually, patients are not required to wear gloves during dialysis treatment. You can find more information about when to wear gloves at <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/gloves.html>. Kidney disease and transplant patients who received the vaccine, who are waiting for the vaccine or who decide not to receive the vaccine still must remember to minimize their risk of exposure.

The DPC Education Center's mission is to educate our community with the knowledge you need to make educated decisions about your healthcare. In the words of Hrant Jamgochian, our DPC Chief Executive Officer, "disease advocacy transcends politics." As advocates and concerned citizens, it is our responsibility to focus on ensuring the best quality of life for all patients. Do your research, seek your providers for counsel and expert advice to help assist you in making the right decision for your health. We at the DPC Education Center urge you to be proactive in your healthcare. I cannot stress enough how important it is to do research and educate yourself about your health. Looking beyond COVID-19, we need to detect kidney disease earlier so patients can have a chance to slow its progression and potentially avoid kidney failure. Approximately 80 million adults are at risk for kidney disease, mostly due to diabetes, hypertension, and cardiovascular disease.

We will also continue to provide information and programs about kidney disease, treatment choices, patient empowerment, communication, medical advancements and tips and tools you can use to improve your health outcomes. I want to thank the kidney community for its continued support with getting out our critical information and spreading the word about our educational content. I hope I can count on your support as we fulfill our mission. I will continue to advocate for us because there is still a lot of work to be done to raise awareness and inform the community about kidney disease. It is an honor to accept this position and to help educate our community, as it will not only help save lives but also my own.

Merida Bourjolly



How I Cope During the COVID-19 Pandemic

By Nina Kasl,
Dialysis Patient

This pandemic has us isolated from things we used to enjoy!

We are unable to visit our friends and families. It is not going to go away anytime soon. Just taking walks by myself was not making me good at all. I knew then I needed to do something.

That something had to be done. I was tired of the isolation I felt. I needed something that I could do on my own or with the immediate family. I made an idea sheet. It showed me what I can do.

I found journaling as a way of expressing myself. You can yell, scream, shout, and cry. No one cares. You can show it to your family, so they understand how and why you feel that way. It is especially a great recall when and if you talk to a counselor.

Working a puzzle is a great way to enjoy spending time alone or with family. You might in fact like playing games with the kids or grandkids.

I love to color. They have adult coloring books. Mandalas and numerous other things. So, get colored pencils out and relax.

Taking care of a plant. Talk to it give it a name. It does not talk back to you and listens to what you say without judging you.

If you have Facebook find a crocheting group, wood working group. Cricut group. Etc.

I learned diamond painting. You can find the kits on Amazon.

A Davita support group is online. They are on Facebook. These people are facing dialysis and pandemic issues. We call ourselves the dialysis warriors. We help

each other through our issues.

Kidney failure patients have so much frustration. Wanting to get on the list. Trying to do everyday things and feeling like a burden to their families. Or the families do not know how to help or what to say.

We go through so many emotions. It is not just emotions it is grief. The stages of grief we go through many times.

Find someone you can confide in. A friend, clergyman. Or what I did is to turn to a therapist. We all need someone to confide in at some time in their life.

As I said I talk to a therapist. She listens to what I say. She will not talk to my family and keeps it between us only. If I want my family to hear what I am going through she helps mediate. There is no judgement just ways to cope with ESRD.



Dialysis Patients and COVID-19:

Should I get the vaccine? If I get the virus, should I take the antibody treatment?

By Alan S. Kliger,
M.D., Clinical Professor of Medicine, Yale School of Medicine, and Co-Chair, American Society of Nephrology (ASN) COVID-19 Response Team. (Updated March 2, 2021)

As 2021 unfolds, the COVID-19 pandemic continues. Dialysis patients continue to isolate at home, socially distance from family and friends, use face coverings and precautions

traveling to dialysis and in the unit. How will this pandemic end? Many patients have important questions about the new vaccines and about new treatments for the infection.

First, some facts about the vaccines:

1. What is a vaccine? An injected vaccine is designed to stimulate your immune system to produce antibodies that attack and kill the virus invading your body. Our immune systems help defend

us from invading organisms. When a new virus attacks the body, cells of the immune system are stimulated to make specialized proteins called antibodies, that recognize the invading virus particles, attach to the virus particles and destroy them. It takes days or weeks for the immune system to develop these specific antibodies, so they are most useful to prevent re-infection of that same virus after

you recover from a first viral illness. Vaccines are given to “jump-start” the immune system to produce these antibodies before the first virus infection, so that they go to work immediately if you catch the virus.

2. Can you get COVID-19 from the vaccine injection? No - the vaccine does not contain virus that causes COVID-19. The Pfizer and Moderna vaccines contain small particles of the mRNA protein that is manufactured to look exactly like the mRNA of the virus. These particles stimulate the immune system to action, but they cannot cause infection themselves. The Johnson and Johnson vaccine introduces the DNA of COVID-19 spike protein into a harmless virus that enters host cells but cannot replicate inside cells or cause illness. In all vaccines with only the genetic instructions of COVID-19, the virus cannot replicate or cause disease.
3. Is the vaccine safe? Each vaccine manufacturer must examine the effect of the vaccine on thousands of people before the FDA gives permission for their use. The FDA has given emergency use authorization for the current 3 vaccines, after these tests showed that they are safe. Now after several millions of doses administered, there are only a very small handful of people that have had anything worse than sore arms, or occasionally some fever, weakness and achiness for 24 – 48 hours after injection.
4. Does the vaccine work? The data presented to the FDA show that the vaccines are highly effective in preventing COVID-19 infection, preventing hospitalization or death from COVID-19. While the vaccines may not work to prevent virus infection 100% of the time, they virtually eliminate the serious effects of COVID-19 causing hospitalization or death. If these vaccines prevent infection in more than 70% or 80% of people immunized, then a phenomenon called “herd immunity” for the whole population reduces the numbers of infections, and eventually may eliminate it completely.
5. Are there special issues for dialysis patients? Yes – there are 2 special issues for dialysis patients:

- a. Patients with chronic kidney disease, and those on dialysis are at high risk of complications if they catch this virus. A recent publication has shown that chronic kidney disease (CKD) has emerged as the most common risk factor for severe disease, and explains the increased risk of severe COVID-19 for approximately 25% of high-risk individuals worldwide. It is therefore particularly important to prevent this infection in vulnerable CKD and dialysis patients.
- b. The vaccine studies in thousands of people leading to FDA authorization, did not include dialysis patients, or those with known impairment of their immune systems. Thus, the safety and efficacy of these 3 vaccines has not been specifically examined in this population. Most experts agree that the safety and effectiveness shown in the rest of the population likely implies that these vaccines are safe and effective for dialysis patients. Careful collection of data on dialysis patients receiving the vaccine should be done over these next several months.
6. When will dialysis patients be able to receive these vaccines? Each state and many municipalities have the authority to set the priorities for vaccine delivery and administration. The CDC, our nation’s authority for infectious diseases, has recommended a prioritization schedule for who gets the vaccine first. That recommendation is this sequence:

Phase 1a: Health Care Providers and residents in long-term care facilities
 Phase 1b: People 75 years and older (21 million) and front-line workers

Phase 1c: People 65-74 years old (32 million), essential workers and people 16-64 years old with high-risk medical conditions (more than 110 million)

Phase 2: People 16-64 years old without high-risk conditions (less than 86 million)

Therefore, most dialysis patients 75 years and older (phase 1b) already have access to the vaccines -- and some 65 - 75 have also become eligible in most locations. In some states, and localities, dialysis facilities have received vaccine to offer patients. As of early March 2021, the CDC, recognizing the

vulnerability of the dialysis population, is speaking with dialysis companies and the American Society of Nephrology to see if there is a way to get vaccine to more dialysis patients earlier. Each state is different – patients need to find out when they qualify for vaccination from their local authorities.

What are monoclonal antibody treatments for COVID-19 infection?

In November 2020, the FDA gave emergency use authorization for monoclonal antibodies, which reduce the viral load (the number of virus in the body) and the severity of COVID-19. For dialysis patients who have early COVID-19 infection, infusion of this medicine gives antibodies to fight the virus before the body’s own immune system or a vaccine are able to develop your own antibodies. This treatment can prevent the life-threatening complications of COVID-19.



