

The **Kidney** Citizen

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As I write the last President's message for 2020, a year filled with many challenges as well as new possibilities, I am reminded of one of Dr. Martin Luther King, Jr's famous quotes. It states, "Our lives begin to end when we are silent about the things that matter." Over the years, and especially now, his quote helps me stay centered and focused on advocating for all renal patients. The COVID-19 pandemic has affected each of us this year, yet we also have seen hope for education and treatment choices for people living with kidney disease.

I joined Dialysis Patient Citizens (DPC) in 2007. I was diagnosed with End-Stage Renal Disease in 2004. I was encouraged by family and medical providers to begin the transplant process. This process included multiple testing and a mammogram. I was then diagnosed with breast cancer. I underwent dialysis and chemotherapy at the same time—delaying the eligibility of transplantation. However, in May 2011, I received a kidney transplant.



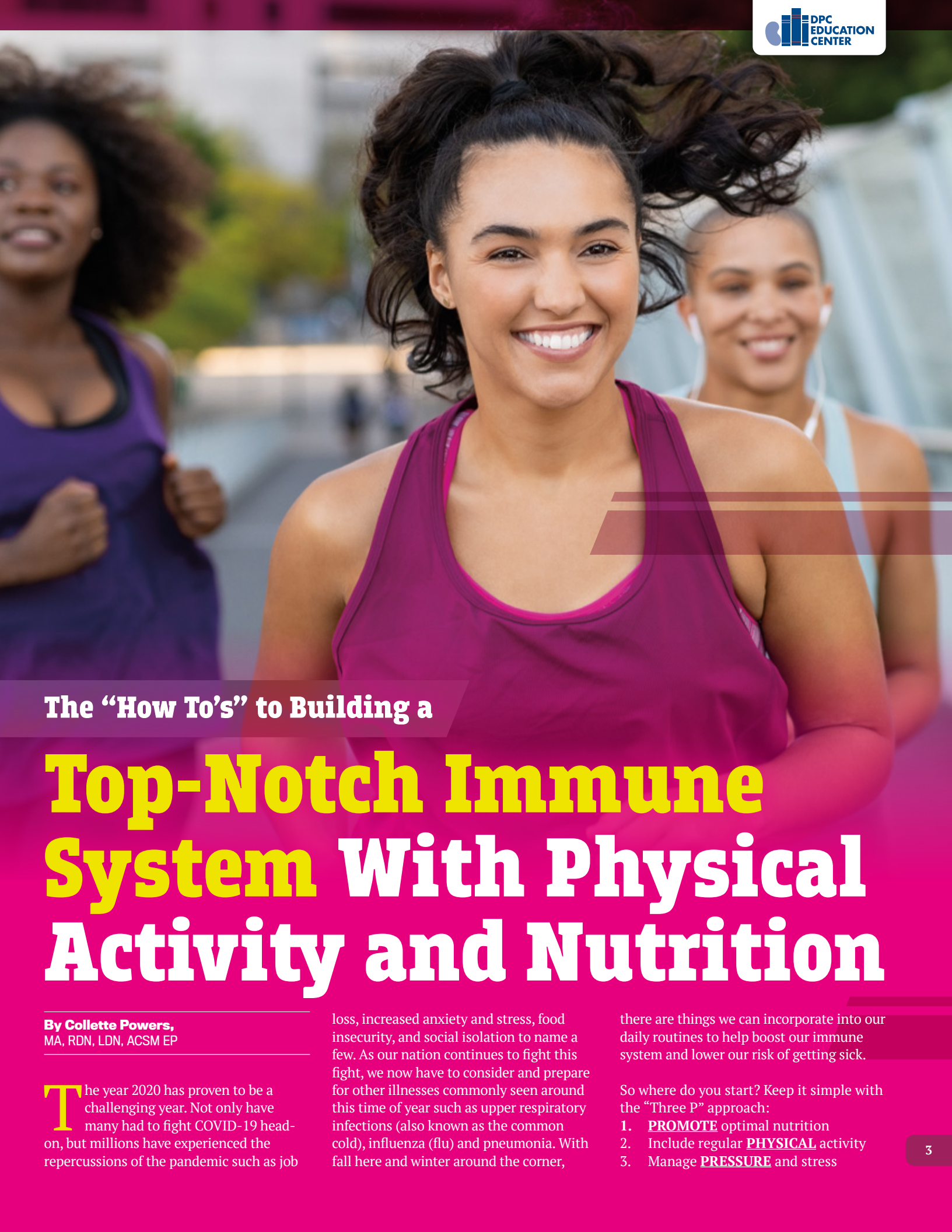
I have served in many board positions at DPC such as: Secretary, Vice President and President. After transplantation, I now serve as President of the Dialysis Patient Citizens Education Center. The Center is dedicated to empowering kidney disease patients through education, with continual collaboration from health professionals. It was founded in 2012 and during my presidency, we have hosted monthly patient education webinars on many unique topics, published this newsletter that includes patient-written articles, updated the web site, sent monthly e-newsletters, and developed online courses for patients where they can learn new information, gather resources, and interact with others. The Center has an abundance of resources that include a mental health partnership with the American Psychological Association, outreach to the underserved, and educational information in both English and Spanish.

My current term on the Board finishes in December. So, after 14 years with this incredible organization and its dedicated patient leaders, I have decided not to seek another two-year term. That means that my time as the President of the DPC Education Center is also coming to an end. However, I want to assure you I will still be very much affiliated with the organization—I plan to assist in launching an online support group for renal patients and caregivers. What an opportunity for all involved! In closing, I will not say good-bye but will say see you later!

Sincerely,

Nancy L. Scott

DPC Education Center
Board President



The “How To’s” to Building a

Top-Notch Immune System With Physical Activity and Nutrition

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

The year 2020 has proven to be a challenging year. Not only have many had to fight COVID-19 head-on, but millions have experienced the repercussions of the pandemic such as job

loss, increased anxiety and stress, food insecurity, and social isolation to name a few. As our nation continues to fight this fight, we now have to consider and prepare for other illnesses commonly seen around this time of year such as upper respiratory infections (also known as the common cold), influenza (flu) and pneumonia. With fall here and winter around the corner,

there are things we can incorporate into our daily routines to help boost our immune system and lower our risk of getting sick.

So where do you start? Keep it simple with the “Three P” approach:

1. **PROMOTE** optimal nutrition
2. Include regular **PHYSICAL** activity
3. Manage **PRESSURE** and stress



PROMOTE Optimal Nutrition

There are many nutrients that help to build and support a strong immune system. Let us first start with one of our key macronutrients: protein. Protein plays a vital role in the healing process and building strong muscles. Various factors impact how much protein one needs as well as the type of protein—such as your current stage of chronic kidney disease, if you are or are not on dialysis, also diagnosed with Diabetes, etc. Generally speaking, those on dialysis often need more “high quality” protein from animal sources—such as chicken, beef, eggs and turkey—where those with earlier stages of kidney disease may benefit from more “low quality” protein that is found in plant-based sources—such as nuts, beans and soy.^{1,2,3} Protein is best absorbed by the body when consumed in smaller increments and spread throughout the day. Speak with your health care provider or registered dietitian to assess your personal needs.

