issue number 11

The Citizen Kidney

A publication of Dialysis Patient Citizens (DPC) Education Center

DPC
EDUCATION
CENTER

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*Also available in Spanish!

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President's Message

I think 2020 is a year of hope, new beginnings and challenges that are not to be ignored. We need to continue to advocate for ourselves, both politically and for our health and well-being. It is helpful to know what bills are in Congress that can affect us, as well as, what we do or do not do that can impact our quality of life. We need to be active and lifelong learners in both arenas.

Many of us may feel overwhelmed by kidney disease and the stressors and pain that it brings. You may be wondering how to find the energy to be more involved when you are in pain, stressed and preoccupied with your health. Stress, which can be a part of both positive and negative events, can deplete a great deal of our energy. Decreasing stress is necessary. In this issue, you will learn about the "Spoon Theory" that looks at our energy level in another way. We also can reframe how we think about events—by focusing on the facts and not catastrophizing the what ifs and what we can or cannot do. Our energy level does not increase or decrease our self-worth.

If you are living with pain on a regular basis, you may find that it is affecting both your physical and mental health. Pain management may be an important topic to explore to add to your quality of life. Besides medication, you may find counseling and self-management steps to be helpful. Although we may always live with pain, we may find some ways to provide some relief. The DPC Education Center also has a new online course on "Understanding Pain and Effective Ways to Live with It." I encourage everyone to check it out!

Kidney disease may affect our lives, but it does not define us. Throughout this newsletter, you will read articles that offer tips and suggestions to live your life well. In addition to new booklets for teens with kidney disease, our new online program will continue to add new courses. Also, we will have monthly patient education webinars. Please explore our resources and watch for the announcements of our monthly webinars—we have a lot more to come. What an exciting year for the DPC Education Center!

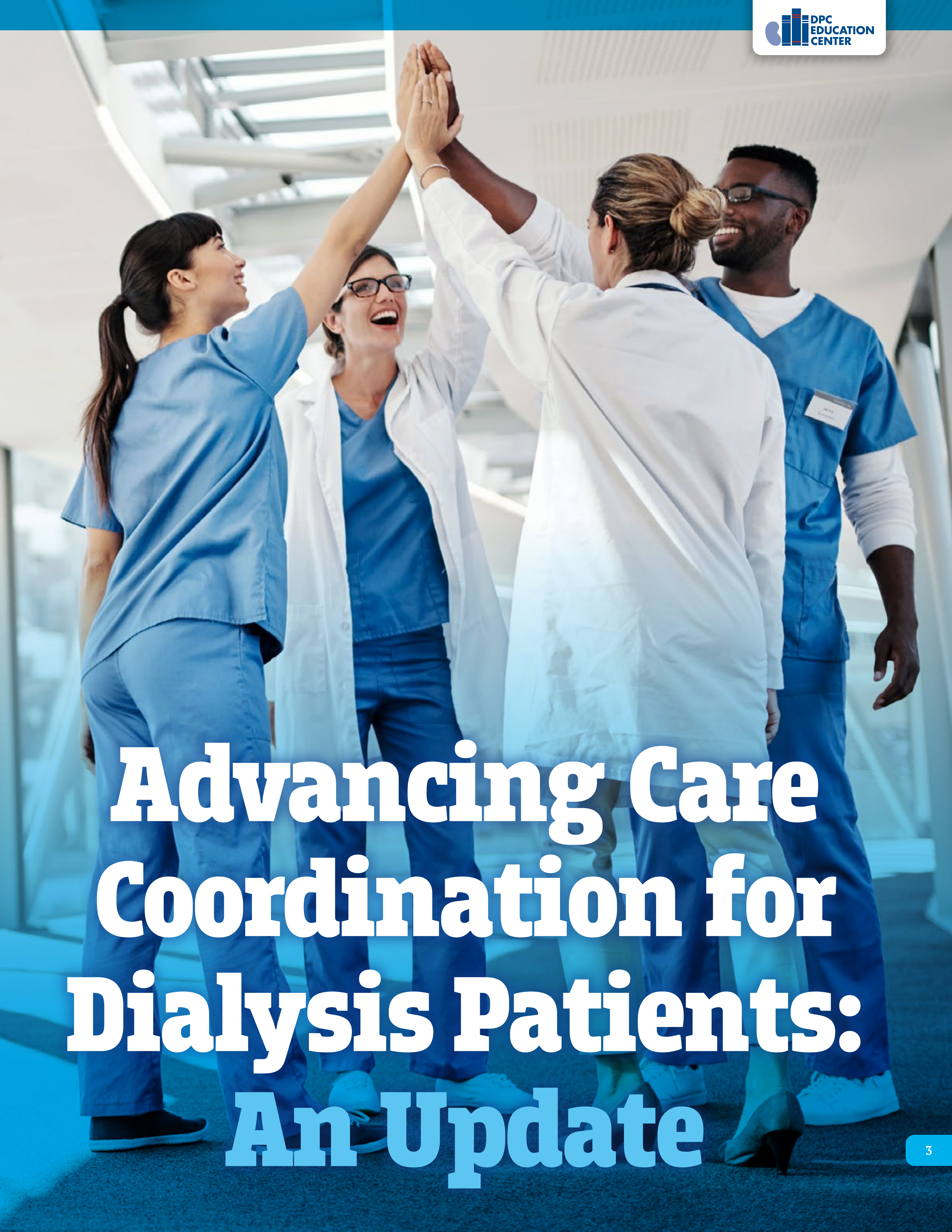
Sincerely,

Nancy L. Scott

DPC Education Center
Board President

Board Members and Advisory Council

DPC EDUCATION CENTER



Advancing Care Coordination for Dialysis Patients: An Update

By Jackson Williams
Vice President of Public Policy,
Dialysis Patient Citizens

Efforts to modernize the delivery of quality care to dialysis patients reach several milestones in 2020: Medicare's first care coordination program for kidney care, the Comprehensive ESRD Care Model, expires at the end of this year; providers have been invited to participate in a new program, the Comprehensive Kidney Care Contracting Model; end-stage renal disease (ESRD) patients will, in October, for the first time have access to their choice of Medicare Advantage plans effective January 1, 2021; and a new bill is being introduced in Congress to create another integrated care option for kidney patients.

Why Care Coordination?

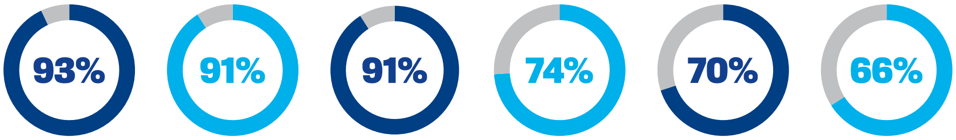
Most dialysis patients are served by "Original Medicare," a program that attempted to duplicate health insurance as it existed in 1965. Under Original Medicare, each provider is paid on a "fee-for-service" basis, and no single entity is accountable for a patient's overall health outcomes. For instance, hospitals, dialysis, and physicians generally provide care separately. Continuity of quality care can break down when there are transitions or handoffs from one setting or one provider to another. Few patients experience as many transitions as those with ESRD: from chronic kidney disease to dialysis, from dialysis to transplant, from hospitals to skilled nursing facilities or home, etc. In Original Medicare, there is no payment for activities by case managers, community health workers or "health coaches" who can try to keep patients from falling through the cracks during such transitions.

