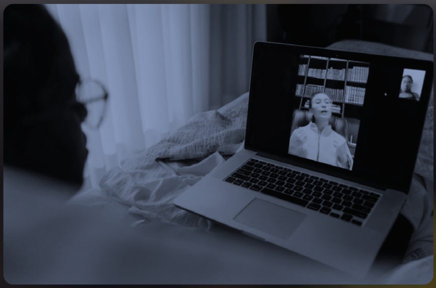
issue number 16

The Citizen Kidney

A publication of Dialysis Patient Citizens (DPC) Education Center

DPC EDUCATION CENTER

NAVIGATING KIDNEY DISEASE



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President's Message

Hello my Kidney Community,

We are now in the last quarter of the year and have the opportunity to either catch up or finish personal projects that are lingering in the background. Many of us have set goals, resolutions, and projects at the beginning of the year that we have left unaccomplished or halfway done. I am here to tell you there is no time like the present to get it done. Since we are in the fall and holiday season, and as we approach the end of the year, this is a great time to strategize a plan to take into the new year.

Use this time to make or reschedule important doctor appointments. It may have been a while since you saw your PCP or had necessary blood work done. Early detection of potential health problems is important in our CKD community. You may need to be referred to specialists, recommended hospital procedures, or provided with more advanced care. Schedule your annual physical to address any health concerns you have and take preventative action. Take this time to speak to your healthcare team about helping you create a personalized health care plan that works best for you. This should include working to meet specific goals, addressing unique needs, and following an individually tailored schedule of lab work, fitness training, immunizations, and other required tests. Ask your doctor to provide recommendations on your exercise routine, as well as advice on following a healthy diet, getting a better night's sleep, managing stress, and assessing your risk of other complications.

It can be difficult to remember everything you want to discuss at your appointment. I always suggest making a list of questions and concerns ahead of time and keeping it in a journal for reference with the following information for every visit: your questions and concerns, medications you currently take, specialists you have seen recently, and a list of improvements you would like to see with your health.

As patients, we have to practice listening to our bodies. Remember, if you do not use it, you lose it! Keep active and stimulate your brain as much as possible with the information we provide on the DPC Education Website and social media pages. With the holidays approaching, we may experience many emotions such as happiness, joy, depression, or anxiety. If you are suffering from feelings of sadness, extreme stress, and alcohol or drug dependence, talk to your social worker, patient advocate, and doctor about ways you can get help.

As ESRD patients, we go through psychological changes on a daily basis. I remember as an ESRD patient I had experiences of feeling lonely and depressed. I had to take time to make sure I reassessed the people I had around me to ensure that if I could not recognize the feelings I was experiencing, then at least my support group would know and reach out, even if it only meant to listen.

Remember to enjoy the season and start the next year on a healthy and positive note. Although holidays reconnect us with loved ones, they can be fraught with complex friends and family dynamics, money worries, dialysis treatment scheduling, and the endless preparation of food. Make time for yourself, it is okay to say no to things you don't want or don't have time to do. It is ok to say no to food selections that will not leave you feeling your best. Plan ahead and set boundaries for your time. Do what you can ahead of time, whether that means having a healthy snack before holiday meals so you do not overindulge on sweets, or preparing your own dialysis friendly meal to bring to the holiday gatherings. Shopping in bulk, meal prepping, and freezing meals can save time, save money, and reduce unhealthy meal choices. Decide what matters most and do things that truly bring you joy.

This time of year triggers depression for a variety of reasons. Do not be embarrassed to ask for help, talk to your doctor about counseling, and reach out to those who are without family and friends during this time of the year. Holidays are especially difficult for those who are alone. Do not give up on your diet and workout plans. Take these couple of months to review and manage your wellness plan. Early detection of underlying disease can sometimes result in better prognosis and better outcomes, especially since CKD and ESRD patients crash into dialysis while already having chronic health conditions. Use this holiday season to also review and update personal and family history, especially if you see numerous providers. Let our DPC Education Center site serve as a reference to keep you informed. Allow our educational information, webinars, and support group to be your partner in your well-being.

Merida Bourjolly

President of DPC Education Center Board of Directors

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Board Members and Advisory Council

Telehealth with a Behavioral Health Professional: What to Know Before You Start

By Kirsten Weir

If you or a family member is managing chronic kidney disease, you're probably thinking a lot about physical health—the health of the kidney and the rest of the body. Caring for your behavioral health is just as important. And with telehealth options that let you see a behavioral health professional from your home, it's more convenient than ever.

"The increased availability and acceptance of telehealth might be one of the few positive changes to come out of the [COVID-19] pandemic," says Amy Walters, PhD, a clinical health psychologist and the director of Behavioral Health Services for St. Luke's Humphreys Diabetes Center.

There are very good reasons to establish care with a behavioral health professional, Walters adds. "Living with chronic disease is stressful. And having a mental health provider on your team is an asset," she says.

When should you see a behavioral health professional?

Kidney disease comes with a lot of challenges. Psychologists or other behavioral health professionals can help in many ways. They can work with you to develop positive coping skills and support you in making healthy lifestyle changes (like taking your medicine on time or changing your diet). Chronic illness can put a strain on relationships with family and friends, and behavioral health professionals can help you manage those social relationships, too. They can also treat illnesses like anxiety and depression, which are more common in adults and children with chronic illnesses.

Seeing a psychologist doesn't have to be a long-term commitment, Walters adds. "Even having just a few appointments can be helpful for learning some basic coping strategies," she says. And if other challenges arise later, you'll already have a relationship with a psychologist. "You can return to care as often as needed," she says.

Traditionally, that care took place in a behavioral health professional's office. Now, telehealth has become the norm. Telehealth, also known as telemedicine, lets you connect with your provider from anywhere. "Telehealth brings the [mental health] provider into your home," says Marlene Maheu, PhD, a clinical psychologist and founder of Telehealth.org.

The Pros and Cons of Telehealth

Telemedicine appointments are usually conducted online using videoconferencing. (Sometimes, though, telehealth is delivered over the phone without video.) Early research shows that video telehealth for behavioral health is as effective as in-person psychotherapy. And telehealth has a lot of benefits:

- **Access:** Telehealth gives you the chance to see behavioral health professionals across your state (and sometimes beyond). This is especially helpful for people in remote or rural areas, where there aren't many psychologists available. Telehealth also improves access to specialists. There may not be a psychologist in your region who has experience helping patients manage chronic illnesses, for example, or who specializes in treating children. With telehealth, you can see specialists in other cities who meet your needs.

- **Safety:** With COVID-19 still circulating, some people prefer to limit their exposure to public spaces, particularly kidney transplant recipients who take immunosuppressing medication. Telehealth is a safe way to access services without having to take a bus or sit in a clinic waiting room. And COVID isn't the only virus to consider, Walters says. During cold and flu season, telehealth can limit your exposure to other illnesses, too.

- **Convenience:** Traveling to a behavioral health appointment can mean taking time off work, traveling to and from the clinic, and paying for transportation or parking. If you have children, you might have to arrange a babysitter while you're at your appointment. Such factors can make it hard to work psychotherapy into your schedule. Telehealth eliminates the travel time and other obstacles that can interfere with planning an appointment.

- **Comfort:** Many people are more comfortable on their own turf. Discussing sensitive topics with a behavioral health provider might seem easier when you're surrounded by the comforts of home.

While telehealth has a lot going for it, it isn't for everyone. Because services are delivered over the computer or the phone, it might not be the best choice for

people who have unreliable technology or trouble using a computer.
Some people find it harder to form a connection with a behavioral health provider when they aren't in the same room. That can be especially true for young children, or for people with vision or hearing problems. Those are factors to think about when considering telehealth, Walters says. "But for most people, the positives of telehealth outweigh the negatives," she adds.