Here are my personal recommendations:

1. I encourage all dialysis patients to speak with your nephrologist and consider getting COVID-19 vaccination as soon as it is available. Given the known risk of COVID-19 infection to dialysis patients, and the data so far available about the vaccines, I believe this is a safe and prudent treatment to consider.
2. If you contract COVID-19 before you get vaccinated, I encourage all dialysis patients to speak with your nephrologist and consider getting an infusion of monoclonal antibodies.
3. I encourage patients residing in states not currently distributing vaccine to dialysis patients to contact your state health departments and legislators to advocate for prompt distribution of vaccine to dialysis patients.



The COVID-19 Vaccine is Finally Here.

**Learn How to Manage Anxiety
and Impatience While You Wait**

By Kirsten Weir

It's been a long and stressful pandemic year. Now that COVID-19 vaccines are becoming available, many people are wrestling with a new burst of emotions: From fear and skepticism to excitement and impatience.

“There is such a range of emotions around the vaccine rollout,” says Elizabeth Christofferson, PhD, a pediatric psychologist and clinical director of transplant psychology at Children’s Hospital of Colorado and an assistant professor at the University of Colorado School of Medicine. “Those emotions are normal and valid — and you can find ways to cope with them.”

Easing Concerns About the Vaccine

Guidelines from the U.S. Centers for Disease Control and Prevention recommend that patients over the age of 16 years (the Moderna, Pfizer and Johnson & Johnson vaccines are not approved for children below 16 years of age) with high-risk medical conditions, including chronic kidney disease and transplant recipients, receive the COVID-19 vaccine in phase 1 of the vaccination process, after healthcare professionals.

But conflicting information has made some people wary about whether the vaccine is safe. For people with chronic kidney disease who are used to being vigilant about their health, that skepticism makes sense. Yet there’s good reason to be optimistic about the vaccine, says Sarah Swartz, MD, medical director of chronic dialysis at Texas Children’s Hospital and an associate professor at Baylor College of Medicine. “The data suggest that when people with chronic kidney disease or transplant recipients get infected with COVID-19, they’re more likely to have a severe infection. The vaccine offers a large chance for protection.”

So far, evidence shows that typical side effects of the vaccine are minimal, such as soreness at the injection site, fatigue, muscle aches, and sometimes a fever that typically lasts no more than a day or two, Swartz says. The vaccines approved so far have been shown to be very effective at preventing infection. And when vaccinated people do catch the virus, they appear to be less likely to experience severe symptoms, she adds. “We strongly urge



our eligible patient population to proceed with vaccination.”

If you’re still feeling anxious, try to make sure you’re gathering information from trusted sources. Instead of relying on friends, family or social media for advice, talk to the medical experts. “If you have any questions or concerns, reach out to your medical team,” Swartz says. “We’re happy to answer questions and make sure your concerns are addressed so that you can make an informed decision with input from a source you trust.”

Managing Stress While You Wait for the Vaccine

While some people are worried about the vaccine, others are eager for the chance to receive it. But the vaccine rollout has gotten off to a slow start, and the process in some communities has been haphazard or confusing. Because of this, you may be feeling frustrated and impatient, or even angry and annoyed at people who have gotten the shot ahead of you.

After a challenging year, those feelings aren’t uncommon. But instead of getting stuck in a cycle of worry, frustration and annoyance, try to remain hopeful, suggests Cortney Taylor Zimmerman, PhD, a licensed psychologist in the renal service and psychology section at Texas Children’s Hospital and assistant professor at Baylor College of Medicine. “This is just another part of the waiting game, but there’s

reason for hope.”

While you wait, you can take steps to manage stress and keep your spirits up.

1. **Keep up healthy habits.** Eating well. Getting regular exercise. Limiting stressful media. Getting enough sleep. If your healthy habits have slipped a little during the pandemic, now’s the time to start getting back in the groove. It’s easier to face the ongoing challenges of COVID if you are rested, nourished and full of energy.
2. **Embrace relaxation techniques.** Activities such as mindfulness meditation, deep breathing, yoga and tai chi are popular because they relax your body and your brain. Not sure where to start? Look for free apps or videos online that can guide you. Or start by just taking time to stop and breathe: Sit down, close your eyes and take 5 or 10 deep breaths in and out.
3. **Name your emotions.** Sometimes, we aren’t sure why we’re feeling down. Figuring out exactly what you’re feeling is a first step toward dealing with it. “Are you anxious? Frustrated? Scared? Naming our feelings can be really powerful,” says Christofferson.
4. **Control what you can.** So much of pandemic life is out of our control. But finding things you can control can help with anxiety. You can make decisions



online games with friends instead of gathering in person. “You have to be thoughtful about how to modify things, but you still have access to those supports,” she adds.

Help for Anxiety and Depression

Unfortunately, getting the vaccine doesn’t mean life will instantly go back to “normal.” The approved vaccines offer a great deal of protection, but they aren’t 100% effective. We also don’t know how long effectiveness will last or if the vaccine’s protection will last as long in transplanted patients who are immunocompromised. And, experts still aren’t sure whether a person who has been vaccinated can spread the virus to others.

“Even after the vaccine, you’ll want to wear a mask and keep your distance, and set limits on what activities you feel safe doing,” says Christofferson.

This may sound disappointing, having to be careful even after getting the vaccine. But you’ve made it this far, and the pandemic won’t last forever. By focusing on healthy coping strategies, you can get over each remaining hurdle as it comes.

And you don’t have to get there all by yourself. “If it feels like anxiety, depression or stress is interfering with your daily life, or you just feel you need more support, it’s important to seek help from a mental health professional,” says Christofferson. The social worker or psychology team at your clinic or hospital should be able to help you connect with a therapist or counselor. You can also ask your doctor for resources.

“This is the time to use all of our stress management strategies,” Christofferson adds. “We can’t let our guard down yet, but there is light at the end of the tunnel.”

about where you go, who you interact with and what you need to feel safe. “Instead of thinking of isolating as being stuck in your house, think of it as choosing to social distance in order to take control of your health,” Zimmerman says. “Similarly, wearing a mask and getting a vaccine are choices you make to stay healthy.”

5. **Be prepared.** Another way to take control is to do what you can to prepare for the vaccine. Talk to your doctor if you have any questions. Spend some time gathering information about how to make a vaccine appointment or sign up on a vaccine waiting list. You can’t make the vaccine become available any sooner, but you can do what you can to prepare.
6. **Distract yourself.** Once you’ve done all you can to take control, try to distract yourself from the worry of waiting. Take a break from reading the news. Stop refreshing your social media feed to find out who is getting vaccinated. Instead, focus on other goals, hobbies and healthy habits.
7. **Imagine the future.** Some people find calm in imagining what they’ll do when the pandemic is over — even

if you aren’t quite sure when those plans will happen. Think about trips you might take or meals you can share with family. “Thinking about those future goals can provide a huge boost in wellbeing,” Zimmerman says.

8. **Revisit the past.** Acknowledge how you feel about missing major events over the past year, such as family reunions, weddings or even going back to school. But instead of dwelling on what you’ve missed, draw on those experiences to remind yourself of how resilient you are. “Think about how you overcame those circumstances and what coping strategies helped you get through them,” Zimmerman says. “Think about all the strengths you have to draw on, and how you can apply them now.” You might have to make some modifications, like playing

Resources

Vaccinate with Confidence from the Centers for Disease Control and Prevention
Coping with the Diagnosis of a Chronic Illness from the American Psychological Association

This content was developed jointly by the American Psychological Association (APA) as part of a partnership with Dialysis Patient Citizens to educate dialysis patients and their families on the psychological and emotional aspects of managing kidney disease.

New Organ Transplant Guideline Promotes Patient Safety, Organ Availability

By **Sridhar Basavaraju**, MD, FACEP, CDR-USPHS and **Heather Ewing Ogle**, MA, MPH

In the United States, there are approximately 90,000 patients with end-stage renal disease waiting for a transplant. For those patients, a kidney transplant could substantially improve their quality of life. Unfortunately, an organ offer may not be available for every patient in need because of the length of the waiting list.