Hospitalization

More than 3 in 5 patients with CKD have been hospitalized in the past two years.

63% of CKD patients say they have been hospitalized in recent years...

Of those being recently hospitalized...



93% say that hospital staff provided them with a written care plan after discharge

91% say they knew who to contact if they had questions about their medical condition or treatment

91% say that they received clear instructions about symptoms to watch for and when to seek further care

74% say that the hospital made arrangements for them to have follow-up visits with a doctor or other health care professionals

70% say someone discussed with them what to do about other medications before being hospitalized

66% say they were given new prescription meds upon discharge

DPC's 2019 Member Survey showed that a significant number of dialysis patients experience fragmented and disorganized care. Eighteen percent of patients say their regular doctor rarely or never helps coordinate or arrange care with other providers, such as specialists. Twenty-two percent of patients say that in the past two years they have had experiences where test results, medical records or reasons for referrals were not available at the time of a scheduled doctor's appointment; doctors ordered a medical test the patient felt was unnecessary because the test had already been done; or doctors recommended treatment that they thought had little or no health benefit.

About a quarter of dialysis patients who've been hospitalized in the past two years say that the hospital made no arrangements for follow-up visits with a doctor after their discharge, nor discussed with them the medications they were using before their hospital stay.

Twenty-eight percent of dialysis patients say their doctor gave them instructions for one of their chronic conditions that conflicted with what they have been told to do for another condition, and that specialists they see did not seem aware of the different chronic conditions they had. These are substantially higher percentages than those patients with other chronic conditions have reported when asked the same questions.

A First Step Toward Integrated Care: The Comprehensive ESRD Care Model

Beginning in October 2015, Medicare's Comprehensive ESRD Care Model established ESRD Seamless Care Organizations (ESCOs) for dialysis patients. ESCOs are formed by partnerships of dialysis providers and nephrologists. This is a pilot project, and Medicare permits ESCOs only in urbanized areas and adjacent counties, so their geographic reach is limited. There are 685 dialysis facilities owned by seven different providers, participating in ESCOs. That is 12 percent of clinics in the U.S., which includes 14 percent of Medicare beneficiaries with ESRD (about 72,000 patients).

The ESCO assumes responsibility for all the patient's Medicare spending (except prescription drugs under Part D). If the ESCO keeps Medicare expenditures below average for an ESRD patient, it earns a bonus. This incentivizes the ESCO to coordinate care and do all it can to avoid complications and hospital stays. To prevent complications, the ESCOs deploy care teams that include nephrologists, nurse practitioners, case managers and pharmacists.

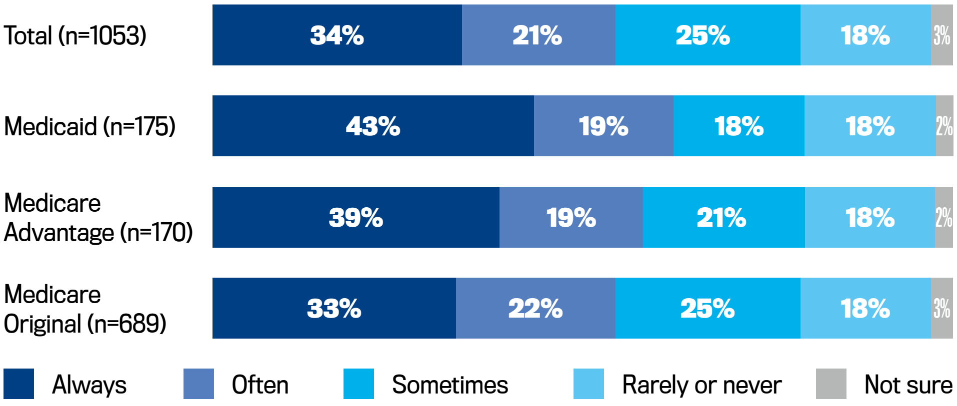
Overall, the ESCOs have been a success: Hospitalizations are down by six percent, and Medicare expenditures have been reduced by about $1,300 per patient each year. But not every individual ESCO has thrived: eight of the 37 ESCOs did not "beat" their benchmarks, so did not share in savings to Medicare. Also, because each ESCO must advance its own money to hire care teams, ESCOs that did not save enough money to cover that investment also finished in the red.

What's Next for Care Coordination for Dialysis Patients?

Last summer, Medicare announced its intention to replace the Comprehensive ESRD Care Model with a Comprehensive Kidney Care Contracting Model. Details are still unclear, so it's unknown how many ESCO sites will continue under the new program, nor whether additional patients will be served.

Frequency of Coordinated Care

1 in 3 patients with CKD say that their doctor always arranges care with other doctors or specialists, if needed. Also, significantly more patients with Medicaid claim that their doctors always arranges care compared to those with Medicare (Original).