How to Find the Right Telehealth Provider

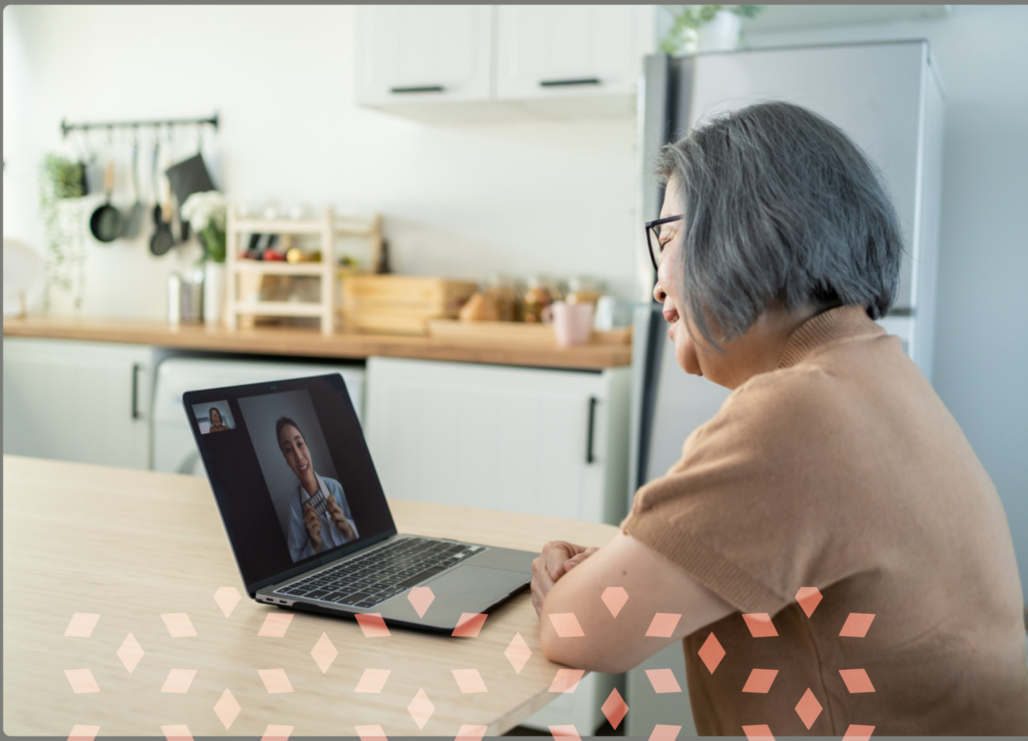
If you're ready to look for a behavioral health provider, start by asking members of your medical team. They may be able to recommend psychologists or other professionals who could see you by telehealth. You could get recommendations from friends or family members. And the APA Psychologist Locator can also help you find a psychologist near you.

While telehealth makes it possible to see a provider hundreds of miles away, it's important to see someone who is licensed to provide care in the state you're in. It's also a good idea to look for someone who has been trained in telehealth, says Kenneth Drude, PhD, a clinical psychologist and professor at Wright State University. "Especially during the pandemic, a lot of people jumped into telehealth," he says. "To ensure quality care, you should ask about what kind of training they've had in providing telehealth services."

Many experts recommend meeting with two or three different behavioral health providers before deciding which is the right fit for you. You want to find someone that you feel comfortable with, so you can speak honestly and be yourself. "It's not necessarily about who you like best, but who you think will be the best fit for taking you where you want to go," Maheu says.

Preparing for a Telehealth Behavioral Health Visit

Your first visit with a psychologist will be similar whether you're in person or on a video call. During your first meeting, you'll focus on getting to know one another. You can let your provider know your concerns and goals. Together you can discuss a plan for moving forward.



When preparing for your telehealth visit, there are some things you can do to help it go smoothly. First, familiarize yourself with the technology. Your provider's office will give you instructions about how to log into the appointment at your scheduled time. If you have questions or have trouble logging on, reach out to your provider's office with questions.

Many behavioral health providers send questionnaires before your first appointment. Filling these out ahead of time lets your provider learn a bit about you and your background.

When the time comes for your appointment, find a quiet location where you can have a private conversation. The fewer the distractions, the more valuable your session will be.

You might feel a little anxious about seeing a behavioral health provider for the first time. But it's often easier when you can do it from the comfort and safety of your own home. And most people who see a behavioral health professional are glad they did. "That individual is there to listen to you, to understand your challenges and to help you make a plan for next steps," Walters says. "It's one more piece of the puzzle in taking care of your overall health."

Kirsten Weir is a health and science writer and regular content contributor for the American Psychological Association.

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

Advanced Care Planning:

Turning “What If?” Into “Here’s How”

By By David L. Mahoney,
MD, FASN, FASDIN

A number of years ago, I attended a lecture on Advance Care Planning. The speaker was a very engaging man who had recently dealt with end-of-life issues for a loved one. There were about 150 people in attendance at the lecture, which began with a series of questions:

“How many of you have life insurance?”
Virtually every hand in the room went up.

“How many of you have a will?”
About three quarters of the hands were raised.

“How many of you have a living will?”
About 10% of hands were raised in response to this question.

I think that this illustrates the fact that we all make certain plans to provide for future events, but very few of us include our health care considerations among them. Patients with kidney disease are faced quite often with making decisions related to their healthcare; thinking about those issues and documenting our wishes in a formal manner can alleviate much of the uncertainty and stress when a major health event occurs. Advance Care Planning is the process of defining a patient’s wishes pertaining to their healthcare and is designed to cover the continuum of their healthcare experience through end-of-life. It involves reflection, communication, and discussion among the patient, family or healthcare proxy, and healthcare professionals. Advance Care Planning may include important legal documents such as an advance directive, which provides clear instruction for the healthcare team about choices and goals of care in the event that a person becomes unable to make those decisions actively at the time of a major health event.

The Center for Medicare and Medicaid Services (CMS) has addressed patients’ rights with respect to advance directives.

CMS regulation 494.70(a)(6) Patients' Rights states that patients must be informed about their right to have advance directives and about the dialysis facility's policies regarding them. In addition, CMS requires that facilities document in the patient's medical record whether or not an advance directive has been executed.

There are several important elements to Advance Care Planning. A healthcare proxy is a person chosen to make medical decisions for a patient who has lost decision-making capacity. An example of when this may apply is in the event of an accident where the patient is rendered unconscious and cannot respond to questions. Physician Orders for Life-Sustaining Treatment (POLST) are another example and are completed when a physician has held a conversation with the patient and documents the patient's wishes regarding choices of care at the time of a significant medical event or at end-of-life. I have said many times that it is impossible for me to honor a patient's wishes if I have not asked what they are.

These discussions can be difficult for patients, family members, caregivers, and clinicians alike. They involve emotions, faith and values, support systems and most importantly, patients' wishes. It is always best to have these conversations at non-urgent times and to ask them as a series of "What if" questions. For example, "Twenty years from now, if you had a stroke, would you want ..." In this manner, the event is clearly non-urgent, and the discussion is rendered much less frightening. But the important information is conveyed. It is also important to remember that this is a dynamic process that is not completed in a single conversation, but is instead the product of ongoing interactions among the patient, family, care team, and physician that evolves over time. Any time a major health event occurs, it is wise to review the Advance Care Plans.

In many instances, particularly for elderly patients, conservative care is chosen as the preferred management of kidney disease and kidney failure.

Treatment consists of preserving existing kidney function and controlling symptoms without pursuing dialysis or transplant. Conservative care allows the patient to have control over their quality of life when life expectancy is limited.

Palliative care is care which is focused on quality of life. Many patients may experience a slow progression of disease rather than a sudden catastrophic event. As disease progresses, many patients will elect palliative or supporting care which has the following goals:

- Relief of symptoms
- Control of pain
- Facilitation of meaningful interactions between patients and their loved ones
- Increased emotional and spiritual wellbeing
- Reduction of caregiver burden

Perhaps the greatest benefit of palliative care is the focus on improving the patient's quality of life.

Finally, hospice care involves a team-oriented approach to medical care, pain management, and emotional and spiritual support as the patient approaches the end of life. Many times, the decision by an end-stage kidney disease (ESKD) patient to pursue hospice care can be confusing and intimidating. Patients are often not aware of hospice benefits available in the setting of ESKD. Patients and families may welcome an opportunity to discuss preferences for care, particularly if they are fearful of a terminal diagnosis. ESKD patients who are Medicare beneficiaries often benefit from hospice care and should inquire about benefits for which they may qualify.