With guidance from the Centers for Disease Control and Prevention (CDC), the U.S. Public Health Service released a new guideline in 2020 that may increase the number of available organs for those in need of a transplant. The recommendations in the new guideline reflect recent improvements to organ donor screening technology for HIV, hepatitis B, and hepatitis C. The guideline will help patients and their healthcare providers feel confident that increased safety measures are in place so that all usable organs can be transplanted safely.

New Testing Requirements

The new guideline has the following recommendations for rigorous testing of organ donors and recipients for HIV, hepatitis B virus, and hepatitis C virus.

All **organ donors** (living and deceased) should be tested:

- Before organ transplant

All **organ recipients** should be tested:

- During the transplant medical evaluation process
- Shortly before transplant
- 4-8 weeks after transplant

The new guideline recommends that the most accurate licensed or approved tests be used for all organ donors. These tests are nucleic acid tests, sometimes called NAT, and they are very accurate.



New Testing Recommendations Improve Patient Safety

The new testing recommendations for organ donors and transplant candidates have a number of benefits for patient safety. Using the most accurate licensed tests means that if an organ donor has HIV, hepatitis B virus, or hepatitis C virus infection, it is very likely it will be detected before transplant.

In the very rare case that an infection spreads from an organ donor to an organ recipient during a transplant, healthcare providers following the new testing recommendations will identify this infection promptly so that treatment can begin immediately. Highly effective therapies have been developed for HIV and hepatitis B virus, and a cure for hepatitis C virus is available.

Hepatitis B Vaccination

The new guideline suggests that during the transplant medical evaluation process, healthcare providers should assess each patient's hepatitis B vaccination status. When possible, transplant healthcare providers can use hepatitis B vaccination

in addition to previously described testing to reduce the risk of infection from donors to recipients.

Understanding Risks and Benefits

The chance of getting HIV, hepatitis B virus, or hepatitis C virus infection through a transplant is very low. With the new testing recommendations, any HIV, hepatitis B virus, or C virus infection as a result of transplant will be quickly identified so therapy may begin.

It's important for transplant patients to have individual risk and benefit conversations with their healthcare team. Studies have shown that patients who accept organ offers, regardless of the history of the donor, have a higher chance of survival than those who decline organ offers. In some cases, patients who decline an organ offer may not receive another offer, may be too sick to accept another offer, or may receive an offer from a donor with a similar history.

For additional information, visit [cdc.gov/transplantsafety](https://www.cdc.gov/transplantsafety).



How to Prepare Your Child for a Hospitalization

By Shani Thornton,
MS, CCLS, RWWP

When your child has a chronic illness, hospitalizations and urgent care visits may become more frequent. Feeling prepared for these medical admissions can help ease anxiety

and fear. Here are a few tips to help create a plan for your family.

Emergency Visit

Pack a bag that can easily be accessed during a medical crisis. The emergency go-bag should include extra clothes, comfort items,

small toys, activities, snacks, phone charger, medical records, emergency contacts, pen and paper. Many families leave their go-bag in their car or have a specific location within their home. It can also be helpful to leave a reminder note to grab items that may not already be packed, such as a phone, tablet, and wallet.

Additional Resources

Children's Books:

First Time Hospital

By, Jess Stockham

Going to the Hospital

By, Fred Rodgers

Going to the Hospital...What Will I

See? By, Jaynie R. Wood

Surgery on Sunday By, Kat Harrison

Taking Your Child to the Doctor or

Hospital By, Patricia Weiner

The Hospital Bedtime Story

By, Jessica Ehret



Hospital Admission

When your child has an upcoming medical procedure that will involve an overnight stay, help them feel prepared by including them. Talk to them about what they will experience in words that they can understand. It is helpful to be honest and answer their questions to the best of your knowledge.

Infants (0-12mos)

Caregivers can help their infants feel prepared by making sure they have comfort items packed, such as a soft blanket, plush toy and pacifier. Infants are able to pick up on their caregiver's emotional responses, so it's important to express confidence and security. When a caregiver is distressed, infants will also respond in a similar way. Distraction items such as bubbles, board books and singing a lullaby can help ease their fears.

Toddlers (1-3 years)

For toddlers, it's best to tell them a day before their admission. Use very simple words that they can understand. It is also recommended to incorporate medical play and items that they may see or experience. Reading books and watching short animated videos about going to the hospital can also help. Pack a bag with comfort items, small toys, and bubbles. Providing opportunities for them to make choices, will also give them a sense of control.

Preschool (3-5 years)

For preschool aged children it is helpful to tell them a few days in advance. Incorporating medical play, books, videos and even creating a short social story about what they will experience

is beneficial. Remember to use simple words that they can understand. Explain what they will experience using their five senses. For example, you will have a blood pressure cuff on your arm. It may feel like a tight hug for a few seconds. You can choose to hold my hand or pretend to blow out birthday candles.

Help your child decide what comfort items they would like to pack. If you are bringing a tablet, it may be helpful to load it with some new games or movies. If the hospital admission is for more than a few days, your child may want to pack their own pillow case, stuffed animal or blanket. It's also helpful to have a small photo album with pictures of family members and pets that your child can look at.

School Age (6-11 years)

Children who are school age should be told about the admission 5-7 days in advance. They may have more questions about the procedure, length of hospital stay, and if it will be painful. Provide them with honest information and validate their feelings. You can begin to help them communicate with their medical team and advocate for themselves. For example, "These are great questions you have. I

think you should ask the nurse or doctor at your pre-op appointment." School age children can also pack comfort items, books, tablets, headphones and music.

Teens (12-18years)

Telling teens at least a week in advance is ideal. They should have an active role in their medical care, communicating and advocating for their needs with the medical team. They may choose to pack toiletries, comfort items, tablets and a phone. It is important to provide them with privacy during their hospital admission. Having an open dialogue about when they would like you at bedside and when they need a break, should be discussed.

Shani Thornton, MS, CCLS, RWWP is a Certified Child Life Specialist and a parent of two boys. She provides child life services through her private practice, in Northern California. She supports families coping with life's challenges of illness, loss, trauma, and transitions. Through therapeutic play, creative arts, education, and emotional support, she helps children process these challenges and create a coping plan to best support their needs. She offers in-home visits, phone/virtual consultations, caregiver workshops, and support to community programs and schools. She is also a Registered Wonders & Worries Provider, serving children who have a loved one with a medical diagnosis. She published a children's preparation book, "It's Time For Your Checkup: What to expect when going to a doctor visit" and is a current Board Member of the Sacramento Chapter of California Play Therapy Association. She can be reached at ChildLifeMommy.com.





DPC's State Advocacy Program Works to Advance State Policies that Improve Dialysis Patient Outcomes

By Kelly Goss,
J.D., LL.M., Western Region Advocacy Director

Historically, health policy issues that impact End Stage Renal Disease (ESRD) patients have largely been focused at the federal level since the vast majority of ESRD patients are on Medicare, a federally-run health insurance program, as their primary insurer. Hence, much of the decision-making with regard to ESRD policies has come either from Congress or from within the U.S. Department of Health and Human Services (HHS) since both have oversight of the Medicare program.

However, in recent years, states have become more actively engaged in health policy legislation, in large part due to their expanded role in the development and implementation of the state health care exchanges following the passage of the Affordable Care Act as well as other political dynamics at play. Rather than continue to have a narrow scope focused primarily on state Medicaid programs and budget issues, several states have begun to introduce broader legislation and regulatory policies that would impact ESRD patients at a much larger level. As a result, DPC has shifted more attention to state policy efforts over the past few years, and in 2019 established a state advocacy program that now includes two dedicated, full-time staff who are focused on state policy issues and government relations across the country.