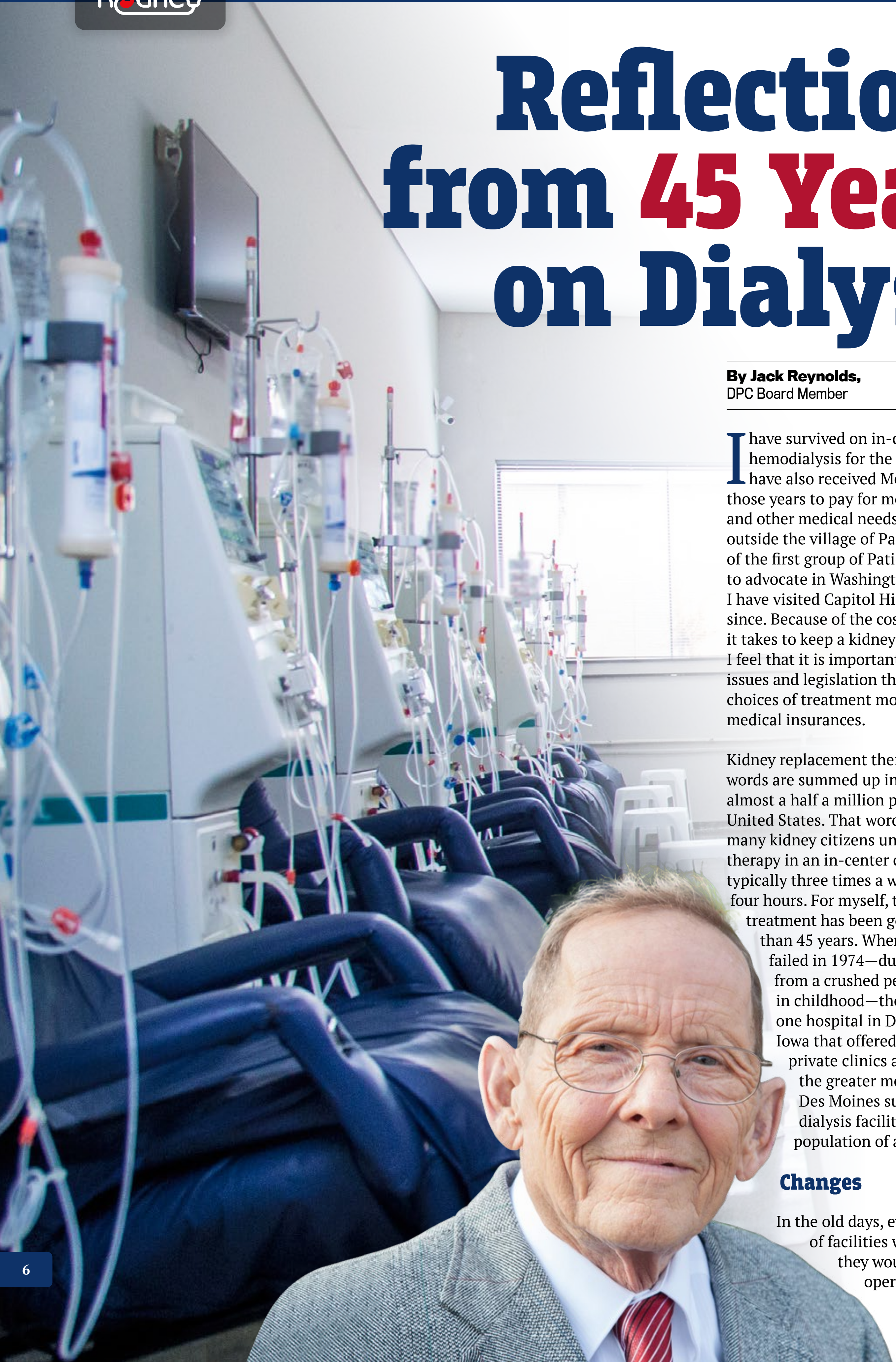
With the start of Medicare open enrollment in October, ESRD patients will for the first time have access to their choice of Medicare Advantage plans, effective in January of 2021. Medicare has not yet finalized rules for 2021 health plans, so it's unknown what choices will become available nor how attractive they will be for dialysis patients. We do know that Medicare Advantage has served two categories of ESRD patients in the past: over-65 enrollees who had Medicare Advantage before their kidneys failed and members of a few "Special Needs Plans" exclusively serving dialysis patients. In these circumstances, Medicare Advantage plans have been effective in coordinating quality care.

Reflections from 45 Years on Dialysis

By Jack Reynolds,
DPC Board Member

I have survived on in-center hemodialysis for the last 45 years. I have also received Medicare for all those years to pay for most of my dialysis and other medical needs. I currently reside outside the village of Palmyra, Iowa. One of the first group of Patient Ambassadors to advocate in Washington, D.C. in 2005, I have visited Capitol Hill many times since. Because of the cost, time and effort it takes to keep a kidney patient healthy, I feel that it is important to be aware of issues and legislation that can impact our choices of treatment modalities, drugs or medical insurances.

Kidney replacement therapy. Those three words are summed up in one word for almost a half a million people in the United States. That word is dialysis, and many kidney citizens undergo their kidney therapy in an in-center clinic setting—typically three times a week for three to four hours. For myself, this regimen of treatment has been going on for more than 45 years. When my kidneys failed in 1974—due to complications from a crushed pelvis suffered in childhood—there was only one hospital in Des Moines, Iowa that offered dialysis and no private clinics at all. Currently, the greater metro area of Des Moines supports nine dialysis facilities with a patient population of around 500.

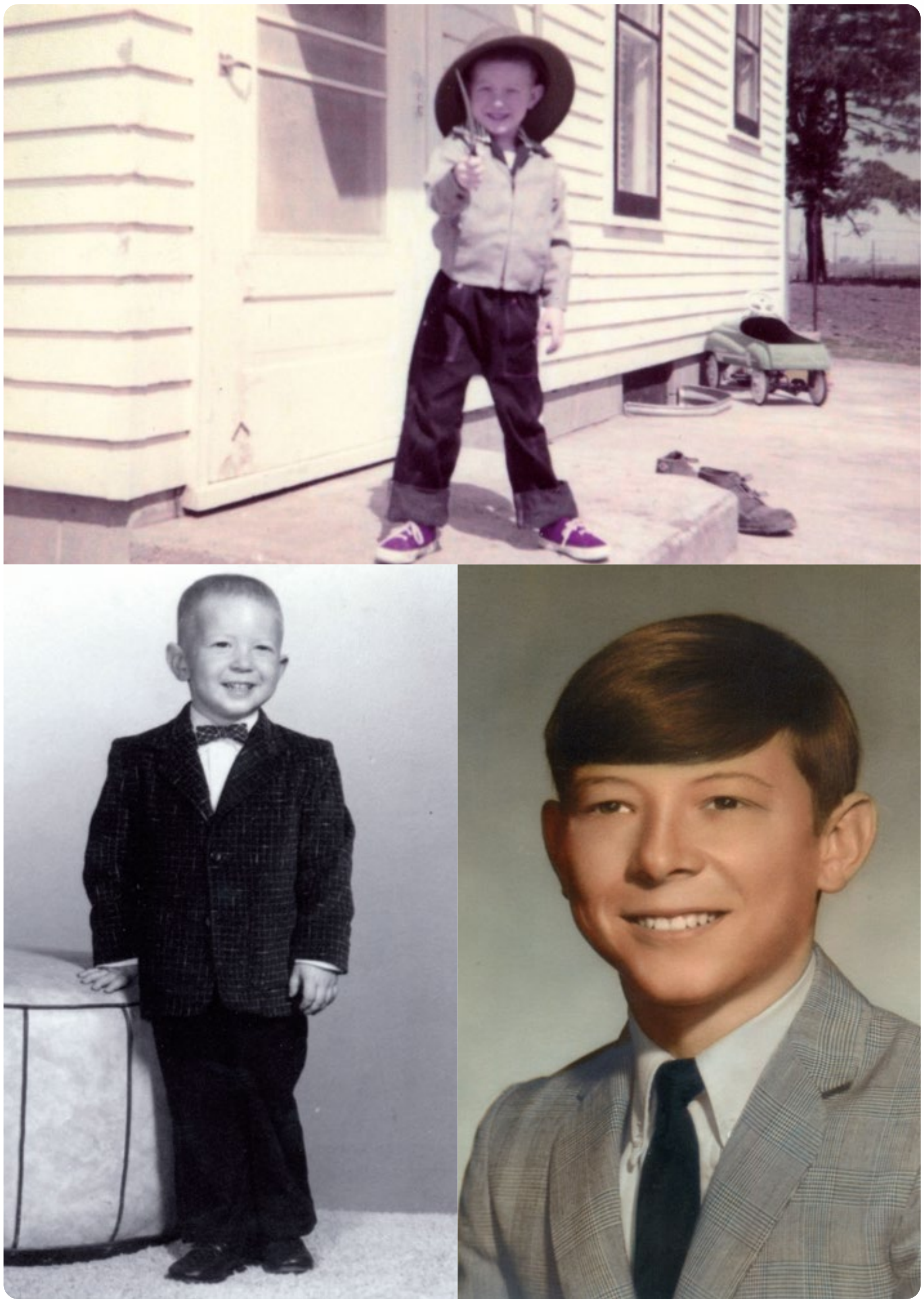


Changes

In the old days, even if the number of facilities were the same, they would have had to operate 24 hours a day

to make sure everyone got treatment due to the fact that it took an hour or more to reset, sterilize and string the dialysis machine for the next customer. Modern dialysis machines, along with high flux dialyzers, allow patients to remove excess fluid and urea waste products with less adverse side effects such as cramping and nausea. However, although patients tend to be healthier overall, treatment times have not decreased substantially.