The primary goal in patient care should be to achieve the best healthcare-related quality of life. By seeking to understand the patient's goals and desires, we have the greatest opportunity to provide the best possible quality of life in accordance with the patient's wishes. Advance Care Planning is essentially the process of documenting the patient's wishes so that they may be honored.

For more information about Advance Care Planning, speak with your social worker or physician.

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
EVIDENCE UPDATE
DECEMBER 2020

Blood Sugar Testing to Manage Type 2 Diabetes in Patients Who Don’t Need Insulin

Checking your blood sugar daily may not help you manage your type 2 diabetes.

If you have type 2 diabetes, it’s important to keep the amount of glucose, or sugar, in your blood at a healthy level. Many patients check their blood sugar at home each day. Patients place a drop of blood from their fingertip onto a test strip; then they insert the strip into a home glucose meter. This test measures your blood sugar level at that moment.

People who use insulin check their blood sugar often so that they know how much insulin to take. But if you don’t use insulin, recent research shows that daily blood sugar testing may not help you manage your type 2 diabetes.

Findings

A recent PCORI-funded study found that people with type 2 diabetes who don’t use insulin did not benefit from daily self-testing. Study participants who checked their blood sugar each day for a year had the same A1c and quality of life as people who didn’t test daily. Even participants who tested daily and received text messages about their results had about the same A1c and quality of life as those who didn’t test daily.

What Do the Findings Mean for Me?

If you don’t need to take insulin, you and your doctor may want to talk about whether daily self-testing is right for you. Your doctor may recommend that you check your blood sugar less often.

Important: People with type 2 diabetes should get an A1c test every few months. An A1c test measures average blood sugar levels over the past three months. For this test, a lab or clinic collects a blood sample and sends the results to you and your doctor. Recent research doesn’t recommend any change to A1c testing. Your doctor can tell you when to schedule your next A1c test.

When deciding how often to check your blood sugar, your doctor will look at your overall health, your latest A1c score, and your lifestyle. Your doctor will also look at your blood sugar control over many months or years.

It's important for people with type 1 diabetes, people with type 2 diabetes who take insulin, and people with a recent type 2 diabetes diagnosis to check their blood sugar each day.

How Do These Findings Fit with Other Research?

Older studies also found that daily testing didn't improve blood sugar control in people with type 2 diabetes whose blood sugar levels were already well controlled. Although some studies found that blood sugar levels in these patients improved slightly, the improvements were too small to make a difference in patients' health.

This PCORI-funded study is different from earlier studies that looked at this topic. For example, the study included more people with type 2 diabetes. It also looked at patients' blood sugar levels for a longer time than earlier studies.

What Questions Should I Ask My Doctor?

Before making any changes to your routine for managing your diabetes, you should talk to your doctor. Here are some questions you may want to ask.

- Based on my blood sugar levels and diabetes management plan, do I need to check my blood sugar daily?
- If I don't need to check it each day, how often should I test my blood sugar?
- What situations would make me need to check my blood sugar more often? For example, if I changed my diet or exercise routine, would I need to test daily?
- Am I up to date in my A1c testing?
- What else can I do to keep my blood sugar under control?

Read more about this study at *www.pcori.org/Donahue018*

SOURCES

© 2011–2020 Patient-Centered Outcomes Research Institute. "Does Daily Self-Monitoring of Blood Sugar Levels Improve Blood Sugar Control and Quality of Life for Patients with Type 2 Diabetes Who Do Not Use Insulin? -- The Monitor Trial." Last Updated February 20, 2020. https://www.pcori.org/Donahue018

Young LA, Buse JB, Weaver MA, et al. Glucose Self-Monitoring in Non-Insulin-Treated Patients with Type 2 Diabetes in Primary Care Settings: A Randomized Trial. *JAMA Internal Medicine*. 2017;177(7):920-9.

About the Study

The research team looked at 450 people with type 2 diabetes. The patients were recruited from 15 primary care clinics in North Carolina. Patients were ages 30 and older. Their A1c levels were between 6.5 percent and 9.5 percent. The patients did not take insulin to control their blood sugar.

Notes:

Will the COVID-19 Pandemic Ever End?

By Alan S. Kliger, MD

Some recent quotes I've heard - - - I'll bet you have too: *"Who can even pay attention when the subject of COVID-19 is raised?" "Enough already – I'm through with it." "What's the difference? Even with vaccines and boosters, I still got COVID twice!"*

After nearly three years of this pandemic, COVID-19 infection has gone from a frightening and deadly disease to a major disruptor of our lives, to annoying background noise for most of us. And yet, the emergence of the Omicron BA.5 variant makes COVID-19 as easy to catch as the measles, and this variant seems to evade the current vaccines' protection from infection and ability to spread. The extraordinary length of time of this pandemic, coupled with the decline in life-threatening complications per person infected each month, has convinced many that the pandemic is over, and it is safe to go back to pre-pandemic "normal" life. When I went shopping yesterday in a large supermarket, where hundreds of shoppers and workers were close to one another indoors, only a small handful of customers were wearing masks.

So where are we really? What should dialysis and transplant patients think and do? Does anything protect us from infection and serious complications? Here is my perspective:

1. COVID-19 remains widespread in our communities. While most healthy people survive the illness if infected, others remain susceptible to complications or even death.

2. Hundreds of people die each day of COVID-19 or with COVID-19 in the US.

3. Long COVID affects about 20% of people who get infected, with long-lasting symptoms. People with mild infections still can later suffer from Long COVID.

4. People who choose to forego vaccination have a much higher likelihood of suffering complications or death if they are infected with COVID-19 than those who get vaccination and booster protection.

5. People taking immunosuppressive medicines, such as transplant patients and others with conditions best treated with these powerful medicines, often do not develop the protection that COVID-19 infection, vaccination, and boosters provide healthy people. For these individuals, COVID-19 remains a high risk for infection and complications.

6. Most dialysis patients have good immune system function and do develop protective antibodies and cell-mediated immunity when they get vaccinated and booster shots.

7. Masks, particularly if they are snug around the nose and mouth, do offer protection from catching COVID-19. It is not perfect protection. It is not a 100% guarantee against catching the infection - - but it surely reduces the chances of catching this very nasty virus.

8. Since dialysis facilities began screening, separating infected patients from others, insisting on well-fitting masks for everyone; since staff all wear clean gowns, use hand hygiene and gloves between patient contact, and give close attention to cleaning of surfaces and dialysis stations between patient shifts, there has been little evidence that anyone catches COVID-19 in the facilities. These protective measures clearly work and should continue for as long as community infection rates remain high.

9. This pandemic has taken a toll on the psychological health of both patients and staff. Life has become much more isolating; stress levels have gone up and for some of us stay high for prolonged periods. This has led to a high incidence of post-traumatic stress disorder. Many staff and patients have suffered from compassion fatigue, after months and months of long working hours, with the worry of catching and carrying infection back home and the fears of what might happen if infection strikes. These challenges require just as much attention as we give to eradicating the infections.

Where does all of this leave us? Again, my thoughts:

1. We are much better off now than we were in the spring of 2020 when the pandemic first struck here in the US. We have vaccines that may not prevent all infections but do prevent most of the serious and life-threatening complications we saw in 2020. We have ways to protect those who have impaired immune systems: monoclonal antibody treatment works. We have new anti-viral medications that stop the serious complications in people who do get infected, although some of these medications cannot be used in people with very low levels of kidney function.
2. Dialysis facilities have done a fabulous job of preventing spread of infection during dialysis treatments.
3. Face masks reduce the chances of serious infection and are most effective if they are well-fitted and snug around the nose and mouth, with no air leakage and all breathing through the mask material rather than around it.
4. A new vaccine has been approved for use, that protects against both old and new strains of COVID-19. If you are at least two months since your last vaccination for COVID, or four months since you had a COVID infection, it is a good idea to get vaccinated with this new vaccine.
5. Outdoor contact with people is the safest to prevent COVID-19 spread. Indoors, the use of face masks and common sense to stay away from anyone with active infection, remain our best strategy to stay healthy and resume more normal lives.