Now let us dig into our immune-boosting vitamins! Please note, the following recommendations are based on obtaining these vitamins from food sources. Taking additional supplementation, unless otherwise directed by your physician, can be extremely dangerous and increase one’s risk for vitamin toxicity. Always

discuss with your doctor before taking any supplements to assess for appropriateness and safety.^{4,5}

Let us first start with Zinc. Zinc is vital in helping the immune system function properly. It also aids with wound healing and appetite regulation. Zinc is most readily absorbed from animal protein sources—like poultry and seafood—and some plant-based proteins—like seeds, beans, and whole grain products.^{4,6} Remember your ACE Vitamins:

Vitamin A: kidney-friendly food sources include broccoli, carrots, red bell peppers, and eggs.
Vitamin C: common food sources include bell peppers, citrus fruits, berries, and melons.
Vitamin E: found in fortified cereals, seeds, nuts, and peanut butter.

So how do you make sure you get enough of these vitamins through food? The Academy of Nutrition and Dietetics recommends striving to eat five to seven servings of vegetables and fruits daily, consume well-balanced meals and eating a variety of choices from the food groups.⁷ Ask for help from your health care provider or your registered dietitian in creating a meal plan if needed.

Include Regular PHYSICAL Activity

According to the American College of Sports Medicine, moderate-intensity physical activity is associated with better immune function and can also help manage stress.⁸ The Physical Activity Guidelines for Americans recommend 150 to 300 minutes of weekly exercise, including a variety of activities, and at least two sessions of strength/resistance training per week. For many this has been difficult because of the COVID-19 pandemic due to social isolation mandates, fitness center closings and loss of jobs to afford gym memberships to name a few. However, there are many ways you can still be active at home! Whether it is walking for 5 minutes, 10 minutes, or even taking a lap around your living room



every 30 minutes, find an activity that will work best for you. Working towards 30 minutes a day most days of the week will get you into the goal range of 150 minutes per week. Remember to always consult your physician before starting a new exercise routine to assess for appropriateness and safety. To learn more about how to include exercise into your lifestyle, check out these other education offerings through the Dialysis Patient Citizens Education Center:

- Online Course: Exercise and the Benefits to You and Your Kidneys
<https://www.dpcedcenter.org/resources/online-courses/exercise-and-the-benefits-to-you-and-your-kidneys/>
- Article: Work Those Kidneys Out!
<https://www.dpcedcenter.org/news-events/news/work-those-kidneys-out/>
- Webinar: Get Your Sweat On! Exercising for Healthier Kidneys
<https://www.dpcedcenter.org/education-webinar/get-your-sweat-on-exercising-for-healthier-kidneys/>

Manage PRESSURE and Stress

According to the American Psychological Association, stress has a significant impact on your immune system.⁹ Studies have shown that the human body, when faced with higher stress levels, creates a physiological response where your natural killer cells that help fight infections significantly reduce. So, with every-day stressors, on top of the extra stressors brought on by the COVID-19 pandemic, how do you reduce stress? Every person is different in finding the approach that works best for them. For some, it may be regular exercise. For others, daily meditation, journaling or listening to calming music, talking to a friend, or simply focusing on getting more sleep may be the trick.⁶ It may only take one activity or it may take several to help you feel at ease. In the end, it is about finding what works for you and keeping with it to create a long-term change. For more ideas on how to help manage stress, check out the Centers for Disease Control and Prevention Coping Stress site at <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/managing-stress-anxiety.html>.

So now you have the “Three P” approach to help get you started. Whichever area you choose to focus on, remember to

keep it simple. Pick one or two things you feel you can realistically do. Any change is better than no change and with time, these new changes will become a normal part of your lifestyle routine!

Still want to learn more? Check out these resources to help support you on your journey. Also tune in on February 25th, 2021 at 2:00 p.m. EST where I will talk more about nutrition and exercise to help build a healthy immune system.

- Academy of Nutrition and Dietetics: Support Your Health With Nutrition:

<https://www.eatright.org/health/wellness/preventing-illness/support-your-health-with-nutrition>

- Academy of Nutrition and Dietetics: How to Keep Your Immune System Healthy: <https://www.eatright.org/health/wellness/preventing-illness/how-to-keep-your-immune-system-healthy>
- National Kidney Foundation: 7 Kidney-Friendly Superfoods: <https://www.kidney.org/content/7-kidney-friendly-superfoods>



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MEDICARE ADVANTAGE

Medicare Advantage Now Open for Enrollment

Between now and December 7, dialysis patients are, for the first time, able to choose a Medicare Advantage plan for their coverage. Medicare Advantage is **an alternative to traditional Medicare** run by private insurance companies. To help kidney patients explore their options, Dialysis Patient Citizens has established Dialysis Plan Choice, an online tool designed in collaboration with Consumers' Checkbook for dialysis patients to quickly and easily compare their current Medicare Fee-For-Service plan with the options available to them through Medicare Advantage.

DialysisPlanChoice.org helps patients and caregivers more easily understand what plans are available to them, the costs are associated with those plans, and, most importantly, which plans will include their care providers.

Dialysis Plan Choice, available at www.DialysisPlanChoice.org, provides

patients with a convenient side-by-side comparison of their current Medicare Fee-For-Service plan and available Medicare Advantage plans, including a cost comparison tool as well as information on whether their current nephrologist and dialysis clinic are included in a Medicare Advantage network. Using Dialysis Plan Choice, patients will also be able to see whether their medications are on Medicare Advantage plan formularies and access information on additional benefits that are not available through traditional Medicare plans, such as dental, vision and hearing services. All of this information is displayed in a simple, mobile-friendly manner that helps patients to easily compare plans using their preferred devices.

Open Enrollment for Plan Year 2021 is available from October 15 until December 7. Also, End-Stage Renal Disease (ESRD) patients who are already enrolled in MA plans now have the opportunity to switch

to a new plan, between January 1 and March 31.

Should I enroll in Medicare Advantage?

The answer is **Maybe**.

Medicare Advantage plans provide all your medical care inside a restricted network of doctors, hospitals, and other providers. Medicare Advantage plans may or may not charge a monthly premium, but unless you have secondary coverage through Medicaid, these plans require a copayment each time you use your benefits up to an annual limit each year.

Medicare Advantage plans involve a trade-off: Beneficiaries give up the complete freedom of choice of providers enjoyed in Original Medicare in exchange for all-in-one coverage, a cap on out-of-pocket costs, and additional benefits, such as eye or dental care. While DialysisPlanChoice.org enables you to quickly determine whether your dialysis clinic and nephrologist are in a plan's network, once you narrow down your choices you should also look to see if your other doctors and preferred hospital are in-network and calculate your projected out-of-pocket cost.

Medicare Advantage insurers are paid a flat monthly fee for each enrollee. This gives the plans an incentive to emphasize preventive care, but can also incentivize them to limit expensive services. Medicare Advantage plans may be beneficial for patients with chronic diseases like ESRD because they are better equipped to coordinate your care and have flexibilities in doing so. However, statistics show that chronically ill beneficiaries are more likely to disenroll from plans and return to Original Medicare than healthy patients.

Dialysis Patient Citizens advocated for ESRD patients to gain the right to enroll in Medicare Advantage plans, but makes no recommendation as to whether ESRD patients are better off in Medicare Advantage plans or Original Medicare. We do urge patients to explore their plan options every year, and exercise your choice as to what options and costs are best for you personally.

You can contact your State Health Insurance Assistance Program (SHIP) for help in evaluating your coverage options, and to find out if you are eligible for any Medicare assistance programs.