Dialysis citizens are more likely to live somewhat longer now, and in my opinion, have a lot more leeway in their adherence to the renal diet. Development and improvement of both oral and intravenous drugs have made it possible for patients to maintain higher hemoglobin values, ward off bone disease and improve their overall health while living with organ failure.



Dialysis Facilities

Modern dialysis providers provide educational materials on various modalities of dialysis, kidney transplantation, diet, and even help in setting up dialysis appointments for trips and vacations. Many people have found that doing dialysis at home has improved their physical well-being and provided a more liberal diet, but the trade-off is having to dialyze much more frequently, although for less time per treatment.

Problems with in-center dialysis facilities include under-staffing, as well as, nephrologists, dietitians and social workers who are responsible for multiple facilities. Another issue that is often overlooked is reliable transportation for kidney clients, many of whom require wheelchairs or are otherwise handicapped. As I live in a small town outside of the metro area, I have been fortunate to be able to drive myself to treatments. There is nothing like driving home in an Iowa snowstorm after dialysis when I am usually quite fatigued!

Keep Learning

As a long time kidney advocate and Board member of Dialysis Patient Citizens, I have found it helpful to look past the weekly grind of my kidney sessions and take time to educate myself on issues and legislation that can affect thousands of kidney citizens. I find understanding the issues and advocating for more effective policies to be helpful in combating the solitude and frustration that can so often hamper the lives of people who require this lifesaving, but severely demanding therapy. If I have learned anything, however, over these many years as a dialysis citizen, it is that if you do not do dialysis well, then it is likely that you will not do anything well. Stay healthy and keep learning!

12 Tips to Cope with Chronic Disease

By Rachel Fintzy Woods,
MA, MFT

So many aspects of life are beyond our control. When the challenges of managing an illness such as chronic kidney disease are added to our plate, we can feel overwhelmed. Emotions such as anger, confusion, fear and sadness are common and natural, especially at the outset of our journey with illness. It can seem as if our world has been turned upside down.

Yet we do have some say in how we deal with the cards we've been dealt, including our medical condition and life itself. We alone are responsible for our actions and our attitudes—the word "responsibility" refers to our ability to respond, after all. We can expand our repertoire of coping skills. We can learn to manage our distressing feelings and to effectively deal with our day in, day out circumstances. As we do so, over time we can grow in patience, resilience and self-compassion—all of which will benefit us and those around us.

Choosing constructive coping mechanisms means that we're taking care of our emotional and physical well-being. We accept our present situation and make healthy choices. We modify how we perceive our situation, our future and the world in ways that are not only bearable but also uplifting. We acknowledge and manage our situation rather than denying or attempting to flee reality.

Some ways in which we can effectively cope with troubling news or times:

1. **Educate yourself about the situation.** Avoid jumping to conclusions. Stick with the facts. As compelling as it may feel to surf the Internet for information, much of what is out there is inaccurate or based on theories or opinions—some of which can scare the wits out of you. If you have questions about your medical condition, consult an expert such as your personal doctor and specialists to whom you've been referred, so you can get advice that's tailored to your specific situation.

2. **Look at all your options.** However daunting the situation, you probably have some reasonable alternatives. At first, just brainstorm and write down anything and everything that comes to mind—don't edit yourself. Next, assess the pros and cons of the possibilities you've listed, then pare your list down to two or three options. From here, choose what seems best to you overall, and begin to break your action steps down into manageable chunks. You can always reevaluate your plan down the line, but for now, making a choice can settle down the mental whirlwind of indecision and second-guessing yourself.

3. **Practice good self-care.** Moderate and healthy meals, as well as sufficient sleep and exercise several days a week (as you are able) will support your immune system, help to regulate your emotions and increase your ability to mentally focus. If we don't take care of our bodies, we increase the chances of catching infections, becoming moody, or feeling cognitively dull or confused. Do your best to avoid short-term "fixes" such as too much alcohol, illegal drugs

(or prescription drugs for unintended purposes), compulsive eating or excessive sleep—none of which help in the long run and may compound your problems.

4. Prioritize social connections. Supportive friends and family can be important sources of comfort, feedback and distraction. None of us is an island. We all need at least one person to support and cheer us on. Also, catching up on what's going on in other people's lives can give you a better perspective of your own situation while strengthening your bond to others.

5. Take time to pray and meditate. Whether you believe in the God of a specific religion, a benevolent force in the universe, nature, or some other Higher Power, a support group, or just that there's something bigger and more powerful than you, take time to connect with this power. It can be a tremendous relief to remember that you needn't (and can't) have all the answers. Turn your problems over to this power, request that the right answers be revealed to you at the appropriate time, sit in the silence and have faith that you'll be provided with the wisdom to do what's necessary.

6. Remember what's most important to you. What are your priorities? Does how you spend your time reflect your values? For a week or so, keep track of your activities and how much time you devote to your pursuits. You may discover that you've wasted time doing things that really don't matter to you. For instance, do you really need to spend hours perusing eBay, binge-watching TV or debating the latest political debacle? Remember that none of us gets more than 24 hours in a day. Use your time wisely.

7. Balance your musts and your wants. Maintain a healthy balance between activities you must do and activities you want to do. We all need time to regain our strength and energy—thus the term recreation (re-creation). Only doing things you have to do can wear you down and lead to a sense of "what's the point." That being said, only doing things you want to do can be self-indulgent. Ideally, do at least one item from both lists every day.

8. Maintain important routines. When we're dealing with uncertainty and change, sticking with some familiar and honored routines can grant us some inner peace and a sense of control. If you enjoy reading the morning paper while sipping your tea, keep this up. If you eagerly anticipate taking an evening bath (if you do not have a catheter), continue this practice. Retaining a familiar schedule can be calming and centering. Build your dialysis routine into a schedule that includes some of your personal calming and "want to do" activities, even if it is doing them while on dialysis.

9. Remember that some days will be better than others. We are not robots. Our feelings of physical, mental and emotional well-being ebb and flow. Pace yourself accordingly. On days when you're particularly rundown or in a funk, don't expect yourself to accomplish the same amount as you accomplished yesterday, when you were feeling better.

10. Have safe people and places where you can express your feelings. Are there friends, family members, a therapist, a pastor or a support group where you feel comfortable sharing what you're going through? Verbalizing your experience can enable you to come up with the best solutions for you and can offer you the opportunity to come to terms with what you're feeling. Another option is to keep a journal. Even if you don't review your writing, the process of handwriting, which takes some time, gives you the chance to sit with your experience. Sometimes ideas and realizations will pop into your mind that might have otherwise escaped you.