From my perspective, the best answer is not at the extremes, but in the middle. I don't think it is wise to keep ourselves isolated and avoid all human contact. But likewise, I don't think it is wise to pretend that the pandemic is over. Human contact – our gift of being with each other and sharing our lives, must continue. So should common sense measures like avoiding most indoor contact with strangers, wearing masks if we do spend time indoors, getting and maintaining CDC-recommended vaccination, boosters, and other medications if you do catch COVID-19. Life has changed since this infection has whirled around the world, and some of those changes may persist for a long time. Still, we now can spend more time back in our "normal" lives, without fearing every moment of contact, and we have more knowledge of how to keep ourselves safe.

Stay safe!

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

Conquering Dialysis Fatigue

By Patricia McCarley, RN, MSN, ACNP and
Felicia Speed, PhD, LMSW

Patients on dialysis may complain of an intense feeling of tiredness or fatigue with 60-97% of patients finding it as important a health outcome as mobility or pain. While it may be difficult to identify the exact cause, patients with chronic kidney disease (CKD) or end stage renal disease (ESRD) have several factors contributing to fatigue, including uremia, an increased level of waste products in the blood, and anemia, a decrease in red blood cell production.

Anemia is a condition in which your body does not produce enough red blood cells to carry oxygen throughout the body. Fatigue is one of the symptoms you may experience when you are anemic. Healthy kidneys make a natural hormone called erythropoietin or EPO. When your kidneys are failing, they will no longer produce normal amounts of the hormone EPO, making it much harder for you to maintain a healthy red blood cell count.

Another common issue for dialysis patients is difficulty sleeping or difficulty achieving quality sleep.

How many hours of sleep are you getting each night? If your answer to this question is seven to eight hours, that's excellent. But if you're only getting five or six hours of sleep each night or waking up in the middle of the night often, there are plenty of steps you can take toward sleeping more soundly and therefore feeling better during the day.

Some common issues people face when it comes to getting enough sleep include restless leg syndrome and sleep apnea. Restless leg

syndrome is a condition that causes an uncontrollable urge to move the legs, typically in the evenings. Sleep apnea is a disorder in which one has difficulty breathing when sleeping.

There are ways you can improve your sleep wellness. One way is to address fluid management. Your care provider can adjust your fluid removal, so just the right amount of fluid is being removed, to help decrease discomfort when it's time to sleep. It is also important to talk with your dietitian and nurse to explore ways to control your fluid intake, while also ensuring you complete your entire treatment. You can try to create a better sleeping environment by taking steps to optimize your bedtime routine and bedroom. Turn your phone and TV off ahead of time or do relaxing activities such as meditating or reading. Be sure to ask your care provider how they can work with you to improve any aspect of your sleep. You can also ask about home treatment, which may result in better fluid management.

If you're on dialysis, you may experience unpleasant side effects such as feeling tired most of the time. If so, you're not alone. Your care team is always here to listen to your concerns about fatigue, tiredness, or poor sleep quality. Once you tell them the issues you are facing, they can put together a plan to address any issues that arise, and whether it can be solved by striving for better sleep, addressing other health conditions, or increasing the frequency of your dialysis treatments.

Navigating a Renal Diet: Decoding the Mystery

By Fanny Sung Whelan,
MS, RDN, LDN

How to navigate a renal diet based on your kidneys' needs

No matter what stage of kidney disease you're in, all of the different diet recommendations can cause your head to spin. Pair it with other conditions you may have, and you've got a real recipe for confusion! So how can you sort out all of the differences in what you can and can't eat? Here we are going to outline the diet guidelines for the different stages of kidney disease. Disclaimer: it is important to discuss any diet changes with your health care team before you proceed. Everyone's needs will differ based on the individual. One diet does not fit all.

What diet should you follow before you start dialysis?

In general, when you are in chronic kidney disease (CKD) stages 1-4, it is important to make diet changes to help meet your new needs based on your disease. In CKD stages 1-4, the main goal is to help slow the progression of kidney failure, which may delay your need to start dialysis. The earlier a kidney-friendly diet is started, the better off you'll be [1]. Calorie needs increase just slightly with CKD, and individual needs based on details such as age, lean body mass, and physical activity

level will need to be discussed with your facility dietitian. A moderately decreased protein intake is recommended, as current research supports a more plant-focused diet although all may need not to be totally plant-based. A diet that focuses on more plant-based proteins will include beans, nuts, seeds, and legumes, especially paired with whole grains for complete combinations of amino acids [1]. Diabetic patients may need a slightly higher protein intake for better glycemic control [2].

Sodium is a mineral that is found in salt and is used in many food preparations [3]. Salt intake is high in the American diet not just from adding it to the foods we cook but also from processed foods that we consume. Salt reduction is beneficial in that it helps to control high blood pressure and reduce fluid retention [2], and it is an important step in helping to control your kidney disease [3]. It can take time adjusting to a diet that is less salty, and here are some tips that can help you achieve that goal.

- Limit salt when cooking food or when you eat. Limiting table salt, kosher salt, sea salt and iodized salt and replacing with fresh herbs, spices, lemon, limes, and vinegars as appropriate can help your food still be flavorful. If you must use salt when cooking, sprinkle on a pinch of sea salt after you are finished cooking the food. Avoid using the saltshaker, which offers less control.
- Use seasonings that do not contain salt, such as garlic powder, onion powder, chili powder, and other herbs and spices. Avoid flavored salts such as garlic salt, onion salt, celery salt, or “seasoned” salt.
- Buy canned vegetables that say “no added salt” on the label.
- Avoid cured and processed meats such as ham, bacon, sausage, hot dogs, lunch meats, bologna, and chicken tenders and nuggets.
- Avoid canned soups unless the labels say reduced sodium level, and only eat half of the can, not the whole can. Reduced sodium canned soups are still high in sodium.
- Look for lower salt or “no salt added” options for packaged foods such as peanut butter or box mixes.
- Learn to read nutrition labels. Avoid foods that have greater than 300 mg of sodium per serving or 600 mg for a frozen dinner and limit yourself to one serving of the lower sodium versions. Avoid foods that list salt in the first five items in the ingredient list.
- Avoid purchasing meats that are packaged “in a solution” or are pre-seasoned [3].
- When dining out, order items that are freshly prepared such as grilled chicken breast or fish and ask for no added salt or sauces.

Potassium is a mineral that aids in muscle movement and control. When your kidneys no longer function properly, potassium can build up in the body. This can cause changes in how your heart beats, which could lead to a heart attack. If your doctor or health care provider has told you that your potassium is high, you will need to avoid or limit certain foods [3]. Not all people with kidney disease need a potassium restriction, so before implementing this restriction, talk with your dietitian about whether or not potassium is something you need to limit. If you do need a potassium restriction, some foods to be aware of include:

- White potatoes and sweet potatoes
- Bananas
- Oranges and orange juice
- Grapefruit juice
- Tomatoes, tomato sauce, and tomato soup
- Melons like cantaloupe and honeydew
- Dried beans
- Pumpkins and winter melons
- Cooked greens such as turnip greens, kale, and Swiss chard

Phosphorus is another mineral that is important to limit or avoid. When phosphorus levels are high in your body, calcium can be pulled from your bones and deposited into your soft tissues like your heart. Bone and heart disease can become a problem, making it more likely for you to break a bone or have a heart attack [3].

Some foods that are high in phosphorus:

- Dairy products like milk, cheese, ice cream, and yogurt - try to limit to one serving a day.
- Some drinks such as colas, Pepper-type colas, certain brands of root beer, alcoholic beer, and some flavored waters and juice drinks. Ask your health care provider for more details if you have questions or concerns about the drinks you choose.
- Packaged and processed foods that contain phosphorus additives. Phosphate additives are used in some foods as a preservative or to improve the flavor, texture or moistness of some foods. Look for the word “phosphate” under the ingredients list. The word can be on its own or combined with other words such as “tetrasodium pyrophosphate.”
- Fast foods and processed foods should be limited or avoided completely.

You’re on dialysis. Now what?

You have now started dialysis. How will your diet needs change? Regardless of whether you are doing in-center hemodialysis (ICHD), peritoneal (PD) or home hemodialysis (HHD), it is safe to say that your dietary needs will be different than before. Your energy and protein needs will change, and your potassium, phosphorus, sodium, and fluid intake will need to be more closely managed [4].