“A Mindful Heart”: Stress Management Tools for Patients Living with Heart Disease and Chronic Kidney Disease



By Stacy Ogbeide,
PsyD, ABPP, CSOWM
DPC Education Center Advisory Council Member

Stress Management—a topic those living with heart disease and chronic kidney disease have heard before but now in 2020, takes a whole new meaning. We are in the COVID-19 pandemic—unprecedented times—that are impacting people physically, financially, socially, spiritually, and emotionally. Maybe your healthcare has been disrupted; treatment disrupted; work, social, and family life disrupted. Your current stress management options are no longer

working, or you don’t have access to your typical stress management options, which is beginning to take a toll on you. Don’t lose heart—I’d like to share a few thoughts and ideas about how to manage your stress levels during these uncharted times.

1. The stress response is real and can impact patients with heart disease and chronic kidney disease.

First and foremost—acknowledge what you are going through. Searching for a “stress-free” life is



unfortunately, probably not going to happen. Life is difficult. And with difficulty comes stress! Some of us like to push through stressful times, ignoring what is going on around us and not giving ourselves time to manage the stress we are experiencing. That approach can work for a short time but eventually, it can take a toll on your health, well-being, as well as your family and social relationships. Once you acknowledge that increased stress is present in your life, then you can figure out what you'd like to do about it. The social worker at your dialysis center is a great resource for managing stress.

2. Try something different—relaxation skills work!

You may have heard about different relaxation skills such as diaphragmatic breathing, progressive muscle relaxation, guided imagery or even mindful meditation. If you are currently using any one of these skills—great! If not, why not try something new? Any one of these relaxation approaches is great to counteract the stress response and the impact of the stress response on your body. It would only take a few minutes out of your day each day, and practice makes permanent. So, go on and try something new. Who knows—you might like it!

3. Thoughts, Emotions, and Behaviors: A Domino Effect

It's true—how we think does impact how we feel and what we do—especially in times of increased stress. Have you ever thought to yourself, “I worked really hard today, and I'm going to have a cheat day and eat whatever I want!” And then, you may start to feel guilty about what you ate due to having heart disease or chronic kidney disease? And then you might think, “Oh well, I'll just have another bite...” And the cycle continues. Learning to recognize your thought patterns and how they impact your emotions and behavior patterns will not only impact the course of your health condition, but also give you another tool for managing stressful times. Finding what your “hot” thoughts (thoughts that trigger unhelpful emotions and behaviors; example: “My health will never get better”) can be a helpful tool because then, you can learn what a useful “cool” thought (thoughts that trigger a helpful emotion and behavior: “I had a hard day today, and that doesn't mean my



health won't get better”) can be to reduce the impact of the stress on your overall health.

4. Last but not least: Self-compassion!

Dr. Kristen Neff has a fantastic definition of self-compassion: “Self-compassion involves acting the same way towards yourself when you are having a difficult time, fail, or notice

something you don't like about yourself. Instead of just ignoring your pain with a “stiff upper lip” mentality, you stop to tell yourself “this is really difficult right now,” how can I comfort and care for myself in this moment?”

Another concrete way to engage in self-compassion is to ask yourself this question: “What would I tell a loved one who is going through the same situation that I am?” or “How would I treat a loved one who is going through the same situation that I am?” Recognizing that you are having a difficult time or in a difficult season is important. Engaging in self-compassion and using any one of the stress management approaches mentioned above (or something else that improves your health and is of value or important to you!) is a great way to show yourself some compassion during stressful times.



Are you a health care/behavioral health professional interested in learning more about stress management for patients with heart disease or chronic kidney disease? If so, check out: <https://psycnet.apa.org/record/2018-34038-001>

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Supporting Your Health and Wellbeing Before, During, and After Kidney Transplant



By **Elizabeth Steinberg Christofferson**, PhD and **Leah Grande**, MA

Preparing for and receiving a kidney transplant, especially during the COVID-19 pandemic, can be an uncertain and overwhelming process. This article discusses tips to promote positive mental and physical health for yourself or your loved ones.

Preparing for a Transplant

There are many different emotions associated with deciding to go on the transplant list, and all of these feelings are normal and valid! You may feel excited about the potential for improved health and energy, fewer restrictions on what you can eat and drink (although you still

want to eat a heart-healthy diet!), more time in your day, and changes in quality of life.⁷ Many patients also feel nervous about the risks of surgery. You may worry about remembering to take anti-rejection (immunosuppressant) medications at the same time every day or have concerns about medication side-effects.⁷ Many people also feel uncertain about the future and worry about the risk of rejection with their new transplant. Perhaps you have lost a kidney transplant in the past and have worries that the new transplant will not be successful.¹⁴ These feelings and worries are normal. Caring for your mental health and overall wellbeing are just as important as caring for your physical health—in fact, the two are very connected! Here are some actions that can help build resilience during this time:

- **Plan and practice taking your medications on time every day.** If you are taking few medications currently, you can start practicing with a sugar pill. Try out different strategies, such as using a timer, pillbox, or app.
- **Take care of your health and keep your appointments with your physicians.** You'll continue to meet with your transplant team before your transplant as they monitor your overall health. Complete any required medical tests and procedures that they require before transplant. Stay organized with an electronic or paper copy of your medical records too.
- **Build a strong relationship with your medical team.** Learn everything you can about transplant surgery, your medications, and what life will be like post-transplant. Write a list of questions for your doctor, so you can share your concerns and learn about the transplant process.⁶
- **Rely on your social supports.** Share your thoughts and feelings with friends, family, and other important people in your life.¹
- **Make connections with the kidney transplant community** through outreach services at the hospital.¹ For example, peer mentors are often available through hospital transplant programs, transplant organizations, kidney organizations, and ESRD Networks.
- **Meet with a mental health provider** for help supporting your emotional wellbeing. Feelings of anxiety and stress are common during the transplant process. Your clinic social worker or a therapist can help to boost your resilience and provide tools to help with recovery and transplant success. Especially if you have a history of

anxiety or depression, it is important to focus on your mental health to prepare for your transplant.⁹

- **Work on quitting use of nicotine, alcohol, and other substances.**⁹ Heavy drinking can harm your kidneys and liver and lead to kidney or liver failure. Other drugs can cause complications, kidney damage, heart failure and even death. Talk to your medical team about pursuing pre-transplant treatment for substance use, as well as post-transplant relapse prevention treatment. Every drug you take passes through your kidneys, so it is important to check with your doctor first before taking any new drug or medicine (e.g., pain medications, antibiotics).⁷
- **Follow diet and exercise guidelines as prescribed by your medical team.** It may be helpful to meet with a dietician and/or physical therapist. Also work on getting adequate sleep (7-9 hours for most adults), as sleep is a huge component of overall health and helps reduce stress, depression, and anxiety symptoms.

Finding a Donor and Being on the Waitlist

Once you've started to pursue a kidney transplant, it can feel daunting being on the transplant waitlist or asking someone to be evaluated as a living donor. It can also feel overwhelming keeping up with recent changes to the donation process and transplant surgeries due to the COVID-19 pandemic. These policies are constantly changing, and it is important to

talk with your hospital to learn more.

Currently, there are over 92,000 people on the kidney transplant waiting list in the United States, and in 2019, there were 23,401 kidney transplants (16,534 deceased donor transplants and 6,867 living donor transplants) (based on data as of August 27, 2020; Organ Procurement and Transplantation Network, 2020). Due to the waiting list, some people also find it helpful to think about talking to family or friends about being a living donor.