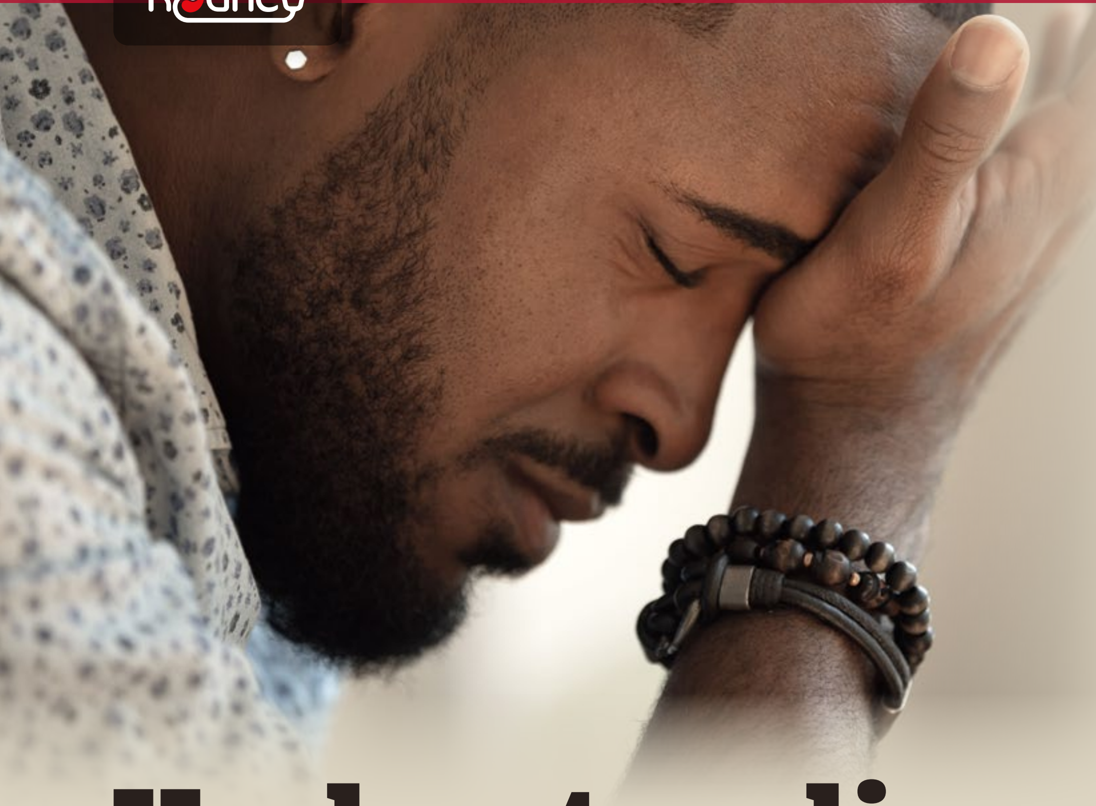
11. Turn your attention to the physical. Doing something manually with your hands or body, like kneading bread, knitting, sewing on a button, cleaning out a closet or washing the dishes can be a good temporary distraction. Focusing on a physical activity can ground you in the present moment, instead of mulling over the future, regretting the past or living in a fantasy land.

12. Help someone else. When we're dealing with a personal crisis, it can be easy to become a bit self-involved. As an antidote, think about who you might be able to assist. It doesn't have to be a huge gesture in order to lighten his/her load and brighten his/her day. Talking to others at the dialysis center, calling a friend or sending someone a card can also help to shift your energy away from your own concerns.

Ideally, experiment with these suggestions at a time when things are going smoothly in your life. This way, you'll have familiarized yourself with the strategies before the next difficult time occurs.

However, even if you're currently going through a rough patch and haven't yet tried out these ideas, you can still implement them. We are all works in progress. The truth is that we never get to a place where life is just smooth sailing from that point on. And thank goodness, because if this were the case, we probably would eventually become bored and cease to grow. So you can look at your challenges as a golden opportunity to build your strength and wisdom.

Rachel Fintzy Woods is a licensed Marriage and Family Therapist in Santa Monica, California. Rachel counsels in the areas of relationships, the mind/body connection, emotion regulation, stress management, mindfulness, emotional eating, compulsive behaviors, self-compassion and effective self-care. Trained in both clinical psychology and theater arts, Rachel works with people to uncover and develop their unique creative gifts and find personal fulfillment. For 18 years, Rachel conducted clinical research studies at University of California, Los Angeles in the areas of mind/body medicine and the interaction of psychological well-being, social support, traumatic injury and substance use. You can read more about Rachel on her website: ***www.rachelfintzy.com.***



Understanding Chronic Pain and Depression

How Chronic Pain Can Impact Your Mental Health When You Have Kidney Disease

By Hannah Calkins

Chronic pain and depression are closely linked and because as many as 60 percent of hemodialysis patients report moderate to severe chronic pain, it's likely that many of them have experienced depression—or are at risk for it. But it may not look or feel the way you expect, according to psychologist Robert Kerns, PhD.

"Depression among people with chronic pain may not be experienced as profound sadness," says Kerns, a professor of psychiatry, neurology and psychology at Yale University. "Other symptoms may be more likely to be present, including loss of interest or engagement in activities you normally enjoy, as well as sleep and appetite dysfunction."

Together, chronic pain and depression can impact management of your kidney disease and take a toll on your quality of life. Fortunately, effective treatments are available, and with the help of medical and mental health professionals, there are steps you can take to feel better.

How Chronic Pain Can Lead to Depression

First, it may be helpful to understand how chronic pain and depression are connected. Psychologist Ravi Prasad, PhD, says the same areas of the brain are involved in regulating both pain and emotion, which is one reason why the two conditions can overlap. But there are other factors at play, he says.

When people living with chronic pain are unable to do the things they want to do, they may pull away from activities that give their lives meaning. Their sleep may be affected. Their motivation may diminish, says Prasad, who is a clinical professor and director of behavioral health in the division of pain medicine at the University of California Davis School of Medicine.

As the pain condition evolves, the depression does too, he says, leading to a "vicious cycle."

It makes sense, then, that people with depression are less likely to be successfully engaged in pain care, which can lead to less effective treatment for their depression, says Kerns.

At the same time, other biological, psychological and social factors may increase your likelihood of developing depression if you have chronic pain, says Kerns. These factors include a family history or genetic predisposition to depression, prior experience of trauma, or economic stressors.

"Some people may also engage in what is known as 'catastrophizing,' or pervasive negative thinking that may magnify the experience of pain and increase the likelihood of depression," says Kerns.

Examples of such thoughts are "my pain is horrible"; "it will never get better"; and "I'm helpless," he says.

Treatments That Work

Chronic pain and depression are complicated to treat. However, evidence-based approaches can alleviate the suffering caused by both conditions—as long as both conditions are addressed.

A major challenge is that people with chronic pain often believe that if their pain were treated effectively, their experiences of depression would also go away, says Kerns. "Evidence suggests this is not the case."