As you begin dialysis, your energy needs will increase, and your mode of dialysis can affect how these needs are met. All forms of dialysis use dialysate solution to clean your blood, but the type that is used in PD contains carbohydrates. The calories from this solution will be absorbed at a rate of 200-800 calories a day. It is important to discuss your specific treatment prescription with your health care provider to get a clear idea of what your energy needs are.

One change that may require adjusting to is the protein increase. Before you started dialysis, you followed a low to moderate protein intake, sometimes a more plant-based protein diet. Now that you are on dialysis, your protein needs will increase and, for some people, the increase will feel drastic. Due to these high protein needs, it can be difficult for dialysis patients to consume enough protein from whole foods. The protein needs of PD patients will be even higher due to the removal of protein in the dialysate solution.

There have been some studies that suggest a plant-based diet can have benefits for dialysis patients, too. A plant-based diet is one that typically includes no animal proteins such as meat, fish, seafood, dairy, and eggs. Those who choose to follow a plant-based diet would consume mainly fruits, vegetables, nuts, seeds, grains, legumes, and beans. The typical dialysis diet has tended to lean away from plant-based diets, in part because these foods are higher in potassium. These restrictions can lead to a diet that is lacking in variety, resulting in limited satisfaction. Not only does liberalizing your diet to include these plant-based foods increase your satisfaction, but it may also lead to other benefits, such as improved cardiovascular health, improved inflammatory markers, healthier gut microbiota, and alleviated constipation. Another benefit of following a plant-based diet may be decreased phosphorus levels, as the phosphorus that is found in plants is less easily absorbed. If you choose to follow a plant-based diet, it is important to make your health care providers aware of your diet changes, as they may want to watch for increased potassium levels and ensure that you are getting enough of the right kinds of proteins [5].

What about PD and HHD? Are there differences in the diet recommendations for these modalities?

The short answer is sometimes! Most of the diet recommendations for PD and HHD will be very similar to ICHD with a few exceptions. In PD, your blood is cleaned by putting a solution in your abdominal cavity, and through osmosis and diffusion, the toxins are removed when the solution is drained from your abdomen. Through this process, a lot of the potassium is removed as well, much more than in ICHD. Many PD patients will need to liberalize their diets to include more high potassium foods. Some people on PD even need to take potassium supplements to keep potassium levels from staying too low. Protein needs will also be slightly higher in PD than ICHD, and because of the protein losses from draining the solution from the body, protein needs can be difficult to meet for some people. Protein supplements, such as shakes, powders, bars, and other protein supplements, are often utilized to help meet those higher needs. Calorie needs may be slightly different as well. Since the PD solution provides some calories, fewer calories in your diet will be needed to meet your needs [6].

For those who choose HHD, you will often be treated with longer dialysis times for more days of the week when compared to ICHD, leading to better dialysis and therefore better outcomes. When your labs are meeting all of the prescribed goals, your diet may be liberalized some. Adequate protein intake will still be important, as will be managing potassium, phosphorus, and fluid, but it may be easier to do so. Each person on HHD is different and unique, so it is important to talk to your health care provider to learn what your specific nutritional needs are, as they may vary from month to month [7].

You got a transplant! Now what do you do?

Congratulations if you have received your long-awaited transplant! At this stage in your journey, you will want to do whatever it takes to make sure your new kidney is being taken care of properly to prolong its life. Taking your anti-rejection medications is a big part of preserving your new kidney, but diet will play a role as well. So, how will your diet needs change?

Your diet needs will be different depending on how long you have had your new kidney. If it is soon after your surgery, you will need to be sure to get enough calories and protein to help heal from surgery and to prevent infection. You may also need to adjust your diet in response to the sudden electrolyte changes you may experience. Your new kidney will be working fervently, and electrolytes like potassium, magnesium, and sodium, may suddenly be too low [8]. Your transplant team will follow you closely in the months after your transplant to make sure your new kidney is working properly and will instruct you on any diet adjustments that you might need to make.

As you settle into a new life with your kidney transplant, your diet needs will shift focus. No longer will sudden electrolyte imbalances be as much of a concern. Now you will have to consider following a diet that will minimize diabetes, obesity, and heart disease [9]. There is limited research on the best diet for post-transplant, but there is a general consensus that following the Mediterranean and DASH diets have protective benefits, as these diets focus on reduced meat and processed foods with increased fruits and vegetables and limited sodium. The Mediterranean diet, which emphasizes high unsaturated fats found in olive oils and fish and low saturated fats found in red meat, has been shown to reduce risk of diabetes, cardiovascular disease, high blood pressure, hyperlipidemia, and mortality in kidney transplant recipients [9]. Closely following a Mediterranean diet has also been shown to improve overall kidney function in transplanted patients [10]. Incorporating the principles of the DASH diet, which reduces sodium intake and controls blood pressure, offers further protective measures to maintain the health of your new kidney [9].
As you continue living with your transplanted kidney, you will have been taking anti-rejection medications, or immunosuppressants, for a long time. These medications can cause certain side effects such as weight gain, dyslipidemia, new onset diabetes, osteoporosis, increased potassium, or decreased magnesium [8]. It will be important to address these concerns with your transplant team, so they can help tailor a diet plan that will fit your individual needs.

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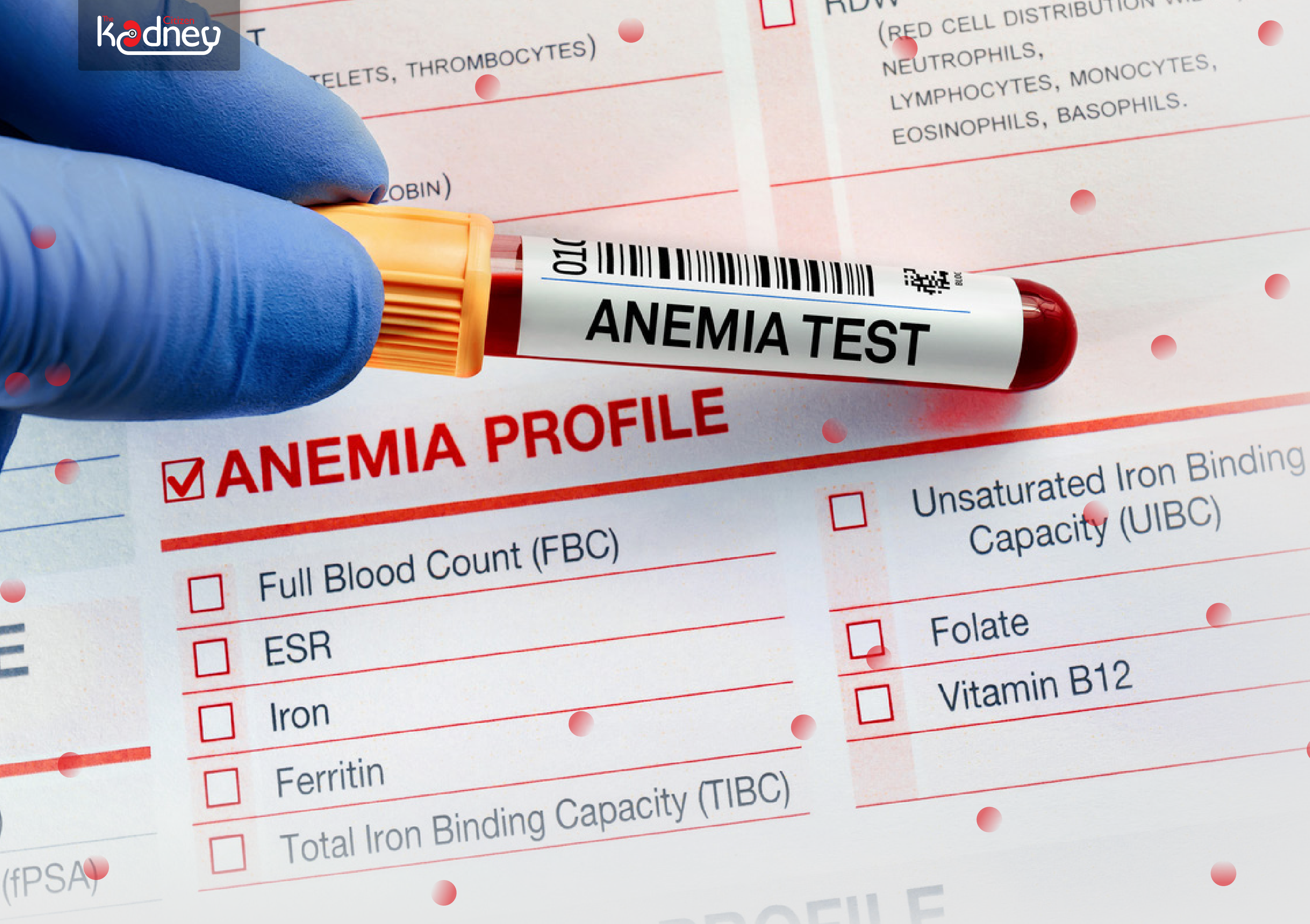
Anemia in People with Chronic Kidney Disease