Although DPC's state advocacy program is still in its infancy, its' staff have already helped lobby legislators to defeat state legislation that threatened patient access to care and vital financial resources to help patients afford their insurance premiums. DPC staff have also made inroads educating policy makers about dialysis patients' needs and have been working with coalition partners to help introduce and advance legislation that provide more support for ESRD patients and lead to better patient outcomes. Examples of such legislation include: expanding access

to Medicare supplemental insurance, or Medigap, for ESRD patients under age 65; increasing caretaker support to assist with home dialysis so that more patients may opt for home dialysis; ensuring protections and benefits for living organ donors so as to increase the supply of kidneys available for transplant; establishing kidney disease prevention and education task forces to increase awareness, slow disease progression and help patients better navigate their treatment options; and supporting telehealth expansion that includes ESRD services so that dialysis

education efforts on behalf of patients with kidney disease and their families. Moreover, it has also enabled us to begin to identify key legislators across the states who can be champions for dialysis patients and in helping us build a stronger base of support across the country to advance the issues important to our patient members while involving our members in the process.

So while DPC's state advocacy program is still relatively new, it is rapidly gaining traction through its engagement efforts with state legislators and other policy stakeholders to educate them on our policy priorities that will lead to



better health outcomes for dialysis patients. We look forward to our continued work with our Patient Ambassadors and Board Members to elevate the voice of ESRD patients and advance our state and federal advocacy priorities, and we encourage those of you not already engaged to reach out to us and to get more involved.

patients have greater flexibility to ensure continued access to vital care.

The COVID-19 pandemic has crippled many state budgets, temporarily halted state legislatures' ability to focus on a plethora of issues unrelated to COVID-19 and presented challenges to engaging face-to-face with state law makers. However, it has also presented an unexpected opportunity for DPC state advocacy staff to focus on relationship-building activities with state legislators and their staff by serving as a helpful resource of COVID-19 information specific to dialysis and transplant patients. This, in turn, has increased awareness about DPC as a valuable patient-led advocacy organization engaged in policy and

For more information regarding DPC's policy priorities, please visit the policy section of our website: <https://www.dialysispatients.org/policy-issues/>.

For general ESRD information and a list of resources in your state, please visit: <https://www.dpcedcenter.org/resources/state-by-state-resources/>.

To join DPC or apply for our Patient Ambassador program to help elevate the voice of dialysis patients, please visit: <https://www.dialysispatients.org/get-involved/>.



ENCOURAGE YOUR FRIENDS AND FAMILY TO JOIN OUR COMMUNITY!

Invite your friends and family to become members of our affiliate organization – Dialysis Patient Citizens (DPC). Membership is free and open to all dialysis and kidney disease patients as well as their families. Our goal is to help empower you to live your life to the fullest, which is why we are sharing this excellent publication

with you. However, we know there are more who can benefit from being a part of our community, including others in your support system. We also know there is strength in numbers, when we tell our lawmakers about the issues that matter to patients. DPC helps our members tell their stories and share their concerns with policy makers.

We also provide tools and resources to help them manage their health. Working together we help to create a unified voice to make a difference with our elected officials to help improve your quality of life. So, what are you waiting for? Encourage your loved ones to join today and help us build a stronger kidney community together!

<https://www.dialysispatients.org/get-involved/join-dpc/general-membership/>

The DPC Education Center has an additional section on its website for Spanish Resources. We have translated our past Kidney Citizen articles and categorized them by topic for easy reference. For example, you will find articles under the topics of Dialysis, Treatment, Transplant, Quality of Life, Diet/Nutrition/ Exercise, Peer Support, Travel, Relationships, Advocacy, Other Illnesses and Advance Care Planning. You will also find the English translations there as well. Check out our updated Spanish Resource page at

SPANISH RESOURCES AVAILABLE!



<https://www.dpcedcenter.org/resources/spanish/>



Join Us by Telephone for Our New Program!

By Kathi Niccum,
EdD, Education Director

In March we launched our first **Patient Support Group** meeting by telephone. Having a support group has been one of our goals for years and we are happy to announce it is now a reality. We chose to have the group meet by phone instead of online in a Zoom meeting because we think most people use the telephone. And we want the support group to be available to all patients at any stage of kidney disease and to their families. On the second Tuesday of each month, at 3:00 pm Eastern, you can join in the conversation or just listen during the one-hour meeting. The facilitator for the group is a kidney patient, who is our past board president for the DPC Education Center, and she will be joined by a DPC staff member on the calls. In addition, there will usually be a different “professional guest” (doctor, nurse, social worker, dietitian, psychologist, etc.) each month. To learn more about each month’s call, visit our web page at <https://www.dpcedcenter.org/news-events/dpc-support-group/>.

Some people will be wondering why they should consider joining a support group.



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) 808-5953
Enter Meeting Code: 253 841 3353

cil DPC EDUCATION CENTER Learn more and RSVP at www.dpcedcenter.org

The advantages are many and it is hard to come up with any reasons not to join. At the top of the list is that you will learn more about kidney disease, know you are not alone, and that hope exists. The telephone support group means you do not have to travel, you do not have to dress up, and you can even use your phone’s speaker if you do not want to hold the phone! You can listen to the experiences of others, share tips that work for you which might then help someone else, and ask questions or listen to the professional guest on the call. You can both learn from others and others can learn from you. You can talk or listen – no one will put you on the spot to share your ideas or your feelings.

The group works because people are respectful of each other. Only one person talks at a time. It is not a gripe session or a time to complain about facilities or staff. It is a time to know that you are not alone in your journey and that there is hope even when there are challenges to overcome. Learning new information helps us feel more confident and in control of the choices we make. The ideas and tips from others who have walked the path of kidney disease are invaluable. We hope you will join us!



Cystinosis: A Rare and Under-Recognized Cause of Kidney Failure

By Ladan Golestaneh,
MD, MS

What is Cystinosis?

Cystinosis, or Nephropathic Cystinosis, is a rare genetic disease that affects boys and girls equally and causes a defect in the way that lysosomes (small organelles in cells that remove waste products) are able to remove an amino acid (protein subunit) called Cystine.¹⁻⁴ The name of the defected gene is

CTNS which affects “Cystinosis”, the protein that normally takes Cystine out of the lysosome. As a result of this defect, Cystine accumulates in the cells of various organs and tissues of the body and causes extensive damage. The disease is progressive, meaning it gets worse with time.⁵ Cystinosis is passed down to affected individuals through an autosomal recessive gene. This means that if both parents are carriers of the CTNS gene (meaning they themselves are not affected but carry the mutation on their

chromosomes 17), then their children have a 1 in 4 chance of getting the disease.^{1,4}

There are three forms of Cystinosis depending on the age at which disease/symptoms occur: 1) infantile (95% of cases), 2) adolescent (late) onset and 3) adult onset.⁵ The rest of this article refers to the infantile form.

The organs most commonly affected are the kidneys, the eyes (causing blindness

and damage to the cornea), the pancreas (leading to diabetes), the thyroid gland (leading to hypothyroidism), the skeletal muscles leading to muscle wasting and swallowing difficulty and the lungs, leading to difficulty breathing.^{1-4,6} (Figure 1)

How is it diagnosed?

Cystinosis is not a common disorder, affecting only 600 individuals in the United States. As a result, it is hard to diagnose. It takes a very astute pediatrician to be able to diagnose affected individuals at a very young age. An elevated Cystine content in white blood cells (granulocytes, a type of white blood cell) makes the diagnosis of Cystinosis. This test can be drawn by any lab or doctor's office but needs to be sent to a special reference lab immediately after collection, for measurement of Cystine content.^{1,4} Genetic testing for CTNS mutations is also available.

What are manifestations of Cystinosis?

Kidneys

The first organ system to be affected is the kidney system which is why pediatric nephrologists are usually the doctors to diagnose it.^{3,4} One of the first signs of the disease is the production of copious amounts of urine with the leakage of electrolytes, bicarbonate, phosphorus, water and salt from the body. This is known as Fanconi syndrome, a condition that can happen with other kidney problems, but is most common and severe with Cystinosis. This condition occurs anywhere from 3-18 months of age in 'Infantile Cystinosis'. These children become dehydrated and malnourished.^{1,4}

If left untreated, Cystinosis kidney damage leads to severe dehydration and electrolyte imbalances, weight loss and malnutrition and eventual end stage kidney disease (ESKD). Affected children have low appetite, ongoing nausea and have difficulty feeding. With the development of Fanconi syndrome, the blood becomes acidic as well which leads to worsening malnutrition. Because of the phosphorus wasting in the urine and Vitamin D deficiency, children can also develop Rickets (weak bones) which can result in bone pain and growth problems.^{2,3}

ESKD usually develops by 10 years of age and is treated with routine dialysis.