Prasad agrees. That's why both chronic pain and depression need to be treated concurrently, he says. Your doctor and a mental health professional can help determine which treatment will work best for you.

Treatment for depression may consist of medication, psychotherapy or both. Cognitive behavioral therapy (CBT) may be especially helpful, says Prasad.

"CBT helps people become more aware of the thought processes that influence their emotional and behavioral health outcomes," says Prasad. "You can apply these strategies to coping with pain and with depression."

If you're able to engage in some physical activity, that may help too, says Prasad. "Exercise won't fix the problem, but it can help you manage your symptoms," he says. "If you're active, you may get better rest, which gives you more energy, and that may motivate you to participate more in the activities you care about. Which, in turn, can improve your mood."

How to Get Help

Your physician or nephrologist may not recognize the signs of depression, so it's important that you speak up if you think you might need help. Let your doctor know if you are feeling sad, anxious, hopeless or guilty; are persistently restless, listless or irritable; are experiencing disturbances in your sleep or appetite; or have lost pleasure in activities you normally enjoy.

If you aren't able to access treatment right away, or if you're interested in learning more about managing pain and depression on your own, Kerns says there are other resources available. The Centers for Medicare and Medicaid Services (CMS) requires annual depression screenings for patients on dialysis. Your dialysis social worker is trained to provide supportive counseling and can help you cope with your feelings.

"There are great books available to support people with both of these conditions, as well as a growing number of evidence-based self-management programs available on the web or for use on smartphones," he says. It's important to note that a self-help book does not and should not take the place of receiving care from a behavioral health professional. Your nephrologist or physician can help you find the right provider.

If you have chronic pain and are concerned about depression, you aren't alone, and help is available. But at the same time, Kerns says, people with chronic pain should understand that depression is not an inevitable consequence of pain.

"Even though rates of depressive disorder are high among people with chronic pain, most people with chronic pain—even those with moderate to severe pain—do not become depressed," he says.

For more information, visit the American Chronic Pain Association's website or check out the resources available from the American Psychological Association. If you are in distress and need to someone to talk to immediately about your mental health, call the National Suicide Prevention Lifeline at 1-800-273-8255.

This article was developed jointly by the American Psychological Association 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.

NEW ONLINE
Pain Management Course

The DPC Education Center is now offering an online, free-to-use resource center to learn more about chronic pain and effective ways to live with it. In the program, you will explore the concept of pain, learn ways to talk about it, and discover methods of managing pain including medication, alternative medicine, nutrition and exercise, self-management, and laughter and humor. You will also have the opportunity to tell your story and hear from others about their experiences

Check out the course at: dpcedcenter.org/paincourse

Care Coordination Fixes One of the Biggest Flaws in the American Health Care System

By Gloria Rohrer,
DPC Patient Ambassador

As a dialysis patient, it has become clear to me that one of the biggest flaws in the American health care system is the disjointed way care is often provided to patients. If patients have chronic conditions alongside other health complications, it can be exceedingly difficult to navigate the different doctors and hospitals we need in order to receive proper care.

When seeing so many different doctors at various clinics and hospitals, patients like me can suffer adverse effects if all our treatments are not designed to address our full medical history, rather than a single disease. This can be because of a lack of communication between our care providers or inadequate follow-up, which can in turn result in avoidable readmissions, medical errors or something much worse.

All of this is especially true for patients suffering from end-stage renal disease (ESRD), who often need dialysis treatment three times per week, in addition to relying on several other doctors and medications to treat accompanying health conditions like diabetes or cardiovascular disease. If an ESRD patient's various treatments are poorly coordinated, it can lead to unnecessary and avoidable pain.

Sadly, I experienced this firsthand. My patient journey began in 1992 when my kidneys began to fail. For the past twenty-eight years, I have received treatment from countless doctors and nurses at various hospitals and dialysis care facilities.

Unlike many other cases of kidney failure, my case was unique because I did not have another underlying condition. Doctors, unable to determine what led to the kidney failure, waited before putting me on dialysis. For the next five years, I underwent weekly dialysis treatments until I finally received "the call," or in my case, a knock on the door at 2:00 a.m. by a police officer telling me that I was going to have a kidney transplant.

Unfortunately, despite a successful surgery, three years later my new kidney failed. What followed was a long road that required emotionally and physically taxing surgeries and, eventually, the loss of my leg. Family activities, like the vacation my husband and I took to Disney World, proved to be too burdensome. A medical emergency could not be treated at the dialysis care facility where I had planned to receive treatment in Florida, so I was rushed to the hospital.

But without a consistent coordinated care system, trips to a hospital emergency room can mean potentially dangerous treatments for dialysis patients like me. For example, nurses generally try to give us fluids as they would an average healthy adult, but for dialysis patients, that treatment can be incredibly harmful.

The lack of care coordination among facilities while in Florida left me without proper treatment and dialysis for a week. After going so long without care, pressure built around my eye and it had to be removed. While my case may just be one of many, no patient should have to share my experience.

Given that dialysis patients like myself often must see several different doctors at different hospitals, we need providers to know our medical histories to efficiently and properly treat us. The system needs to recognize that us dialysis patients have different needs than the average patient. Care coordination can offer us a more focused, personalized treatment plan that is key to a better health care system.

Members of Congress have already shown they acknowledge how vital coordinated care is to not just improving a patient's treatment, but our overall quality of life. Lawmakers like Representative Jason Smith (R-MO), Representative Earl Blumenauer (D-OR), Senator Todd Young (R-IN) and others took the lead on this issue previously when they introduced the Dialysis PATIENTS Demonstration Act. They had enormous bipartisan and bicameral support, receiving more than 200 cosponsors in the House and Senate. Now Congress is positioned to take the next step in instituting coordinated quality care.

Lawmakers have made improvements on the Dialysis PATIENTS Demonstration Act with a new bill they are working on called the BETTER Kidney Care Act. It provides a coordinated care framework for ESRD patients, offering a holistic treatment plan designed to cut down on duplicative services, reduce health care costs and provide dialysis patients with the services we need but aren't covered by Medicare, like dental care and transportation to and from treatment centers. The BETTER Kidney Care Act changes dialysis patients' lives for the better by treating us as an entire patient as opposed to any single disease.

Legislation like the BETTER Kidney Care Act provides much-needed relief to patients like me. This kind of legislation restores confidence in medical care providers when diagnosing and administering the proper treatment. Let's encourage our policymakers to focus on improving care coordination by supporting this bill.

Identifying Sepsis Risk and Symptoms

By Marijke Vroomen Durning, RN

People who live with kidney disease are more susceptible to contracting infections than the general public. A weakened immune system, frequent hospital or clinical visits/stays, and possible points of entry for infection (catheters, ports, etc.) all contribute to this increased risk. Unfortunately, some of these infections can lead to sepsis, which can be life altering, even fatal for thousands of people.

Sepsis is your body's inflammatory response to an infection. It can be any type of infection—viral, as with influenza; bacterial, as with a urinary tract infection (UTI); even fungal or parasitic. No one knows why two people may get the same infection, but one may develop sepsis

while the other does not. Sepsis can, and does, occur in people of all ages who are usually very healthy and fit, as well as those who have underlying health problems, like kidney disease.