By Jay Wish, MD

Anemia is defined as a lower-than-normal level of hemoglobin in the blood. Hemoglobin is the protein in red blood cells that carries oxygen to all tissues and allows those tissues to carry on their functions, including the creation of building blocks for energy. Hemoglobin is what makes red blood cells red, and this explains why people with low hemoglobin levels may appear pale. Hemoglobin levels less than 13 in men and less than 12 in women is considered anemia. Anemia is common in people with chronic kidney disease (CKD) and may have many causes. It is estimated that 15.4% of people with CKD (stages 1-5) have anemia, compared to 6.35% of people without CKD. The frequency of anemia increases with the stage of chronic kidney disease: around 10% in mild CKD (stages 1-2), around 20% in moderate CKD (stage 3), around 50% in severe CKD (stages 4-5), and around 90% in people undergoing dialysis. There are a number of reasons why people with CKD develop anemia.

The kidney is the major source of the hormone erythropoietin, or EPO. The kidney has cells that sense the amount of oxygen in the surrounding kidney tissue, which is the amount of oxygen delivered by the red blood cells minus the amount of oxygen which the kidney cells consume. If the hemoglobin level is low (anemia), the lungs are not able to absorb oxygen from the air, or the person is living at high altitude where the oxygen level in the air is low, the cells in a normal kidney will sense that low oxygen level in the surrounding kidney tissue and will respond by making EPO. EPO will travel to the bone marrow and lead to increased production of red blood cells, correcting the anemia or even making the hemoglobin level higher than normal to compensate for lung disease or living at high altitude. In a person with chronic kidney disease the production of EPO is lower than normal, primarily because of fewer EPO-making cells. However, the amount of oxygen in the kidney tissue might be normal because the diseased kidney is consuming lower amounts of oxygen, so the oxygen-sensing cells do not increase the production of EPO despite the presence of anemia.

The other major cause of anemia in people with CKD is iron deficiency. Iron is an essential component of hemoglobin and is what makes hemoglobin red. Think what happens when iron rusts – it turns red. People with chronic kidney disease may become iron deficient for a variety of reasons. A diet low in red meat (as is becoming increasingly popular) may provide insufficient amounts of iron to meet daily demands. The body has a number of mechanisms to prevent the over-absorption of iron from the diet since once iron is absorbed there is no physiologic way to get rid of it. Oral iron supplements containing ferrous iron must be oxidized by stomach acid to the ferric iron form, so any medication that decreases stomach acid production (proton pump inhibitors such as omeprazole, histamine-2 blockers such as famotidine) or food which neutralizes stomach acid may decrease the absorption of these iron supplements. The absorption of oral iron supplements by the small intestine is under the control of a hormone called hepcidin. Hepcidin is stimulated in the setting of inflammation or iron excess. Since CKD is often accompanied by inflammation, hepcidin levels are elevated and increase with advanced stages of CKD.



The inflammation may be due to a variety of factors related to the kidney disease itself or to other conditions including diabetes, heart failure, the presence of a dialysis catheter, or poor oral hygiene. Hepcidin also traps iron that's already in the body into storage sites and makes it unavailable to travel to the bone marrow to support the synthesis of hemoglobin. This is called functional iron deficiency and generally does not respond to iron supplements administered by mouth, as may absolute iron deficiency which the iron stores in the body are low. Oral iron supplements are often poorly tolerated due to upset stomach and/or constipation, leading to the need for supplemental iron to be administered intravenously (IV). IV iron administration is very common in in-center hemodialysis patients who can receive it through the hemodialysis blood circuit during the treatment. People with CKD not on dialysis or on home dialysis who need IV iron will come to an infusion center to receive the medication which is usually well-tolerated although there are rarely allergic reactions.

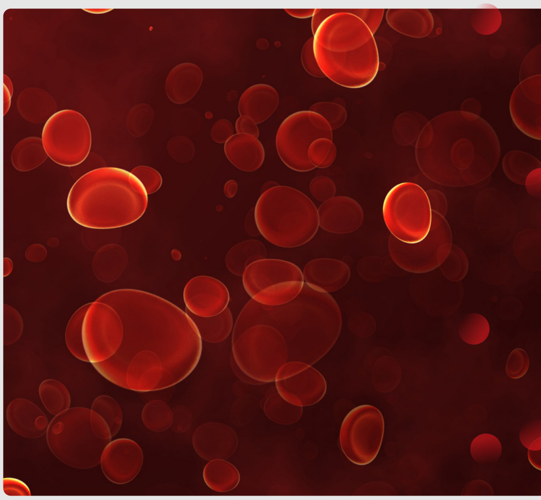
Other causes of anemia in patients with CKD include blood loss (particularly among in-center hemodialysis patients due to blood remaining in the dialyzer circuit following rinse-back, frequent blood testing, or vascular access procedures), which may be compounded by abnormalities in the blood clotting system due to the kidney disease itself and/or medications. It's known that the life span of red blood cells is less than normal in patient with CKD (reduced by as much as 50%). The accumulation of waste products in people with CKD may decrease red blood cell production even in the presence of normal amounts of EPO and iron.

The symptoms of anemia are variable. Every person with anemia does not experience the same symptoms at a given hemoglobin level and not every symptom that may be associated with anemia is necessarily due to anemia since many people have multiple diseases than can contribute to these symptoms. The most common symptoms of anemia are fatigue and lack of energy. Since the anemia of CKD tends to be gradual in onset as the kidney function declines, the person affected may adapt to the anemia both physiologically and psychologically so that the symptoms are less than had the hemoglobin fallen to the same level over a much shorter period of time. Most people with CKD do not develop symptoms of anemia until the hemoglobin level is less than 10, and many do not develop symptoms until the hemoglobin level is even lower. A study comparing symptoms among people with CKD with and without anemia, with which I was involved, (Kidney Medicine, 2022, volume 4, page 100439) showed that those with anemia had small but significant increases in symptoms, poorer physical well-being, poor social/family well-being, poorer functional well-being, and increased impairment in activity, work productivity, and work time missed due to health. However, it should be noted that those without anemia also had significant symptoms, well-being issues, and activity impairment related to their CKD, concomitant illnesses, and/or medications. Other symptoms that have been attributed to anemia include leg cramps, impaired sleep, and decreased libido. Studies designed to assess the effect of anemia correction in people with CKD (with synthetic forms of EPO) have been unsuccessful in consistently demonstrating a decrease in anemia-related symptoms while increasing the risk of cardiovascular complications such as vascular access thrombosis in patients on hemodialysis, heart attack, stroke, heart failure, and deep venous thrombosis/pulmonary embolism.