However, it can feel scary or uncomfortable asking family or friends to be a living donor. Sometimes people worry about the potential health risks for a family member or friend if they were to donate an organ or worry about the guilt they will feel if their donor experiences negative outcomes. Others worry that they will feel obligated towards their donor or their donor will have a "hold over them" in the future.¹⁴ Even if you do not want to ask someone to be a donor, it can be helpful to share your story to make others aware of your need. Some people decide to share their story with their social groups, co-workers, places of worship, or local newspaper.⁷ The U.S. Government Information on Organ Donation and Transplantation at <https://www.organdonor.gov/awareness/materials/print-brochures.html> has a variety of educational brochures and information that you can share with potential donors. You can also check with your hospital transplant program, kidney organizations, and transplant organizations for their

material. Additionally, some transplant centers participate in kidney paired exchange programs when a patient's living donor is not a good match for them, so be sure to ask your transplant center about this option too. You also can view the video recording of *Helping Your Donor Find You* at <https://www.dpcedcenter.org/education-webinar/having-your-donor-find-you/>.

The financial aspects of chronic illness, End-Stage Renal Disease, dialysis, and transplant may also cause distress or challenges, and it is important to explore resources to decrease this stress. There are several organizations that help with the financial burden of transplant through organized fundraising for transplant recipients or living donors and additional resources that may be helpful in terms of the logistical and financial aspects of being a transplant recipient or living donor:

- National Foundation for Transplants: <https://transplants.org>
- National Kidney Foundation List of Additional Resources: https://www.kidney.org/patients/resources_Transplant
- National Living Donor Assistance Center: <https://www.livingdonorassistance.org>
- AST Live Donor Toolkit: <https://www.myast.org/patient-information/live-donor-toolkit>

You may not have the option of a living donor, or you may want to pursue options for both living and deceased donation. Following an evaluation at a transplant hospital, you may be placed on the United Network for Organ Sharing (UNOS) national transplant waiting list for a deceased donor. UNOS matches recipients with deceased donor organs in a fair and transparent system, using a combination of blood-type and antibody matching, time with kidney failure, and a few other factors that give people priority on the list. It can be anxiety-provoking and frustrating being on the waiting list and wondering when you might receive a call. Even after receiving a call and going into the hospital, you may find that the donor kidney is not healthy or that your body has a negative reaction to the donor's blood.¹² Anxiety and depressive symptoms can increase while being on the kidney waitlist; it is important to rely on your social supports, peer mentors, a therapist, and the psychosocial team at your center for help during this time.³





stress and improve sleep.⁵ Check out smartphone apps like Breathe2Relax, Headspace, Calm, and Ten Percent. These strategies are also helpful to continue after transplant at home!

Life After Transplant

Take time to care for your mental health. Although mental health can improve after transplant,¹³ you can still be at risk for anxiety and depression.¹⁰ About one in four people with a kidney transplant meet criteria for depression.² Coping with illness and going through a transplant can be very stressful and sometimes people experience symptoms of post-traumatic stress or PTSD.^{4,11} It is important to care for your mental health because it affects your physical health as well. Feeling depressed and down is related to additional health problems, such as forgetting to take medications or loss of the transplant (graft failure).² It may also be helpful to talk to your provider and ask for help from others if you notice problems with your thinking or memory. Chronic kidney disease is related to some cognitive problems over time, but these can improve after surgery.⁸ However, some problems with learning and memory may remain. It is important to connect with your social supports and medical team if you feel memory problems may be affecting your adherence to medications.

Additionally, some people experience a range of emotions towards their deceased or living donors. Recipients may feel extreme gratitude, but also guilt, especially if their donor was a deceased donor. It is important to discuss these thoughts and feelings with your social supports and your psychosocial team (social workers, psychologists) at your center. Organ procurement organizations (OPOs) can help direct a thank you note

Preparing for Your Medical Stay

- Pack your bags early! Especially if you are on the deceased donor list, you'll want to be prepared to leave as soon as you receive the call that there is an organ available. Bring your insurance information, a list of your medications, an extra 24-hour supply of medication and any other necessities.
- Also bring comfortable clothes, blankets, books, pictures, electronic devices and anything that would help you feel comfortable and occupied during your hospital stay.⁶
- Due to new safety precautions for COVID-19, many hospitals are limiting the number of visitors during medical stays. Make a plan with your medical team, family and friends about who can visit you in the hospital. This can be a difficult decision, and many patients and families feel sad that they cannot access their full social supports.
- Make a plan for who can drive you from the hospital and care for you when you return home.⁶ During the COVID-19 pandemic, it is especially important to think carefully about your interactions with others following transplant. During the initial post-transplant period, patients take higher steroids and are most at risk for having a compromised immune system. Many people are careful to limit their exposure to COVID-19 infection, even though this social isolation during recovery can be challenging. You can learn more about transplant and COVID-19 on the American Society of Transplantation website: <https://www.myast.org/covid-19-information>.

During Your Medical Stay

Being in the hospital can feel stressful, disorienting, boring, and uncomfortable. It's okay to feel sad or upset. Having limited visitors during the pandemic can also feel lonely and isolating.

- Talk with a member of your psychosocial team. You can ask about music and art therapy services or visits from a therapy dog.
- Connect with friends and family virtually when you feel ready for it, and also get plenty of rest. Remember that while your friends and family may all reach out to you, you aren't obligated to talk to them until you're ready. Some recipients ask a family member or friend to send out updates to their primary network so that they don't have to worry about this as they recover in the hospital.
- Share your needs and advocate for your wellbeing. Your medical team wants to hear your concerns and to make sure you are comfortable.
- Practice meditation and mindfulness strategies to cope with pain and



to the deceased donor family, if you feel that this would be helpful or important for you. However, there is no expectation that you must be in contact with your deceased donor family, and everyone has their own individual response to the process and journey of being a recipient or a donor.



It is important to take your medications every day and at the same time. It can help to:

- Set a recurring alarm on your phone, use a smartphone app, or use a pillbox. The MediSafe, Pill Reminder, RxRemind, and Round Health apps are a great way to set up your medication reminders.
- Write down the days and times you take your medicine on a calendar or in a noticeable location.
- Place medications where you can see them (but out of reach from children or pets).
- Have an accountability partner (family member, spouse) who checks in with you about how you've been doing with taking your medication.
- Schedule your medications around daily routines and use pairing of routines to establish habits (e.g., always taking your medication before bed and after you brush your teeth).
- Keep a small supply of your medication at work, in your bag, or other places.⁷ Store medication at room temperature in a protected container.

It is a marathon, not a sprint! Here are some factors for long-term success:

- Meet with your healthcare team regularly. Ask questions and communicate your needs and concerns.
- Build strong social supports and ask for help when you need it. Meet with a therapist or mental health provider to support your emotional wellbeing.
- Eat a heart-healthy diet. Strive for a low fat, low salt diet and drink plenty of fluids. Depending on your medications or if you have diabetes or other health

Having a Kidney Transplant During COVID-19

By Jewel Edwards-Ashman

I started the year 2020 anticipating that I'd enter kidney failure and have to undergo my second kidney transplant. But I didn't expect to start doing home dialysis and eventually have transplant surgery in the middle of a pandemic.

Transplant surgery in ordinary circumstances comes with a high level of stress and anxiety. Having a kidney transplant during a public health crisis only exacerbated those feelings for me. To reduce my stress and manage my emotions, here are three things I did:

I prioritized self-care. Most Americans, even those who aren't living with chronic illness, have been experiencing significant stress this year. News and events surrounding the pandemic, the election and racism have pushed our mental health to its limit. Adding "have a kidney transplant" to that list only increased my stress levels. To help myself relax, I turned my manual peritoneal dialysis sessions leading up to my transplant into "self-care sessions." During exchanges, I listened to a guided meditation, read a book or video-called members of my family. All these activities helped me calm my mind and injected moments of joy into my day.