When you have an infection, your immune system tries to fight it off, alone or with medications. Most of the time it's successful, but sometimes, your immune system overreacts and instead of attacking the infection, it starts to attack your body. This is sepsis. Untreated sepsis can lead to organ dysfunction, a drop in blood pressure and septic shock.

Currently, the only way to prevent sepsis is to prevent or quickly identify and treat infections. This means that everyone should know what sepsis is, what to watch for in terms of infections and sepsis, and when to seek help. If you have a loved one living with kidney disease or kidney dysfunction, you can help reduce the risk of serious illness from sepsis by watching for the signs and symptoms and by getting medical help as quickly as possible.

The Importance of Time

Once sepsis develops, quick identification and treatment is key to protect the body from permanent damage—like amputations or death. Your chances of dying from sepsis increase by up to eight percent for every hour it is not effectively treated. Just like there is a golden hour for saving people from a heart attack or stroke, there is a golden hour for sepsis. Sepsis Alliance developed the mnemonic, TIME™ to help people remember the most basic of symptoms:

T: Temperature is higher or lower than normal.
I: There is an infection present, or there is reason to suspect an infection.
M: Change in mental status, such as excess drowsiness or confusion.
E: Extreme pain or feeling like you might die.

Other signs and symptoms of sepsis may include:

- Drop in blood pressure
- Rapid heartbeat
- Rapid respirations (breathing)
- Chills (shivering)
- Little or no urine output
- Skin rash or change of skin color

It's not unusual for people with sepsis to think that they just need to sleep it off. They may think they have the flu or some bug that is going around. But many survivors say that they were saved because a loved one refused to allow them to "go sleep it off," and insisted that they go to an emergency room or call 911.

Older People

As people age, their immune system can become weaker or they may have chronic illnesses, such as diabetes, that can lower their ability to fight infections. Older people may also take more medications, some that could affect their immune system. If kidney disease is thrown into the mix, their risk for getting an infection rises. But what makes detecting an infection in older people more difficult is they often don't show common symptoms. For example, older people with UTIs may not complain of pain or burning when urinating, or they may not notice that they are urinating more often. For many, the first sign of infection could be a change in their mental status. Someone who is usually very sharp may show signs of confusion. Someone who is already confused may exhibit a sudden deterioration.

If your loved one appears to be changing quickly, even without obvious signs of infection, it is worth contacting your doctor or going to an urgent care clinic to rule out an infection.

Children

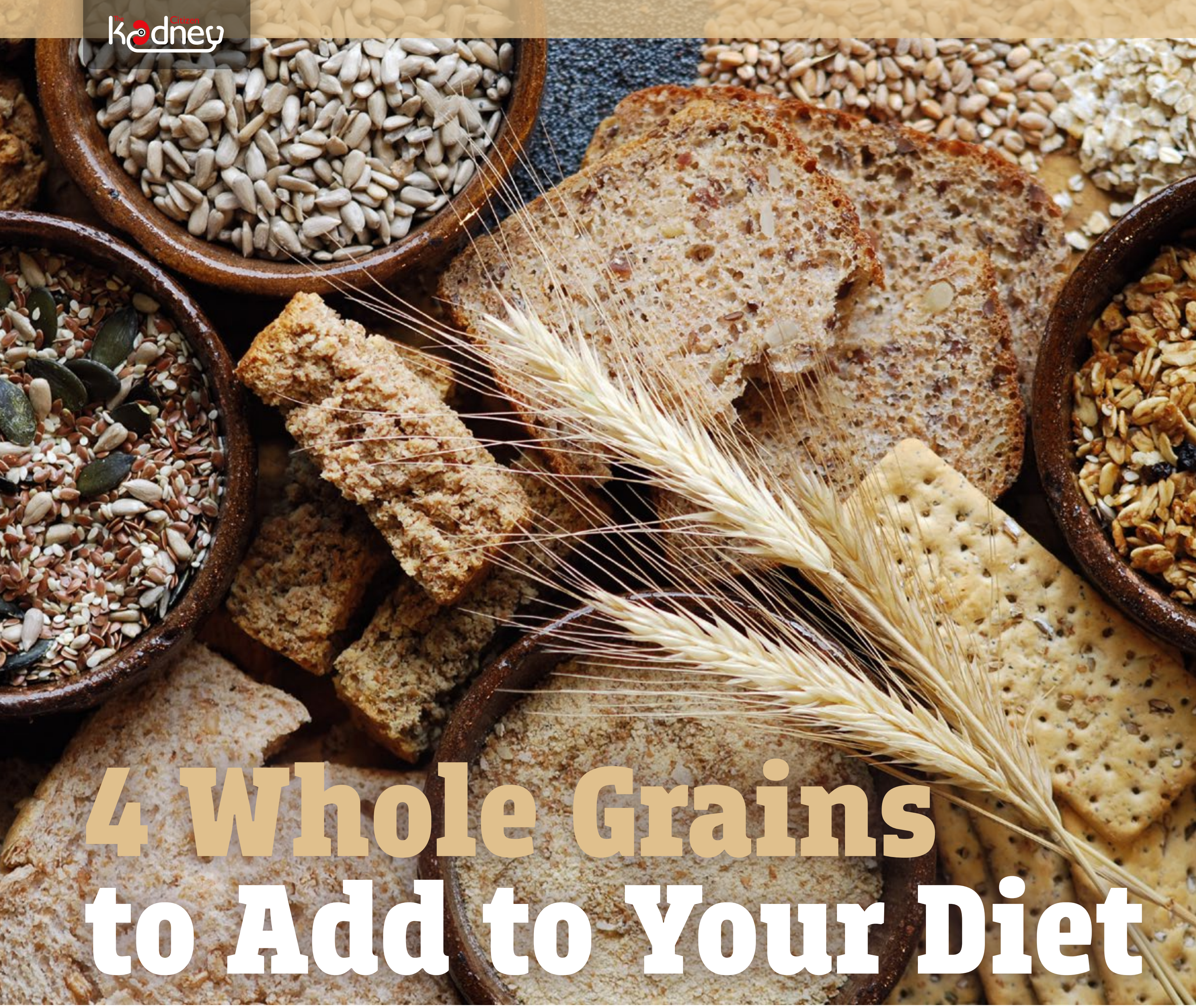
Children are vulnerable to infections because they get viruses and other infections from each other at school, daycare or while playing together. Children also may not be consistent with good hand washing, or they may get a cut or scrape that their parents don't notice until an infection sets in.

If your child starts to act out of character, think about who he or she has been in contact with or if he or she may have gotten hurt. Check for scrapes, bug bites or cuts that could be infected. Signs and symptoms of sepsis include those for adults, but children can have other ways of showing sepsis, including:

- Reduced sucking (for infants)
- Poor or no appetite
- Slower movements
- Seizures
- Change in skin color (bluish or ashen color)

If someone, child or adult, starts to show signs of infection or sepsis but there is nothing obvious—like exposure to someone who had the flu—think back to the past few weeks. Did he or she have any type of invasive treatment (an IV, new fistula, urinary catheter, surgical treatment, etc.)? Was there an injury, a skin tear, a scrape, anything that may have gotten infected? While there may not be an obvious infection, any invasive treatment or injury that opens the skin or exposes the body to external bacteria puts you at risk for developing an infection.