The international guidelines for the treatment of anemia of CKD recommend that all patients with CKD stage 3 or greater be tested at least annually for the presence of anemia with a complete blood count including hemoglobin level (more often in later stages of CKD or if anemia is present). If anemia is present, an evaluation for the cause of anemia should be undertaken with blood iron studies and possibly blood vitamin levels for folate and vitamin B12. If the person is iron deficient, evaluation for iron loss in the gastrointestinal tract may be appropriate. Treatment with an iron supplement can be by mouth or IV. Oral iron supplements may not be effective due to side effects which may limit adherence or to a severe degree of iron deficiency. Your provider might decide to go directly to an IV iron supplement, which may require several doses in an infusion center to provide a sufficient amount of iron to correct the deficiency. As noted above, people on in-center hemodialysis generally receive IV iron regularly through their blood circuit on the dialysis machine. If a person with CKD remains severely anemic (hemoglobin less than 10), then consideration is given to the use of synthetic form of EPO which is administered under the skin or IV. There are three forms of synthetic EPO currently available in the US: epoetin alfa (Epogen, Procrit or Retacrit), darbepoetin alfa (Aranesp), and pegylated epoetin beta (Mircera). They all have the same effectiveness in treating anemia and side effects, and their difference is in how often they are administered with epoetin alfa the most often and pegylated epoetin beta the least often. Your provider's choice of a synthetic EPO drug will likely be determined by which form your insurance covers or which form is on the formulary of your dialysis provider. Because of the cardiovascular complications mentioned above associated with the use of the EPO drugs, the Food and Drug Administration (FDA) recommends that these agents be initiated only when the hemoglobin is less than 10 and that the dose be decreased or discontinued when the hemoglobin is greater than 10 in non-dialysis patients with CKD, and when the hemoglobin is greater than 11 in dialysis patients. The FDA does not acknowledge any quality-of-life benefit from these drugs, and views them only as a method to avoid blood transfusion. Blood transfusion is a last-resort treatment for anemia and is generally reserved for people with hemoglobin less than 7 or with sudden blood loss. The decision to prescribe a blood transfusion is made based on the severity of the anemia, the symptoms, the clinical setting, and rapidity of hemoglobin decrease. Blood transfusions may be associated with acute reactions, infections, and iron overload. More importantly for people with CKD, transfusions trigger the production of antibodies to human proteins, which may limit the options for future kidney transplantation from living or deceased donors.

The treatment of anemia in people with CKD can be inconvenient for many patients not receiving in-center hemodialysis because it may require regular visits to a clinic or infusion center for the administration of EPO drugs or IV iron. There is a new class of anemia drugs currently under development, approved in other countries but not yet in the US, that is orally administered and may substitute for the EPO drugs. This class of drugs, called HIF (for hypoxia inducible factor) stabilizers, stimulate the EPO-producing cells in the kidneys and liver to make more EPO by making the oxygen sensors sense less oxygen. This allows people with CKD, even those on dialysis or whose kidneys have been removed, to make enough EPO to stimulate the bone marrow to produce more red blood cells and increase the hemoglobin level. There are three such agents which completed large scale global studies in people with CKD on dialysis and not on dialysis to demonstrate they are equally effective as EPO drugs in raising hemoglobin levels. The FDA did not approve two of these drugs due to safety concerns, but their manufacturers have the opportunity to do additional studies and request further review by the FDA for approval. The third HIF stabilizer drug is currently undergoing its first review by the FDA with a decision expected in early 2023.

In summary, anemia is common in people with CKD and is often associated with symptoms including fatigue, lack of energy, poor sense of well-being, sleep disturbances, leg cramps, and lack of libido. However, since many people with CKD also have other conditions and medications which may produce similar symptoms, it is often difficult to determine to what degree the anemia is contributing to their symptoms. Studies of anemia correction in people with CKD using EPO drugs failed to demonstrate a compelling improvement in anemia symptoms, while significant increases in cardiovascular complications occurred. The best approach to anemia in patients with CKD is early detection with regular screening for hemoglobin level, evaluation for iron and vitamin deficiency and blood loss. Iron deficiency is common in people with CKD due to dietary habits or prescriptions which restrict iron-rich foods, blood loss, and the adverse effects of inflammation on dietary iron absorption and release from internal stores. Iron supplementation, if needed can be oral or IV. If the person with CKD who is not iron deficient continues to have hemoglobin less than 10, consideration should be using an EPO drug, primarily avoid transfusion and not with expectation it will significantly improve symptoms.



Jay Wish, MD is Professor of Clinical Medicine at Indiana University School of Medicine and Chief Medical Officer for Out-Patient Dialysis at Indiana University Health in Indianapolis, IN. He has been in nephrology practice for over 40 years. He is particularly interested in anemia of chronic kidney disease and has written over 50 articles and book chapters on the subject.

The Social Worker – Patient Relationship:

One Social Worker’s Reflections

By Jean Carosella, LCSW

In April 2021, I retired from dialysis social work after working in the same clinic for almost 44 years. I had actually planned to retire a year earlier but the pandemic played a major role in my staying on another year. I just couldn’t leave knowing the stress and worry that COVID was creating for everyone in the clinic, patients and staff alike. But now a year into retirement, I can see one positive outcome for me as a result of the pandemic. COVID forced me to slow down and take the time to reflect on what my role as a dialysis social worker has meant to me.

I started my job in dialysis one week after graduating with my master’s degree in social work. I may have held the piece of paper saying I had all the education in the world, but I had very little life or professional experience. I knew dialysis had “something to do with kidneys” but it surely was not a topic covered in any of my social work classes. The first year was rough. I struggled, trying to figure out my role and how I could be helpful to patients and their families. I thought I was supposed to talk to them at every single visit about the meaning of their illness and how it affected their lives. But I eventually realized as they politely listened to me while stealing glances back at their TV screens, that there was so much more to my role. And the most important part was getting to know them as people with lives outside of those dialysis chairs. Only after I worked to make that personal connection could I earn their trust. It was then that our work together could begin. I had to get over my own worries about whether or not I could do the job and I had to be willing and open to hear each person’s story. By putting myself in the position of listener and learner, I was invited into their lives. What a gift for me!

Over the years I worked with patients on issues that were important to them - things you would expect and others “outside the box.” We talked about some of the usual topics such as transplant and the importance of staying in touch with the transplant team; fistulas, grafts, and catheters and their doctors’ recommendations; the dreaded monthly bloodwork results; and the benefits of coming for every treatment as prescribed. But in other situations, the issues presented weren’t so routine. In one case, a patient asked me to help him speak up for himself with his car mechanic who was charging him extremely high fees to repair his car. Together, we educated the shop manager about dialysis and transplant and the patient’s need to have a working vehicle for his job and his treatment. And we got the car bill reduced!

I have always believed that it was a privilege to talk to patients about concerns they had on their minds - from health issues to relationship problems to financial worries to feelings of depression and sadness to fears about loss and death. We all make choices in our lives about who we can trust with such personal matters.

When I was chosen to be that person, I wanted to do everything I possibly could to be a good listener, provide helpful ideas, and reinforce the personal strengths they had in order to help them cope. It was one of the most meaningful parts of my job to be able to provide support when times were the toughest.

During the course of my social work career, I sometimes had social workers outside of dialysis ask me about my work. They would say things like, "wow, that sounds depressing" or "I couldn't work with sick people." I was always shocked by their attitudes. In all my years working in dialysis, I can honestly say that I was never truly depressed by the work. Yes, I felt sad at times about what patients had to go through or frustrated when I couldn't find a resource to help them. But how often do social workers get the chance to form long-term meaningful relationships with a group of people who are brave enough to cope with illness every day and still maintain hope in their lives? How often do you get an opportunity to work with patients who have mastered the art of multi-tasking, doing their dialysis, keeping up with their home and often a job, family and personal relationships, and a spiritual life?

I have shared wonderful laughs with patients and families in good times and we sometimes cried together during times of great sadness. I have cheered them on when they've succeeded in reaching their goals and I have encouraged them to use their strengths when life handed them difficult challenges. It has been my honor to be invited to walk this road with our patients for so many years and I feel blessed personally and professionally for the opportunity I've been given.

But making a personal connection with your social worker is a "process". It doesn't happen in one meeting, and it requires effort on the part of the patients and social workers to create a positive working relationship. As social workers, the best way that we can help you is by getting to know you, your family, and other important people in your life. In my work, I would never have dreamed of saying to a patient, "I know how you feel." How could I? I've never had to sit through a four-hour hemodialysis treatment or perform peritoneal dialysis myself. I haven't been required to restrict my fluids, watch my potassium, etc., etc. In learning about you, your support systems, as well as the challenges you face in your life, we can better understand your unique experience as a dialysis patient.