I kept in touch with family and friends. Most people are physical distancing, and hospitals are following protocols to protect patients from contracting COVID-19. Because of this I've had to attend some doctor's appointments by myself, and I've awakened in the recovery room after several post-transplant procedures without a

familiar face to greet me. Still, it's important to keep your support system of family and friends involved in your treatment for kidney disease. Leading up to my second transplant, my family and I held meetings via video call where I gave updates on the evaluation process and the surgery. On the day of the transplant, a few hours after waking up, I texted everyone to let them know that the surgery went well and that I was OK.

I talked with a therapist about how I'm feeling. For the past few years, I've been seeing a licensed psychologist to help me cope with the mental and emotional issues that accompany living with a chronic illness. My therapist has also helped me come to terms with the fact that I had to live through kidney failure a second time. Whether you've just been diagnosed with kidney disease or have been living with it several years, it's never too late to seek professional help. The social worker at your dialysis center can connect you with resources. You can also visit the American Psychological Association website at [APA.org](https://www.apa.org) to find a licensed psychologist in your area.



Additional resources on stress and coping are available below and at [APA.org](https://www.apa.org):

- Stress Facts and Tips
<https://www.apa.org/topics/stress>
- Healthy Ways to Handle Life's Stressors
<https://www.apa.org/topics/stress-tips>
- How to Choose a Therapist
<https://www.apa.org/topics/choose-therapist>

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conditions, you may still have some dietary restrictions.

- Exercise regularly and maintain a healthy weight. Ensure adequate sleep. Continue relaxation, meditation, and mindfulness practices. Even one minute of deep breathing can be so helpful during a stressful moment!
- To learn more about kidney transplant FAQs and how to stay healthy after a transplant, you can use the Care After Kidney Transplant smartphone app.

For prolonged or more significant mental health difficulties before, during, or after kidney transplant, know your resources in case of a crisis or for getting established with a mental health provider:

- Ask your psychosocial providers (social workers, psychologists) through your transplant team to help you find a local mental health provider, call your insurance company for referrals, or use [Psychology Today](#). Many providers are offering telehealth because of the COVID-19 pandemic.

- Crisis Chat: 1-800-273-TALK
- American Psychological Association, Centers for Disease Control and Prevention, and National Alliance on Mental Illness websites

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Make Your Wishes About You (My Way)

By Elizabeth Anderson,
LCSW, DSW and Dale Lupu, MPH, PhD

When I was first told I had chronic kidney disease (CKD), I was grateful that there were lifesaving treatments, but I was also scared because I didn't have a plan. I worried that I might be in pain or become a burden to my family. I felt better when I was able to discuss my desires and healthcare decisions with my family and healthcare team.

What kind of medical care would you want if you were too ill to express your wishes? Like most people, you may not have thought about it, or you may have a difficult time discussing it with your family and kidney care team. However, planning for your healthcare in the event that you cannot speak for yourself may help decrease your worries. This process is called advance care planning.

Some people know exactly what they would want to happen if they became very ill. For other people, these decisions take time and thought. It helps to talk to a friend or family member and to ask your kidney care team to help you make a plan and put it in writing.

The Coalition for Supportive Care for Kidney Patients has outlined five steps to help you with your advance care planning:

1. Choose someone to make healthcare decisions for you if you get sick and cannot speak for yourself.
2. Think about what kind of healthcare you would want if you were unlikely to get better. Discuss your wishes with your family and friends.
3. Write your wishes down in a legal form, known as an advance directive (sometimes called a "living will" or a medical power of attorney).
4. Give a copy of your advance directive to your healthcare agent and your kidney care team. Continue talking to your family about your wishes.
5. Discuss with your kidney care team when

a medical order form (usually called POLST or MOLST) might be right for you.

The guide from the Coalition's project called Make Your Wishes About You (My Way) is available for free. (<http://go.gwu.edu/MyWayACP>). The My Way guide is written especially for patients with kidney disease. It guides patients through the steps of advance care planning and gives helpful worksheets and tips.

You can begin to work on each of the five steps for advance care planning by following these detailed instructions from the My Way patient guide:

STEP 1: Who is your healthcare agent?

Choose someone—such as a trusted family member or friend—to act as your healthcare agent. This person will make healthcare decisions for you if you get sick and cannot speak for yourself.

- A healthcare agent has no authority in your healthcare unless you are unable to make decisions for yourself.
- A healthcare agent has no power over any other part of your life (e.g., finances, will, etc.).
- If you do not have a healthcare agent, then your kidney care team will usually ask your next of kin.
- A healthcare agent is only official if you complete an advance directive. Be sure to share the advance directive with family and your kidney care team so they know who to turn to if needed.

STEP 2: What would you want people to know if you got sick and were not

able to speak for yourself?

Think about what kind of healthcare you would want if you were unlikely to get better. If you got so sick that you could no longer do most of your daily activities, or if you were near the end of your life, what would you prefer to be the focus of your care?

- Staying alive at all costs, no matter the pain or discomfort involved.
- Being as comfortable as possible, even if it meant you might not live as long.
- Not sure or it depends on the situation.

Each person has a different view of what they would want at the end of life based on his or her personal values and current health status. Talk to your kidney care team to learn more about the risks and benefits of different treatments for you.

STEP 3: How do I make my medical wishes known?

Write your wishes down in a form called an advance directive (sometimes called a "living will" or a medical power of attorney). Your kidney care team can help.

- An advance directive is a legal document that allows you to have control of your healthcare decisions if you are ever unable to speak for yourself.
- Use the form that is recognized in the state where you live. Two sites that have free forms for each state:
 - Prepare For your Care: (<https://prepareforyourcare.org/advance-directive>)
 - Caring info (<https://www.nhpco.org/advancedirective/>).
- Share the completed form with your healthcare agent, family members,

friends, and kidney care team.

- Advance directives can be changed any time. Simply destroy the old document and create and date a new one.

Advance directives should be reviewed throughout a person's entire life, especially:

- Before each annual exam
- After any major life change (birth, marriage, divorce, remarriage)
- After any major medical change, such as diagnosis of chronic kidney disease or hospitalization
- After losing the ability to live independently

STEP 4: How do I start the conversation?

Talk to your family and friends about the care you would want. Give a copy of your advance directive to them and your kidney care team. Avoid family conflict in a health crisis by talking about your wishes ahead of time. Ask family members to reflect on someone else's experience with chronic illness.

- If you are part of a spiritual community, talk to your spiritual leader for guidance.
- Ask your kidney care team to help you find a social worker. They will have ideas about how to start conversations. Social workers can give you resources and get documents you need.

STEP 5: Discuss with your kidney care team when a medical order form (called POLST or MOLST) might be right for you.

POLST stands for "Physician Orders for Life-Sustaining Treatment," and MOLST stands for "Medical Orders for Life-Sustaining Treatment." The POLST form is a portable medical order form that records a patient's treatment wishes so that emergency personnel know what treatments the patient wants in the event of a medical emergency. It helps individuals with serious illness or frailty to communicate their treatment decisions. The POLST form may be especially helpful if you are at risk for unexpected hospitalization or transfer to a different care setting. POLST is known by different names in different states; for a list of names, visit www.polst.org/programs-in-your-state.

Action Items

- Think about what you want your future medical care to be like.
- Seek input from your family, kidney care team, and/or spiritual leader.
- Tell your family and friends your wishes.
- Formally ask someone you trust to be your healthcare agent.
- Fill out an advance directive, naming a



healthcare agent.