Dialysis is designed to replace the function of the kidneys such as waste removal and fluid removal, but those individuals with residual urine output require less ultrafiltration with dialysis.¹ In this way the indications for dialysis with Cystinosis are similar to other causes of ESKD.^{2,3,5} Patients with Cystinosis can also receive kidney transplants (usually from family members) as treatment for their ESKD. While the medication burden imposed by the receipt of a kidney transplant can be overwhelming, fortunately the effects of Cystinosis never recur in the transplanted kidney.⁴ In effect, patients with ESKD who receive a kidney transplant do not exhibit the complications of Fanconi syndrome but they still have manifestations of Cystinosis in their other organs and must remain vigilant with remaining adherent to their Cystine lowering and anti-rejection transplant medications.

Eyes and other organs

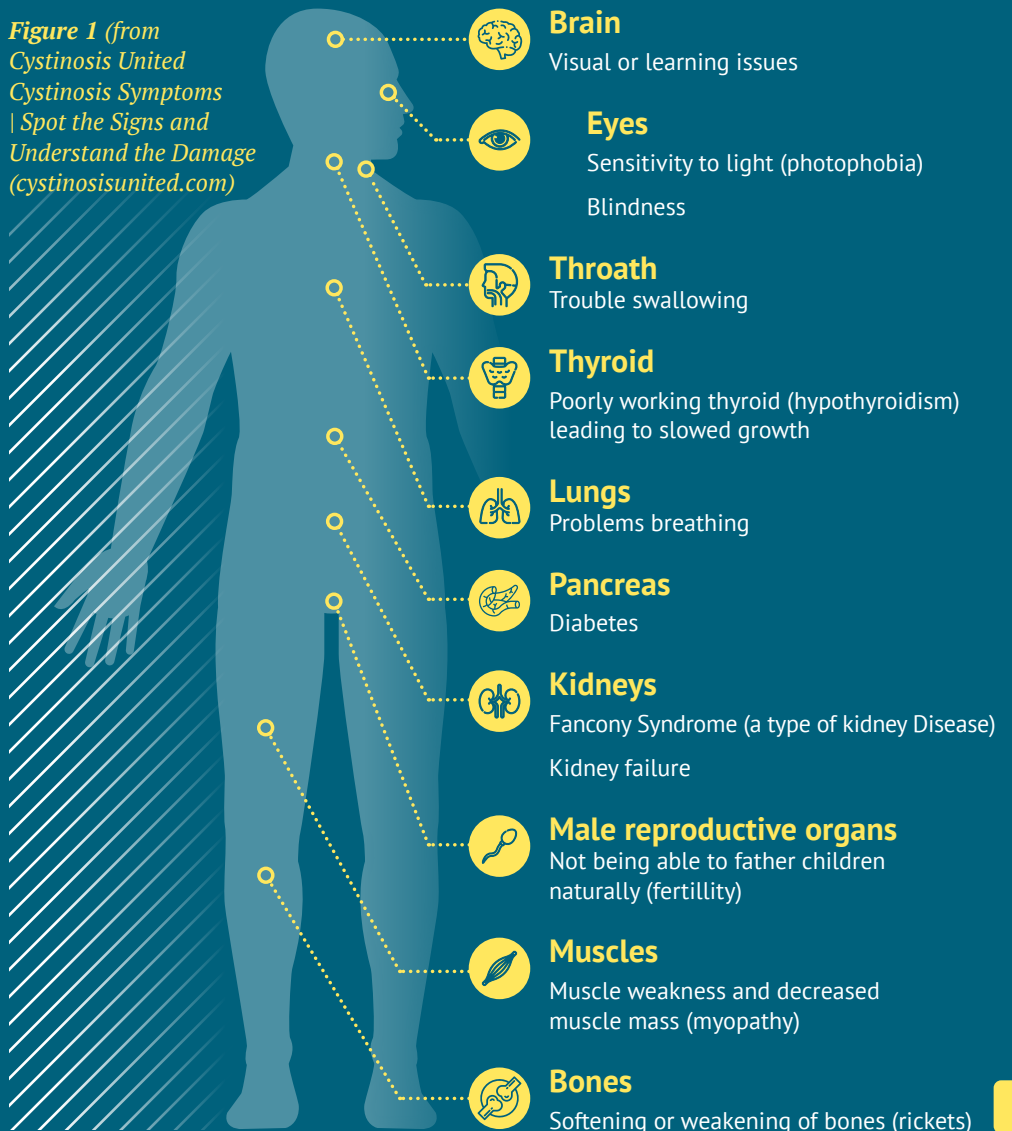
Cystine crystals accumulate in the eyes which makes it hard for affected patients to tolerate light (photosensitivity). The crystal deposits can damage the surface of the eyes and eventually lead to ulceration of the cornea and damage to the retina and blindness.^{2,5,6}

Cystinosis can also result in hormone deficiencies such as thyroid, insulin (diabetes) and testosterone because of the effect of Cystine accumulation in the thyroid, pancreas gland and the gonads.^{2,5,6}

Cystinosis also causes muscle weakness and wasting causing mobility problems and difficulty swallowing.^{2,5,6}

Finally, while individuals with Cystinosis have normal intelligence they may have problems with visual/spatial thinking and certain neuropathies.²

Figure 1 (from Cystinosis United Cystinosis Symptoms | Spot the Signs and Understand the Damage (cystinosisunited.com))





be more hands on and who have more resources available) to adult providers.

The future

Because of advances in research and therapies, Cystinosis can be well managed if Cysteamine therapy is started early and the patient is managed by a team of providers well versed in all aspects of the disease. However, ESKD and other organ manifestations of the disease though delayed with therapy, are inevitable. Also, the burden of adherence to available therapies make quality of life more difficult to attain. Major strides have been made by researcher who are studying ways to treat Cystinosis. They are focusing on transplanting stem cells (cells that have the capacity to turn into any type of organ cell) with normal Cystinosis (the protein that is missing in patients with Cystinosis) function into affected patients. But it is still too early to declare this approach a success.²

My Personal Story

As an adult nephrologist, I have had the privilege of caring for those individuals with Cystinosis who have reached adulthood. They were transitioned to me from the pediatric nephrologists in my institution. Initially I had difficulty because I did not have expertise in handling the many needs of these patients, despite the best efforts of the pediatric doctors to educate me. It was the amazing communication, self-management skills of my patients, and their patience with me while I learned how best to care for them, that made our collaboration successful. Today I can boast that my adult Cystinosis patients are extremely high functioning and continue their excellent progress towards living close to normal lifestyles despite the burden of their multifaceted disease.

Treatments for Cystinosis

Thankfully, advances in research have resulted in development of effective therapies for Cystinosis called “Cystine depleting therapy”.⁶ Cysteamine is the main agent and it was approved for use in the 1990s. The most widely used form is “Cystagon™”. If the drug is started at a young age it can delay ESKD up to 10 years. But even if started after ESKD onset, it can prevent complications of Cystinosis that affect other organs. Cystine depleting therapy needs to continue after kidney transplantation.^{2,4} Cysteamine is difficult to take. A typical patient can take up to 6-7 pills every 6 hours throughout the day. The dosing of the medication depends on how much it reduces the level of Cystine in the WBC cells, and these levels are monitored. It also produces side effects like a sulfur smell to the breath and emanating from the body, and nausea and vomiting.⁴ Thankfully a delayed release formulation of Cysteamine (Procysbi™) was introduced in 2013 that allows for every 12 hours.⁶ The pill burden for this formulation, however, remains high. Cysteamine does not help with the eye manifestations of Cystinosis. For that, patients use cysteamine hydrochloride eye drop that dissolve cystine crystals. They have to self-administer drops up to 10 times a day, which is very difficult to follow and for that reason most patients use the medication less frequently.