Every patient should be assigned their own social worker as they begin their course of dialysis treatments. You should meet your social worker very early on in the process, hopefully even on your first day in the clinic. You may feel overwhelmed, nervous, or scared about beginning treatment and confused about how this social worker can possibly help you. From day one, your motto should be, "when in doubt, reach out." Don't be afraid to ask the social worker to explain their role and how they work with patients. For many of you, this is the first time that you have ever had personal contact with social workers. Sometimes, we have ideas about what people do in their jobs and our information may not be totally accurate. So be sure and "reach out."

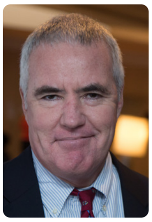
You may observe that the social worker is meeting with many patients during the course of a day. Maybe they look busy all the time, or they are often on the phone, or you hear them getting paged a lot. Don't assume that they are too busy for you! The social worker should be stopping by on a regular basis during your treatments to check in, follow up on any issues you are working on together, and determine if you have any new concerns that they can assist with. If you don't see them on a particular day, ask your nurse or technician to request a visit from the social worker during your next treatment. Or, you can ask that they call you if you prefer a phone contact. If you are uncomfortable having talks in the clinic area, ask the social worker if you can make an appointment to meet privately in their office.

It can be scary to "open up" and trust a new person in your life, especially when you are already dealing with major changes in your health. Sometimes you may feel down with no clear reasons for these feelings. Asking the social worker to meet with you to discuss these concerns can offer you a different viewpoint, provide food for thought, and may help you develop an action plan for change. Sometimes, just talking to the social worker can offer emotional relief, particularly if you find it difficult to have these conversations with other people in your life.

Even the most skilled and experienced social workers cannot always resolve every problem that comes up. But every social worker's goal is to help you maintain the best quality of life for YOU. They are your advocate, helping you to recognize your personal strengths and skills to cope with your illness and working with you to find community and personal resources (family, friends, church, agencies) to keep you healthy, both physically and emotionally. Social workers have not lived the life of dialysis patients, but they have worked with hundreds of patients who are experiencing similar fears and challenges. They have the training and the compassion to help you and encourage you when you need it most if you allow them to become an important part of your treatment team. So, WHEN IN DOUBT, REACH OUT!!

Jean Carosella, LCSW is a past chair of the National Council of Nephrology Social Workers and a recipient of the CNSW Robert W. Whitlock Lifetime Achievement Award. She has written extensively and presented on nephrology topics including the importance of empathy in patient/staff relationships and the treatment experience of dialysis patients suffering from both diabetes and renal disease.

Supreme Court Erases Kidney Patients’ Insurance Protections



By Megan Hashbarger, DPC Vice President of Government Relations and **Jackson Williams,** DPC Vice President of Public Policy

A U.S. Supreme Court ruling has nullified the law that protects dialysis patients from discrimination by insurers, threatening the system of financing kidney care that has stood for 40 years.

The Court ruled that employer health plans may limit dialysis benefits. For four decades, employers understood the law as prohibiting limitations that only applied to dialysis. Some health benefit consultants encouraged a few small employers to disregard the law by paying no more than Medicare rates for dialysis. DaVita sued them, and one of the cases was appealed to the Supreme Court.

The decision means that employers and insurers can impose low rates for dialysis or use other benefit limitations to encourage ESRD patients to drop coverage and switch to Medicare. For affected patients, losing employer coverage can mean reduced access to physicians, loss of dental benefits, lost dependent coverage, or higher cost-sharing.

“DPC is deeply disappointed by today’s Supreme Court decision,” said DPC Board President Andrew Conkling. “Congress long ago reaffirmed privately-insured patients’ right to continue on their employer-sponsored plan for 30 months. This has played an important role in preserving patient choice and incenting plans to detect and treat Chronic Kidney Disease. To allow these plans to shift patients to Medicare before the expiration of this period represents immediate and profound risks for kidney patients and their families across the nation. As the dissenting justices stated, Congress will have to fix a statute that the Court has broken. We and other ESRD patient advocates will go back to Congress immediately to clarify the rules once and for all.”

Less reimbursement from commercial insurance means less money in the dialysis care system. This comes at a time when many health care providers are struggling to hire staff and must pay more to attract and retain workers. For many clinics, Medicare rates alone aren’t enough to break even. At best, that means fewer options for dialysis patients. At worst, communities that already have limited options and funding could have a harder time accessing treatment close to home.

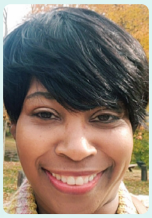
The ESRD provisions of the Medicare Secondary Payer statute are intended to save Medicare money while incentivizing good preventive care. The decision is likely to impose significant costs on the federal government. Restoring kidney patients’ rights will save the government money.

The decision also weakens insurers’ incentives to detect and treat Chronic Kidney Disease (CKD) early, to extend patients’ kidney function; or to prepare CKD patients for a stable transition to ESRD. Employers may be less likely to pay for kidney-preserving Rx drugs—which are already underused—and more likely to pass ESRD patients on to Medicare who didn’t receive appropriate transitional care.

In order to address this concern, a group of bipartisan, bicameral Members of Congress have come together and introduced The Restore Protections for Dialysis Patients Act (H.R. 8594/S. 4750) which would codify into law the right for dialysis patients to stay on their private insurance for 30 months. This legislation is extremely important for patients and also saves the federal government money by delaying patients going immediately into Medicare.

We encourage all our members to reach out to their Member of Congress and encourage them to cosponsor The Restore Protections for Dialysis Patients Act (H.R. 8594/S. 4750). For more information, please visit our website at www.DialysisPatients.org/MSP

Building Legacy Through Advocacy



By Yolonda Brisbane,
DPC Grassroots Manager

As the Grassroots Manager for Dialysis Patients Citizens (DPC) Yolonda recruits and coaches new DPC patient advocates, helps plan and execute our Annual Advocacy Day, and hosts Patient Ambassador training calls. She came to DPC having led youth ambassador programs for the New York State Office of Children and Family Services and the Boys and Girls Clubs of America. For her, elevating the voices of dialysis patients is personal work.

"When I was fourteen, I lost my father to kidney failure when he refused to go on dialysis. I had no clue about what dialysis was. Years later, my mother had to go on dialysis. My brother and I learned all that we could and decided that as a family, this time we would win. That included learning about our mother's renal dietary needs, how to understand her monthly lab reports, and building a partnership with the staff at her dialysis center. I began creating tasty recipes so that my mother did not feel left out and soon everyone was eating her food. It has been 16 years. My mother is now 80 years old and still going strong. Eight years ago, both my brother and a younger cousin had to go on dialysis. My cousin recently received a kidney transplant. My brother is finalizing the process of placement on the transplant list."

Yolonda learned about DPC in 2013 when her mother became a Patient Advocate. "I was amazed at the work that this organization engaged in, how DPC trained and prepared the patients to meet with members of Congress and serve as leaders within their respective communities and dialysis centers. I found myself participating in DPC monthly support calls, and webinars, and reading DPC's Kidney Citizen Magazine. I witnessed an organization that was truly mission-focused and patient-led and found myself getting involved with local advocacy efforts."

Today, Yolonda is honored to be the first person to welcome new members to DPC, letting them know what resources and support they have available, and telling them about opportunities to help shape legislation that improves the quality of life for dialysis patients. The resolve and courage that dialysis patients and their families have, and the wealth of knowledge and support the patients are for one another, inspires Yolonda every day.

"I come from a family of Dialysis Warriors and know that behind each call, there is a face, a name, a family, and an advocate within. Whether you are a kidney patient, family member, friend or partner-in-care, there is always work to do and legislation to impact. There is a space waiting for your story and your voice. **There is a space waiting for you to create your legacy.**

Anyone interested in joining DPC as a member or Patient Advocate, may visit our website at **https://www.dialysispatients.org** and/or contact Yolonda directly at 1-866-877-4242.

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Learn from Kidney Disease Experts!

We have recordings of past webinars on our web site at

https://www.dpcedcenter.org/news-events/education-webinars/

Recently, we divided them into categories to make it easier to find topics of interest.

Now you can search Kidney Disease & Treatment, Staying Healthy, Quality of Life, and Other Topics to find and watch webinars when it is convenient for you. We also have recordings in Spanish on dietary topics under the Staying Healthy section and they are also listed on our Spanish Resource page at

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