- Provide copies of your advance directive to your kidney care team and other doctors.
- Provide copies of your advance directive to your healthcare agent.
- Ask your kidney care team to record your wishes as medical orders, often called POLST or MOLST.

If you need additional help in reflecting on your healthcare wishes and goals, this worksheet from the My Way Patient Guide may help you.

WORKSHEET

1. The person I would like to make healthcare decisions in the event I could not is:

2. I think that the following side effects would be worth enduring if it meant I could regain my health: _____

3. If I were very sick, I would not want to have these treatments:

4. I would like my healthcare team and healthcare agent to know the following things about my spiritual/religious life: _____

5. It might be difficult to talk to my family, friends, and kidney care team about my advance directive because: _____

6. I plan to make this discussion easier by: _____

7. The healthcare team members I need to talk to are: _____

8. I will complete an advance directive by this date: _____

9. I will provide a copy of my advance directive to my healthcare agent and kidney care team by this date: _____

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Additional Resources

1. The Coalition for Supportive Care of Kidney Patients' website has many resources about advance care planning for people with kidney disease: <https://www.kidneysupportivecare.org>
2. Prepare for your Care is a website with a step by step program, including video stories, to help with advance care planning: <https://prepareforyourcare.org/welcome>
3. Prepare for your Care also has easy-to-read advance directive documents for every state and in several languages: <https://prepareforyourcare.org/advance-directive>
4. The Conversation Project helps people express their wishes for end-of-life care, saying the place these conversations should begin "is at the kitchen table—not in the intensive care unit": <https://theconversationproject.org/>

Kidney Patients and Coronavirus: What Have We Learned?

Last updated September 2020

By Alan S. Kliger, MD

The COVID-19 pandemic has changed life for virtually everyone on the planet. For most of this year, we have all gone through many troubling emotions: fear, disbelief, anxiety, anger, mistrust, cynicism. We also have learned so much, and have looked to the future for trust, hope, anticipation, and most of all the ability to get on with life beyond face masks, social distancing, closed schools and closed businesses, and to a time we don't have to worry every time someone walks toward us: might they be the one who infects me.

In the midst of such upheaval, people with chronic kidney disease, including those who receive dialysis treatment or who have a kidney transplant, have experienced particular challenges that others don't have to worry about. Here are some of the things we have learned about those particular challenges:

1. People with kidney disease are at higher risk of complications or even death if they contract SARS CoV-2, the virus that causes COVID-19.
2. People of color appear to be at higher risk of complications should they acquire this infection. Since people of color are also more likely to have kidney disease, this is a particularly vulnerable population.
3. In-center dialysis patients cannot shelter at home during an outbreak—

they must come for their dialysis treatments to a dialysis facility three times a week or more. To prevent the spread of virus, dialysis units must follow strict procedures with facemasks, hand washing and staff procedures to keep the environment free of virus.

4. Transplant patients—who take medicines to prevent rejection—have suppressed immune systems and are at higher risk of infections and their complications.
5. When dialysis patients return to the facility after a hospitalization for COVID-19, they sometimes have persistent positive PCR tests for the virus. This likely represents a very sensitive test detecting viral particles long after infection is over and after there is any real chance of them spreading infection. Nonetheless, this is a challenge for the dialysis facility that wants to assure that no patients in a facility have infections that may spread.
6. Home dialysis patients, either home

hemo- or home peritoneal dialysis patients, have the advantage of both sheltering at home and receiving dialysis treatments, thus reducing their risk of acquiring the viral infection. For some, this may be an inducement to switch from in-center to home treatment.

It is important to look back at how so many things changed during this year, and to recognize that science is not a collection of facts, but rather is a dynamic process where new evidence and new findings from rigorous testing of hypotheses, result in changing recommendations. For example, the Centers for Disease Control and Prevention (CDC) first recommended that individuals who had no symptoms of infection and were not caring for or near those with infection, need not use face masks. This advice was based on the evidence of other coronaviruses we have seen in our community over



and safety of hydroxychloroquine for COVID-19. The results of those studies were clear: hydroxychloroquine does not improve the condition of patients with COVID-19. Furthermore, there may be a signal that the drug has some harmful side effects in a small number of treated patients. Thus, doctors understanding and respecting the science stopped using this drug for COVID-19 and warned that some patients may even suffer negative side effects if it is used. When good science is used, best practice changes. This is not “mixed signals,” or “waffling,” but rather changing practice to protect patients as more information is obtained, changing and improving clinical practice.

the years. In those previous infections, infection spread occurred mostly from people with symptoms of infection. As we learned more about this particular coronavirus, the SARS CoV-2 virus, we saw that approximately 25 percent of infected people have no symptoms or only mild symptoms of infection, and another 25 percent of those infected can spread the infection for days before they develop any symptoms at all. Thus, it became clear that many people spread this infection when they have absolutely no symptoms of illness. This new information caused the scientists at CDC to change their guidance—and advised that all of us should use face coverings when we are indoors with people beyond our household members, or outdoors when social distancing is impossible, or large groups of people moving about bring us in closer range of one another. This is not “confusion” among the “so-called experts,” but rather is good science changing recommendations when new data changes our understanding of what is happening.

Another example is the hydroxychloroquine story. Hydroxychloroquine is a drug that has been effective for many years in treating malaria, rheumatoid arthritis and lupus erythematosus. These diseases are “approved uses” of this drug, because there is good evidence that has been published showing the effectiveness of the medication far outweighs the potential side effects for most patients. Doctors also have used hydroxychloroquine for several diseases that are not on this approved list, including sarcoidosis, dermatomyositis, porphyria cutanea tarda, and Sjogren

syndrome. For these diseases, there are some reports of patients who benefit from hydroxychloroquine treatment, but there is not the solid evidence that treatment is safe and effective as there is for the approved uses. These are called “off-label” uses of the drug. When COVID-19 first appeared, there were some individual case reports of patients who appeared to do well after treatment with hydroxychloroquine. With no other evidence available, many doctors used this medicine as an “off-label” treatment for COVID-19, hoping it would be as helpful as it appeared to be for the very small numbers of patients reported in those first case reports. But in addition, doctors wanted clearer evidence that the drug was effective and safe for COVID-19 patients, and so several human studies were started to test the effectiveness

We continue to learn about this infection, sometimes with new insights that change our practice, and sometimes with more questions than answers. For example, as COVID-19 has spread across the country, with new “hot spots” developing and then declining, others developing and staying “hot,” and yet others flaring up again after the disease had run its course, the reasons for these differences are not clear. Many have hypotheses about these differences: early openings of businesses and schools, lack of appropriate social distancing and face covering by a weary populace anxious for life to return toward normal. In some cases, the evidence supports these hypotheses; in other cases there is no clear cause/effect explanation. We often must make public policy and treatment decisions based on imperfect evidence—but in any case, must make the best choices we can. Science is not a



perfect set of facts. Science is a process—a way of evaluating what we see, what we experience, and testing ways to improve outcomes.