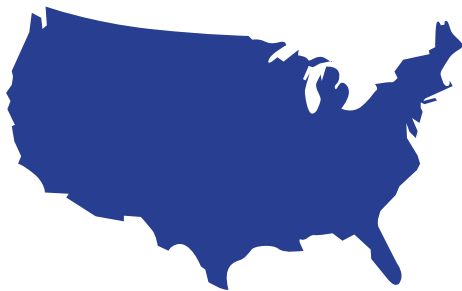
Ultimately, a multidisciplinary team of professionals are needed to care for patients with Cystinosis. These include nephrologists, transplant specialists (for those who are transplanted), endocrinologists (for the thyroid and diabetes issues as well as growth and sex hormone deficiencies), nutritionists (for the malnutrition), neurologists and physical therapists for the muscle weakness and pulmonologists for the breathing issues that may arise, among others. Because the well-being of patients is so indelibly linked to adherence to medication regimens and because these patients face many challenges with this diagnosis and all of its manifestation, special attention should be paid to sustaining mental health and a positive outlook for patients with Cystinosis. This is particularly crucial during the transition from pediatric providers (who tend to

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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](https://www.cystinosisunited.com), and follow us on Facebook to join the conversation. *Scan the QR code!*



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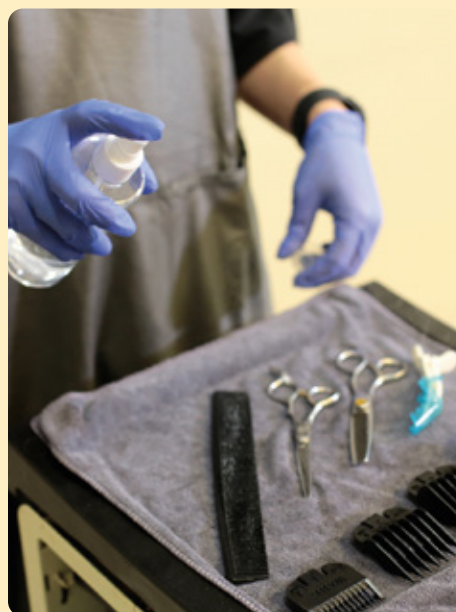
My Experience Working During the COVID-19 Pandemic While Living With A Kidney Transplant

By **Merida Bourjolly**,
DPC Education Center President

Anxiety of coming back

I am sure everyone has felt the impact of the COVID-19 pandemic. This is the first time I have experienced a complete shut down in my industry due to a virus. Additionally, the lockdown provided an opportunity for a pause and a chance to rethink my priorities and what is meaningful.

From a financial perspective, this shut down taught me how to adapt to uncertain economic times. I am really grateful for technology that helped us connect virtually, provided an opportunity to work, and to make it through a stressful time. Sustaining a business without revenue is



not the only financial undertaking I faced; before reopening, I had invested in masks, gloves and social distancing measures for myself and my clients. My need to provide for my family made me nervous about balancing my own health and their safety. Earning a living meant sending myself back into an environment that left me exposed while hearing the COVID-19 numbers were increasing.

Grooming is a treasured jewel to many, there is no question that clients miss their stylists. Clients reached out during the lockdown, and a few clients asked me to make house calls which would have put my health at risk. Few professional encounters require prolonged bouts of close contact like appointments at hair or beauty salons. Customers are

clamoring to fix gray roots, shaggy beards and chipped nails in reopened salons after months in lockdown, despite stark changes to how these services can now be offered.

Hoping that everyone would be truthful about their condition

My first day back to work was filled with so many emotions such as being excited to return to some sort of normalcy. Yet my mind was filled with anxiety of being at risk of contracting COVID-19. I was happy to get back to what I love doing which is servicing my clients. I felt comfortable and reassured to return to the salon with the extreme measures I have taken to make sure the clients and myself are safe. In return I hoped that my clients would honor and take the same precautions I was taking to not expose them to COVID-19 and be truthful to protect me.

As a transplant recipient and a Licensed Cosmetologist, I have a new level of anxiety now of catching the virus from people who do not seem sick or have symptoms. I might be exposed to the virus when I provide services to my clients. As stylist we are in close contact with clients, coworkers, vendors, service providers, and delivery people. Transplant patients may be at higher risk for severe complications or fatality from COVID-19 because people who receive a donor kidney are often on immune-suppressing medications making our immune system low. This feeling caused me to research taking further precautions. Such as wearing longer sleeve clothing, supplying the clients with face shields and disposable capes.

After a couple of weeks my brain is accustomed to what to do, to not leave myself exposed due to taking antirejection drugs to avoid compromising my health.

It is especially important, to create a safe space by implementing responsible safeguards and to follow all of CDC guidelines when servicing the clients, especially since I am in the “personal care services” category. To lower the chance of getting the coronavirus that causes COVID-19, transplant patients should follow the CDC’s guidance on how to avoid catching or spreading germs.



I require all who enter the salon to wear a mask and get their temperature checked. I presently wear a face shield and a mask while servicing clients. I do not service walk-in clientele; clients must call in their appointments.

We also have a questionnaire, that customers must fill out upon their arrival. This questionnaire includes detailed questions of a clients travel, in and out of state, their contact or exposure, and all temperatures recorded and kept on file. If the mask becomes wet, visibly soiled, or contaminated at work, we provide new ones to the clients.

I do my best to remember and practice not touching my face, mouth, nose, or eyes after touching different surfaces or frequently touched items such as tables, sinks, combs, cash, or merchandise within the salon. I practice staying at least 6 feet away from clients and coworkers, when possible. We limit gatherings inside the salon, we leave every other styling chair empty and clients are not allowed to bring additional people to their appointments.

Some of these precautions were not difficult for me to get use to because as a transplant recipient wearing a mask in public and at work was a precaution I was familiar with.

We clean and disinfect frequently touched surfaces between each client such as styling chairs, hair washing sinks, massage tables, credit card devices, keypads, all non-porous multi-use tools, such as shears, clippers, nippers, brushes, combs, etc. and other items that clients routinely touch.

It took some time to get used to cleaning and disinfecting the following areas or items on a routine daily basis such as countertops, doorknobs, toilets (including

handles), tables, light switches, phones, faucets, bathroom sinks, keyboards, etc.

I wash my hands regularly with soap and water for at least 20 seconds. I use an alcohol-based hand sanitizer containing at least 60% alcohol if soap and water are not available.

We have signs up that say “Please cover your coughs and sneezes and wash your hands regularly.” Our signs also ask clients if they are experiencing symptoms to stay home.

I also realised that the people that come to me may have the same anxiety and fears of getting their hair done.

Hair salons reopen, and clients rush back. Many beauty salons and barbershops are booked solid with appointments, showing how much grooming is a treasured experience. Perhaps our collective desire for a haircut or nice nails is not so surprising. For many segments of society, beauty services are central to a sense of identity. And heading back to salons after a collective social trauma could be one way to recover some normalcy. In most states, hair salons and beauty parlors reopened earlier than other businesses that were deemed nonessential.

The COVID-19 pandemic has created new challenges in the ways many people work and connect with others, which may raise feelings of stress, anxiety, and depression. Communication was important – explaining to clients that their safety is important to me and why it is important to have protocols implemented to keep all of us protected. That way we can help the customers feel comfortable returning to the salon. Now that COVID-19 vaccinations are more available to more groups of people, they may bring a peace of mind to everyone.

Getting Fit After Transplant

By Collette Powers, MA, RDN, LDN, ACSM EP

First of all, let us start off by saying a huge congratulations! Whether you are preparing for a transplant or already received a kidney transplant, you have taken a pro-active step in your own healthcare. This is a major accomplishment and one worth much recognition. Kudos to you!

As part of the transplant journey, you learn a great deal of information regarding the transplant process. Topics may range between diet management, medication management and organ infection/rejection prevention to name a few, but what about physical activity? Can you exercise after receiving your new kidney? Should you exercise? Is it safe to exercise? These are all great questions that we will dive into addressing right now!