So where are we now in this pandemic? What are the important lessons for people with kidney disease? Here are some of my thoughts—not facts, but my thoughts based on the evidence I have seen so far:

1. I think we have a long way to go. Life will not return to “normal” until most of us are protected from this infection, either with natural immunity after we’ve had COVID-19, or after immunization with an effective vaccine. Even so there will be challenges. People may choose to forego immunization. The virus may mutate, requiring re-vaccination at intervals, perhaps like the influenza (“flu”) immunizations we all are offered every year. We also don’t yet know how much protection there is against re-infection once someone gets COVID-19 and recovers.
2. Social distancing, use of face coverings, frequent hand cleaning will be with us for a long time. For now, we should all recognize this as our new “normal.” Here again, science will help: in places where there has been little viral spread, we can loosen these restrictions carefully—but be prepared to re-institute them when evidence shows these areas are again increasing infection and spread.
3. Kidney patients will remain a particularly vulnerable group. Kidney patients, their families and caretakers must remain vigilant taking steps to avoid exposure to infection and taking steps to stay as healthy as possible to fight the infection should it occur.
4. These many lifestyle changes have a profound effect on our mental health and on our ability to deal with other stress. It sometimes seems that everything has changed, when we cannot hug our children or parents who are not household contacts, or when so much of our lives is spent within the four walls of our homes, or when there are no open baseball stadiums, no movie theaters or concert halls to share beautiful performances, no church, mosque or synagogue services to share in person, no neighborhood barbecues. Also, uncertainty makes life so difficult. When can my business be the way it was, or go back to work full-time, and until then how can I pay my bills? Will schools be able to teach all the children



in person again, and when? When can we stop worrying and have some time to enjoy life?

Finally, this year has shown us how resilient kidney patients and their caretakers have been. Here are some encouraging facts:

1. Most kidney patients who contract COVID-19 survive the illness with few ill effects.
2. Spread of infection within dialysis facilities now is very rare. After some reports of virus spread between staff and patients in European dialysis facilities early in the pandemic, aggressive management with patient screening, isolation of infected individuals or those patients under investigation for infection, and strict mask use, staff use of personal protective equipment and environmental cleaning procedures, there have been few or no reports of virus spread within US dialysis facilities.
3. Mental health resources are available

for kidney patients suffering the stress and complications of this awful pandemic. The American Society of Nephrology has a list online of those resources, as do the dialysis chain organizations.

4. Several SARS CoV-2 vaccines are in development and may be widely available as soon as 2021.
5. Most kidney transplant programs are back operating at full-strength.
6. Home dialysis is a safe and effective treatment choice in a pandemic, and patients have been taking advantage of that alternative.

Stay safe. Use face coverings where needed, and social distance as a way of life. Stay tuned to the science, as our practice continues to change and improve as we learn more about this virus disease.

Alan S. Klinger, MD is Clinical Professor of Medicine, Yale School of Medicine, and Co-Chair, American Society of Nephrology (ASN) COVID-19 Response Team.

Are There Living Kidney Donor Registries?

By Harvey Myssel

I've often been asked: "Where can I register to get a living donor?" Unlike deceased donation where there's one national list, (although you can multi-list because some areas have a shorter wait time) there's no such list for someone looking for a living donor. You must find your own living donor. When you do have someone that is able to be a living donor, many are not compatible with their recipient. Thirty to 50 percent of donor/recipient pairs are not compatible with each other.

In such a situation the incompatible donor could still help the person in need by getting involved in a paired exchange. What this incompatible pair needs to know is that there are many paired exchange options. A paired exchange occurs, when two or more incompatible donor/recipient pairs swap their incompatible donors as is shown here. In this example there are two pairs, but there could be three, four or an unlimited number of pairs.

Paired exchanges have already increased the number of living kidney transplants by more than 1,000 a year, and since so many donors are not compatible with their recipient, this number is likely to continue to grow. To maximize your chances of being paired with another

(or more than one) incompatible pair, you should be aware of all the paired exchange options. One of the barriers to increasing the number of paired exchanges is that a centralized national program of ALL incompatible pairs does not exist. The likelihood of being matched with another incompatible pair is increased when there is a large pool of incompatible pairs.

Here are the different types of paired exchange programs that have been developed:

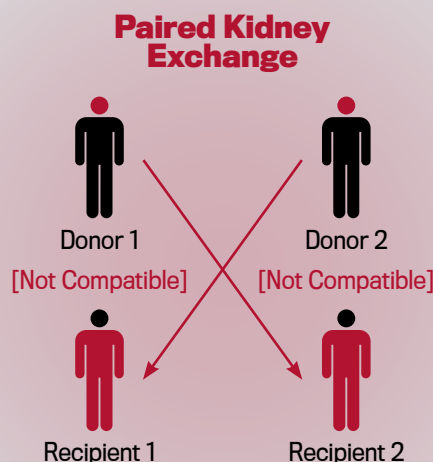
1. If your transplant hospital has a paired exchange program, then they will try to match you with the other incompatible pairs that are registered at their hospital.

2. Some hospitals share some or all of their incompatible pairs with other local hospitals or ones in different parts of the US.
3. Hospitals have transplant centers in different markets, and they share their information within those hospitals.
4. There are three national paired exchange organizations—Alliance for Paired Donation, National Kidney Registry and the UNOS Paired Exchange Program. These organizations have developed a "co-op" type relationship with many transplant centers. These centers list their incompatible pairs with one or more "co-op." To register with one of the paired exchange programs, an incompatible pair needs to register with one of their affiliates.
5. You can register with multiple centers for a paired exchange and with multiple "co-op" organizations. With private health insurance, you need to check to make sure you are covered at other hospitals. Those with Medicare are covered at all transplant hospitals.

Here is the information about the 3 "co-op" type of organizations:

Alliance for Paired Donation
www.paireddonation.org

Alliance affiliated centers
www.paireddonation.org/transplant-center/





A New Look on Life

By Michael Ramirez

The worst day of my life became the best day of my life. “Your kidneys are failing,” my physician said to me. My first thought, “What does that mean?” My doctor confirmed, “You need to see a specialist.” I learned that a nephrologist is a kidney doctor, and that was the type of specialist I needed. I trusted my doctor so I asked, “Who should I see? Who do you trust?” My doctor referred me to his choice of nephrologist—and so I made an appointment right away. If your doctor says you need to see a nephrologist, don’t wait months to make the appointment. Some people will research the different nephrologists in the area, look at patient reviews, look at the distance to their office and identify the types of treatment they do. And then make an appointment. That is a good way to do it too; just don’t wait too long.

During our first appointment, the nephrologist explained what could happen and that my kidney function was deteriorating. I asked questions so that I would understand clearly what he told me. Make sure you ask questions while you are at the appointment—it is much harder to call the office after you are back home to try to talk to your doctor. Barring a miracle, I was told my kidneys would fail within a matter of time. That was hard to hear,

and I had to force myself to listen closely. It is easy to zone out when given serious news and then to miss much of what was being said. Take someone with you to your appointment if you can or at least take notes. The nephrologist laid it on the line for me, and I took it to heart and knew I would follow his instructions! People forget a lot of what they hear, so always ask your doctor and health care team to give you written instructions.

I believe your health depends on establishing a trusting, respectful and knowledgeable relationship with your medical professionals. This includes your general practitioner, nephrologist, dietitian, social worker, behavioral health provider, nurses, technicians and the end-stage renal disease community. They assisted me in my next phase of well-being. It is important to accept and provide yourself the time to face the shock and disbelief that your life, as you knew it, is changing. You may be sad and angry at what you cannot do or what you need to change in your daily life. You will become a new person, and your old way of life will be over. You must change, you must adapt and you need to retrain yourself to have a good life—the quality life you deserve.

The result of your efforts will be that you are still ALIVE! And that, my fellow patient, says it all!