So, to start, why are we talking about exercise? Studies have shown several benefits to partaking of regular physical activity as part of a healthy lifestyle (1,2,3,4). Such benefits include better blood pressure control, improved sleeping patterns, strengthening of muscles and bones, improved blood circulation and increased energy (5,6). Exercise has also been shown to help with managing stress and can help with reaching an ideal healthy body weight. Even more specific to post-kidney transplant recipients, regular aerobic

or “cardio” exercise plays a vital role in decreasing one’s risk for cardiovascular disease and metabolic syndrome. What is metabolic syndrome? Metabolic syndrome is defined as having at least three of the following: high blood pressure, high blood triglyceride levels, low HDL cholesterol (also known as high-density lipoprotein), excess abdominal fat and/or high blood sugar levels (7). Transplant recipients are at an increased risk for developing metabolic syndrome as a result of medication side effects from their anti-rejection medications, changes to dietary habits, and lack of exercise (8). The anti-rejection medications, or immunosuppressants, also can increase one’s risk for bone disease like osteoporosis. Weight-bearing exercises are a great way to combat this by helping to strengthen the bones and supporting muscles. Thus, incorporating various exercise types into your lifestyle can be one pro-active approach in keeping your health on track.

Okay so we know the benefits of exercise and how it can promote better health. However, one study found that less than 60% of transplant recipients participate in the recommended guidelines for physical activity (9). Why is that? A few of the reasons include low confidence level and low self-efficacy, or ability, to start and stay active. Do any of these reasons resonate with you? Keep reading further to learn how to address these concerns to leave you feeling more empowered to be physically active!

To start, let us first review what the recommendations are for physical activity. The Physical Activity Guidelines for Americans and the World Health Organization recommend at least 150 to 300 minutes weekly of moderate-intensity exercise (like brisk walking) or 75 to 150 minutes a week of vigorous-intensity (like jogging) and at least two sessions of strength/resistance training per week (10,11). Now I am not saying go from 0 to 300 minutes. There are many factors to consider when starting and progressing with an exercise plan, what I also call the **START** approach:

1. **Safety.** After receiving a kidney transplant, you may be limited to certain types of activities for the first several weeks as your body heals. Every person’s needs and physical capabilities are different. Some may feel they can walk miles day one where others may need extra support such as partaking of a physical rehabilitation program. **Speak with your healthcare provider about what types of activities and how much you should strive for BEFORE starting.** The Cleveland Clinic has a suggested list of questions to ask your provider (5):
 - a. How much exercise can I do each day?
 - b. How often can I exercise each week?
 - c. What type of exercise should I do?
 - d. What type of activities should I avoid?
 - e. Should I take my medicines at a certain time around my exercise schedule?

Remember, do not exercise if you have a fever or are not feeling well. Stop exercising if you experience shortness of breath, chest pain, dizziness or lightheadedness. Call your doctor if the symptoms do not go away and/or if you notice any swelling (5). Certain immunosuppressants can impact one's muscle coordination so notify your health care provider of any changes you observe (12).

2. **Timing.** Now this topic can be taken into consideration in many ways. First is the time of day for when you plan to be active. Many of the immunosuppressants can have undesirable side effects that can impact your physical activity efforts like nausea or diarrhea. To lower your risk of stomach upset, wait 1 to 1½ hours after eating to partake of physical activity (5,6). As noted above, ask your provider about how to adjust your medication regimen to work with your exercise schedule. Second is in reference to the time of day but with respect to your environment. Immunosuppressants can increase one's skin sensitivity to light and one's risk for skin cancer (8). Be mindful of exercising in direct sun without protection (e.g. hat, sunscreen, etc.). Avoid extreme temperatures (e.g. too hot, cold, or humid) as that can impact your body's ability to naturally cool and interfere with blood circulation to your muscles and organs. Third, you guessed it, also time of day but with respect to how you feel. Some may feel their best in the morning where others need a few hours to "wake up". There is no rule that states you have to exercise at a certain time of day to get the best results. The important thing is to keep yourself safe. Trying to force yourself to exercise when you feel sleepy or fatigued can put you at risk for injury. Plus, who wants to force themselves to do something. Exercise should be an activity you look forward to!

3. **Assessment.** Ask yourself and make arrangements to set yourself up for success to partake of regular exercise. In other words, come up with your plan:

- a. What is my goal? Is it to lose weight, gain strength, manage stress etc.?
- b. What types of activities have I been cleared to do (or not do) by my provider? Which of those activities

- c. Where will I exercise? At home, at a gym, etc.
- d. Do I need any special equipment or space? If at home, do I have space set aside for me to exercise?
- e. What times(s) of day can I set aside to fit in exercise? How much time per day do I have to fit in exercise?

As we discussed earlier, each person's physical abilities will vary. However, an ideal exercise plan includes four components (13):

- Aerobic—walking, bicycling, swimming, dancing
- Strength—lifting weights, toe raises, squats, push-ups
- Flexibility—stretching, yoga, tai chi
- Balance—standing on one leg, walking backwards, heel-toe walking

Discuss with your provider which types of exercises in these categories would be the most appropriate for you. For more in-depth information about these components of exercise, along with supporting resources, check out the resource section at the end of this article!

4. **Rough draft.** So now that you know what your overall goal is and have the things in place to get started, it is time to come up with your rough draft. I call it the rough draft because you may need more revisions or "drafts" until you find that sweet spot that works for you AND THAT IS OKAY!!! If you have ever tried to make a lifestyle change before, you likely know that often it takes going back to the drawing board. Do not get

discouraged! Creating change takes time and is a learning experience. You will learn through trialing what works and does not work for you, whether it is your exercise preferences, abilities, or simply a change in schedule. Hey, life happens!

So, to get started, create your SMART goal. Not to be confused with START as we have been discussing, SMART stands for Specific, Measurable, Attainable, Realistic, and Time-based. Often many focus on the end result and forget about the steps it takes to get there. By focusing on the smaller steps, you can create a more reasonable approach and learn what works for you or what does not. To help illustrate, I will use this example, "I will walk 10 minutes every day before I make dinner for one month."

Specific: what is the exact action that will take place? Answer: walk 10 minutes
Measurable: can I track if I walked 10 minutes? Yes, with a watch, phone, timer, etc. I can also determine if it did it daily by keeping a log, writing on a calendar, etc.
Attainable: is this doable to fit into my schedule? In other words, will this goal work as part of your routine/lifestyle.
Realistic: is this a goal that can realistically be done? Consider being realistic not only in the goal itself but also in how many goals overall you set. For example, is it realistic and setting yourself up for success to work on 2 goals or 10 at a time?
Time-based: when will I plan to reach this goal? I have given myself a timeline of one month. Giving yourself a timeline allows you the opportunity for self-evaluation, which is a vital part of the learning process and also with moving forward with



your journey. For more information and examples of SMART goals, check out these resources.

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- American Kidney Foundation 2014. Making 2014 a Year of SMART Health Goals. Accessed 8 January 2021, <https://www.kidneyfund.org/kidney-today/smart-health-goals.html>.

Triumph. Every time you complete the specific action step and when you reach your timeline, give your self some credit! Positive reinforcement encourages positive behavior. Whether you achieved your goal with flying colors or experienced

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a few hiccups, celebrate yourself for your hard work and for sticking with it. Now that you have reached your timeline, ask yourself are you ready to bump things up or do you need to go back and create a new “rough draft”?

Alright so we have our START approach with our SMART goals, we are ready to get active! To further support you along in your exercise journey, take a look at these following resources. And again, kudos to you for taking charge in your healthcare journey!

Exercise Resources

Check out our newest course, “Exercise and the Benefits to You and Your Kidneys” (14). This course provides more in-depth information about the benefits of exercise, how to get started and progress your exercise plan, suggested workout templates, motivation tips, staying active during the COVID pandemic and more, <https://www.dpcedcenter.org/resources/online-courses/exercise-and-the-benefits-to-you-and-your-kidneys/>

Additional resources you may find helpful:

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What We Learned from Care Partners

By Kathi Niccum,
EdD, Education Director

The 2020 DPC Member Survey included a section for caregivers/care partners. From the 146 respondents, 84% were women and the average age was 55.6 years. The caregivers did much of the grocery or other shopping, the housework, meal preparation, managing finances and helped with transportation and other outside services. But besides playing a key role in managing the household, they also were involved in nursing tasks, helped monitor the severity of their care recipient's condition, helped communicate with health care professionals and helped their care recipient advocate for themselves regarding health care providers, community services, and government agencies.

Caregiving activities may happen gradually or suddenly. Sixty-four percent (64%) of the caregivers in the survey said

they did not have a choice in taking on the responsibility of caregiving. For 20% of the respondents, the emotional stress of caregiving was very much a strain. Many of the caregivers held jobs and 74% had to take time off work, went in late or left early to provide care.