National Kidney Registry
www.kidneyregistry.org

NKR affiliated centers
www.kidneytransplantcenters.org

UNOS
www.transplantpro.org

UNOS affiliated centers
www.unos.org/wp-content/uploads/unos/OPTNKPDPCCentersByState.pdf

You should ask if your hospital is involved with one or more of the “co-op” programs. Some hospitals will keep the pairs that are easy to match and offer the more difficult pairs to their exchange member(s). This is not an efficient way of maximizing paired exchanges.

Here’s what you could do to maximize your chances of being matched with another incompatible pair:

1. Register with your original transplant center’s paired exchange program.
2. If your center is not affiliated with one of the “co-op” organizations, find transplant centers that are affiliated.
3. The National Kidney Registry is completing 70 percent of all paired exchanges. Since they are the major player, you should try to first get registered at a transplant center that is affiliated with National Kidney Registry, then look at other options. Registering with many transplant programs may not be easy, but it will increase the odds of being matched with another incompatible pair.

Harvey Mysel is a 2-time kidney transplant recipient and Founder of the Living Kidney Donors Network, a 501(c)3 non-profit organization that offers workshops, webcasts and private consultation educating people in need so they could be successful at finding a living donor.

“You Want to Slit My Throat?”: What is a Parathyroidectomy?

By **Keith A. Bellovich, DO**
and **Mirjana Dimitrijevic, MD**

Parathyroidectomy is the surgical removal of one or more of your parathyroid glands. It stems from the Greek ektomia = “cutting out” which means to surgically remove something from your body. The parathyroid glands are made of tissue slightly larger than a single grain of rice, located around your Adam’s apple that

produce parathyroid hormone (PTH) and control the levels of calcium in your body. PTH stimulates the conversion of calcidiol (25-hydroxyvitamin D) to calcitriol (activated vitamin D) within kidney tubular cells, which leads to the absorption of calcium in your diet from your small intestines.

Most people have four parathyroid glands. Supernumerary (more than four) parathyroid glands occur in about 3

percent of individuals and can be found anywhere from as high as your nose to as low as the bottom of your breastbone.

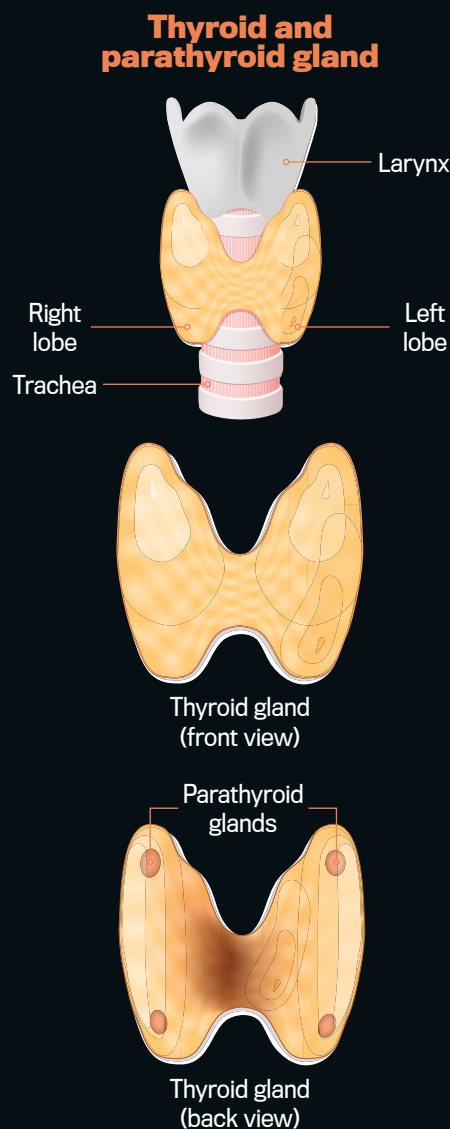
Chronic kidney disease is commonly associated with mineral imbalance and bone metabolism, which shows up as abnormalities of calcium, phosphorus, and parathyroid hormone starting as early as CKD stage three. Changes in mineral metabolism and bone structure develop early in the course of

chronic kidney disease, often without any noticeable symptoms, and can worsen with progressive loss of kidney function. Symptomatic patients with persistent and progressive elevations of serum parathyroid hormone (hyperparathyroidism) that cannot be lowered to acceptable levels by medical therapy (known as a refractory hyperparathyroidism) should be referred to a surgeon for parathyroidectomy.

The most common symptoms in severe cases may include high blood calcium and/or phosphorus levels, bone and/or joint pain, a proneness to fractures despite minor trauma, proximal muscle weakness, calcium deposits in your skin or soft tissues, and itching. Some studies have suggested that parathyroidectomy may benefit selected patients who have PTH >1000 pg/mL that fails to respond to medical treatments by your doctor even if you don't have any symptoms. Among such patients, parathyroidectomy may reduce mortality, cardiovascular risk, the risk of fracture, improvement in anemia, nutritional status, and the ability to fight off infection.

Most importantly, you should only consider consulting a surgeon for parathyroidectomy after discussing it with your kidney doctor and insuring that it is the right procedure for you. Patients considering parathyroid surgery may require imaging studies such as sestamibi scintigraphy (MIBI-SPECT imaging) and/or ultrasound or CT of the neck to assist with operative planning and identify these glands more clearly. General anesthesia is required for most patients undergoing parathyroidectomy with bilateral neck exploration.

Most end-stage renal disease (ESRD) patients requiring surgery will have multi-gland hyperplasia, for which a subtotal, near-total, or total parathyroidectomy is typically performed as the initial surgery. For patients with an existing or planned kidney transplant, a total parathyroidectomy should be avoided as it is associated with the highest risk of postoperative permanent hypocalcemia. A surgeon may offer an alternative procedure where a portion of one of the glands is placed elsewhere in your body to avoid complete removal of all parathyroid tissue. An autograft can be placed subcutaneously or intramuscularly in the neck (sternocleidomastoid muscle), chest or nondominant forearm.



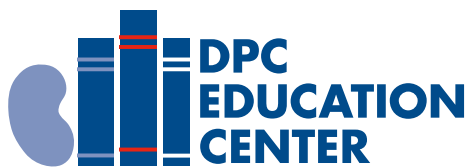
functioning kidney transplant. Patients on dialysis are more likely to develop transient hypocalcemia after parathyroid surgery due to a condition called Hungry Bone Syndrome. This condition occurs when there is rapid reabsorption of calcium from the tissue deposits into your bones immediately following parathyroidectomy, which may lead to prolonged and symptomatic low blood calcium causing weakness, cramps, spasms or even seizures. For this reason, patients undergoing parathyroid surgery are typically admitted to the hospital for close observation and frequent testing of blood calcium levels. Other complications may include bleeding, a sore throat or difficulty swallowing initially.

Patients usually require preoperative calcitriol (vitamin D) supplements, as well as oral or intravenous calcium, magnesium, and calcitriol (vitamin D) supplements after surgery. Pain is usually modest and controllable with mild analgesics. Parathyroid surgery for ESRD patients is safe and has a similar complication rate to surgery for healthy, non-dialysis dependent patients. Typically, hospitalization is required for no more than a few days, but medicine and monitoring may be necessary for longer periods of time. Once stabilized patients often feel more energy, less joint pain and sometimes less itching.

As always, if you have any questions about your care, consult with your doctor first to make sure the treatment is right for your condition.

Parathyroidectomy may be safer if performed prior to transplantation. Parathyroidectomy performed after transplantation has been associated with abrupt deterioration of renal allograft function, so always talk it over with your transplant specialist for those with a

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