Overall, most caregivers said that their caregiving responsibilities had no effect on their own overall health. However, 27% did say it had a negative impact on their health. One of the most frequent challenges for caregivers was being tired and exhausted. The changing role was also a challenge mentioned over 50% of the time. The care recipient's behavior was also a challenge, especially when the person was too tired to do much or was depressed and moody.

When caregivers were asked what would be most helpful to them as a care partner, 48% said it would help a lot to know ways to improve the quality of life of the person with kidney disease. This was followed by knowing ways to improve their own

quality of life and knowing about caregiver resources with kidney disease.

The DPC Education Center strives to meet the needs of its members. We now have a monthly Telephone Support Group meetings that are open to patients and caregivers on the second Tuesday of each month. Learn more on our web site at <https://www.dpcedcenter.org/news-events/dpc-support-group/>. In addition, there is a section on quality of life at <https://www.dpcedcenter.org/quality-of-life/> and all the monthly patient education webinars, which are recorded, are open to caregivers. The November 2020 webinar specifically was on "Looking Out for the Caregiver." That recording and additional caregiver resources are available at <https://www.dpcedcenter.org/education-webinar/looking-out-for-the-caregiver/>. You may also be interested in our online programs that provide information and a variety of resources, as well as the opportunity to interact with others at <https://www.dpcedcenter.org/resources/online-courses/>.

Ask your Nephrologist: What is happening to my skin and nails?

Keith A. Bellovich, DO

There is a broad range of skin manifestations when having to depend on dialysis. Skin disorders can affect a patient's quality of life and can negatively impact their mental and physical health.

Itching (uremic pruritus) is by far the most common complaint that patients suffer. But dry skin (xerosis cutis) and skin discoloration are also common complaints in patient with severe loss of kidney function. Dry skin is caused by reduction in the size of sweat glands and atrophy of sebaceous or oil producing glands. Dry skin increases the susceptibility to infections and this is aggravated by delayed wound healing of the skin.

Alterations in the color of your skin, in particular darkening of the palms and soles and membranes in your mouth can be seen relatively early during progression of the disease.

Other aspects of the skin for CKD patients include increased susceptibility to low temperatures, increased hair growth on the cheeks and thickening of the eyebrows. The blood flow to your skin is significantly reduced in dialysis patients which results in half and half nails, also called Lindsay's Nails which are typical findings in dialysis patients. This leads to a white discoloration in the half of your nails closest to your body and red/brownish color of the outer aspect of the nails. The discoloration comes from melanin deposition within the nail and excessive development of connective tissue between the nail and bone that reduces blood supply. This usually remains unchanged after

dialysis but may disappear after a kidney transplant.

Hyperpigmentation and pallor are commonly seen in dialysis patients.

Over time, many patients develop a yellowish hue, which has been attributed to retained urochromes and carotene which are substances that are usually excreted by the kidneys. When they accumulate they become deposited in the epidermis and subcutaneous tissues. A brownish hyperpigmentation is also common, mostly in sun-exposed areas. This hyperpigmentation results from an

increase in melanin production because of an increase in poorly dialyzable melanocyte stimulating hormone.

Patients with this condition tend to have a grayish, almost metallic color skin.

Another discoloration can be uremic frost which is a fine white-to-yellow crystalline powder like appearance on the skin surface after sweat dries. When the blood urea nitrogen (BUN) level is very high, the concentration of urea in sweat is increased significantly. Evaporation from sweat results in the deposition of urea crystals on the skin. Uremic frost is commonly found in the beard, face, neck, and trunk. This can be very concerning and must be brought to the attention of your caregivers to insure you are getting adequate dialysis.



Fingernail-discoloration is from Clinical Kidney Journal 2014;7: 418-419

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their experiences and most importantly, showcase the freedom they have in controlling their own destiny and journey. This is powerful and impactful.

The barriers the patient was anticipating soon become less of a concern as they witness another patient sharing their positive experience. The only absolute hurdles to PD are the inability to avoid water, pet/hygiene issues where a room cannot be isolated in a home. Partners are not necessary. The hurdle of bringing healthcare to the home environment is often overblown as family members tend to be very supportive of home-based therapies. It also allows for the family member to remain at home/work and not have the burden of transporting their loved one to dialysis 3x/week or dealing with the post dialysis fatigue and increased hospitalizations associated with in center HD.

There Is No Place Like Home

By **Shaminder Gupta,**
MD, Nephrologist

End Stage Renal Disease (ESRD) is a life changing diagnosis and impacts both the patient and the family.

While waiting for renal transplantation, renal replacement therapy (RRT) is required to sustain life. RRT, also known as dialysis, can be provided either in-center or at home. Home therapies can either be via peritoneum (PD) or via fistula (HHD).

Patients are concerned about their own abilities to provide this life sustaining therapy on their own. This is natural and should be anticipated as a barrier. Most of us, including medical professionals, would also share these apprehensions. Success at home depends on the initial attitude of the patient who is being asked to consider the therapy and depends on how it is delivered initially to the patient.

Common questions include: Is there enough space in my house? What about my partner? What if I have pets? Will it disturb my own family dynamics?

It is natural to have these questions about home dialysis. Space is always a concern, but the reality is that a small amount of private space is needed. This space has to be dedicated to home dialysis and be kept clean and free of pets. Pets are not a dealbreaker. They simply have to be kept

away from areas where home dialysis is performed. For PD patients, this is usually the bedroom. For HHD patients, the supply bags have to be kept in an area away from possible intrusion.

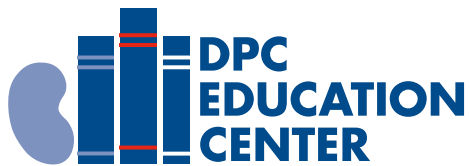
The most important question usually relates to life partners. Life partners are invested in the health of the patient and they usually are also very supportive of any care plan that improves outcomes and quality of life. Patients do not want to burden others with their own health issues; however, it has been my experience that home dialysis improves patient outcomes and this both directly and indirectly affect the partner in a positive way. There is a happier partner, no travel requirements, more time at home together and a more positive attitude towards the treatment plan.

Peritoneal dialysis is very difficult to describe in words to a patient. It is also more daunting when a video is watched about the process. I have found that direct interaction between a perspective patient and an established patient is the most effective way to educate the patient holistically. The established patients had the same questions as the perspective patients and can fully attest to the nature of the treatment, both positive and negative. PD patients often have positive experiences, and this is conveyed at this meeting. The approach also illustrates how patients teaching patients should be utilized in education. PD patients share

HHD patients have similar concerns. They also have additional concerns about self cannulation. This can be overcome by continual support of the patient and care partner. Introduction to other patients who do HHD is imperative in success of this model. Self-cannulation fear abates with strong support of the patient. Family members teaching other family members creates powerful bonds between them and creates bonds between the patient and HHD nurses. The positive experiences of HHD patients when shared with perspective patients helps alleviate the natural fears patients have. Self-care builds confidence in patients and this translates into positive attitudes and improved outcomes.

Home dialysis also better prepares patients for transplantation. Labs are better and patient engagement translates into better transplant candidacy.

Learning to do home dialysis is similar to learning to drive. When learning to drive, it is an overwhelming task, yet most people learn to do it. There are many buttons, sensors, radars, and complex decision making. After a few months of practice, operating the vehicle becomes routine. The key is support for the new driver through supervision and gradual autonomy. Home dialysis proficiency is similar. When given the proper support and timeline, patients can master the therapy and then learn to teach others. Home dialysis nurses and staff provide the support needed to learn and provide the individualized attention necessary to be successful for both the patient and their caregivers.



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New Exercise Course

The DPC Education Center is now offering an online, free-to-use resource center to learn more about Exercise and the Benefits to You and Your Kidneys. In the program, you will be able to identify the four components of a well-balanced exercise program, develop a personalized exercise program, identify some motivators for you to exercise and take the first steps to begin your exercise routine. You will also have the opportunity to tell your story and hear from others about their experiences.



Check out the course at: dpcedcenter.org/exercisecourse