Marijke Vroomen Durning is the Director of Content Sepsis Alliance.



4 Whole Grains to Add to Your Diet

By María Eugenia Rodríguez León, MS, RD, CSR, LND, Registered Dietitian Nutritionist
https://menutritionpr.com

One of the recommendations given for following a healthy diet is choosing half of your daily grains as whole grains. Whole grains can help in preventing some diseases (e.g., diabetes, cancer, high blood pressure and heart disease).[1] A whole grain has the three original parts of the seed: bran, germ and endosperm.[2]

Bran is the edible part surrounding the seed. It contains antioxidants, B vitamins and fiber.

Germ is the seed embryo. It is the part that has the potential to become a new plant. It contains B vitamins, protein, minerals and healthy fats.

Endosperm is the germ's food. It is the bulk of the seed and provides energy so that the plant can grow. It contains carbohydrates, protein and small amounts of vitamins and minerals.

Refined grains have the germ and bran removed—leaving only the endosperm. This causes them to lose protein, fiber, potassium and phosphorus, among other nutrients.

In the past, people with kidney disease were recommended to limit whole grains because they had a higher phosphorus and potassium content. We know that our body absorbs less phosphorus from plant sources than from animal sources and from processed foods and beverages with added phosphorous (also known as phosphate additives).

Low-potassium food can be defined as food with fewer than 200 mg of potassium per serving. The alternatives presented below are all low in potassium.

The fiber content of whole grains can also help you manage or prevent constipation. Constipation is a common problem among people with kidney disease. Avoiding constipation can also help you manage potassium. People with kidney disease eliminate more potassium through the stools.

Finally, some people feel that the renal diet is very limited with few options. Including whole grains will give you more variety in your diet. Try new foods and recipes. Enjoy a varied diet with these whole grains.

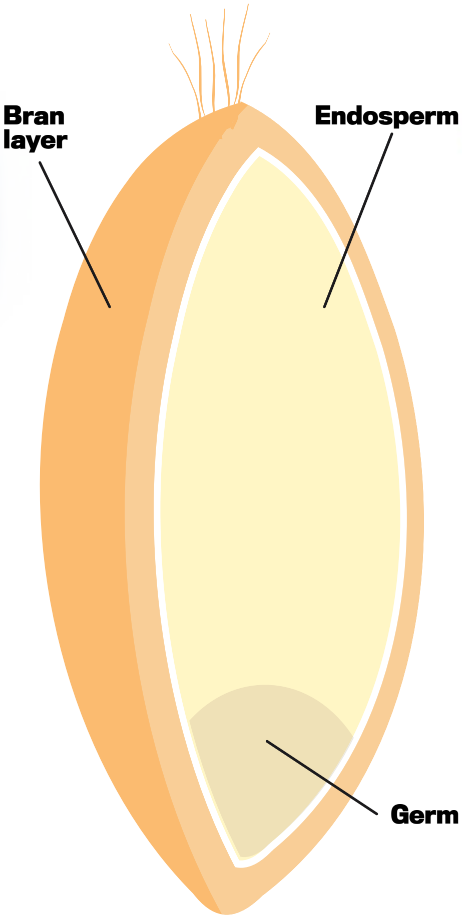
1. Bulgur

Is wheat that has been precooked and broken into small pieces. It is frequently used in the eastern Mediterranean. Maybe you have eaten it in tabbouleh (a Lebanese salad) or in a pilaf.

Cooking: Boil 2 cups of liquid with 1 cup of bulgur. Simmer for 10 to 12 minutes

Nutritional Value (½ cup cooked)

- 76 Calories
- 3 g Protein
- 17 g Carbohydrates
- 4 g Fiber
- 62 mg Potassium
- 36 mg Phosphorus



3. Whole-grain Rice

Rice is common in many diets. It does not contain gluten. White rice is not a good source of fiber because it is a refined grain. Whole grain rice can be easily exchanged in any recipe that calls for white rice. Whole grain rice comes in a variety of colors—brown, black and red—which are all equally healthy.

Cooking: Boil 2 to 2 ½ cups of liquid with 1 cup of brown rice. Simmer for 35 to 45 minutes.

Nutritional Value (½ cup cooked)

Brown Rice	vs.	**White Rice**
109 Calories		121 Calories
2 g Protein		2 g Protein
23 g Carbohydrates		27 g Carbohydrates
1.8 g Fiber		0.3 g Fiber
77 mg Potassium		27 mg Potassium
75 mg Phosphorus		34 mg Phosphorus

2. Barley

Has a very hard outer shell and is difficult to remove without losing some of the bran. Pearl barley is easy to buy but has some of its bran removed. Although it is not completely a whole grain, pearl barley is still a good fiber source. It can be used in risotto, salads and soups.

Cooking: Boil 2 cups of liquid with 1 cup of pearl barley. Simmer for 30 to 40 minutes.

Nutritional Value (½ cup cooked)

- 97 Calories
- 2 g Protein
- 22 g Carbohydrates
- 3 g Fiber
- 73 mg Potassium
- 42 mg Phosphorus

4. Oats

Oatmeal is a common breakfast choice. It can be prepared with milk or water. When prepared with milk, cooked oatmeal will have more phosphorus and potassium than if it is prepared with water or other milk substitutes low in phosphorus and potassium. Oats come in different forms: traditional rolled oats and steel cut oats, which are nutritionally similar, but differ in cook time. The amount of liquid and cooking time will vary depending on the oats you buy.

In addition to hot oatmeal, you can prepare overnight oats (leave it in the fridge from the night before) or baked oatmeal for breakfast. Also, you can use oats in different recipes such as granola, meatballs, cookies, smoothies or bars.

Nutritional Value (1/2 cup raw oats)

- 154 calories
- 5 g protein
- 28 g carbohydrates
- 4.1 g fiber
- 147 mg potassium

166 mg phosphorous

Food	Phosphorous (mg)	Potassium (mg)
½ cup raw oats (or prepared with water)	166	146
Oatmeal prepared with ½ cup raw oats and 8 ounces cow's milk	398	512
Oatmeal prepared with ½ cup raw oats, 4 ounces cow's milk and 4 ounces water	282	329
Oatmeal prepared with ½ cup raw oats and 8 ounces almond milk (Silk)	186	176
Oatmeal prepared with ½ cup raw oats and 8 ounces unenriched rice milk (Rice Dream Classic)	196	176

References

1. Sparks, Brittany. Is there room for more than white rice in the renal diet? A new look at ancient grains. J Ren Nutr. 2018;28:e15-e18.
2. Oldways Whole Grains Council. Whole Grains A to Z. Available at: https://wholegrainscouncil.org/whole-grains-101/whole-grains-z

4 Cereales integrales para incorporar en tu alimentación

Por María Eugenia Rodríguez León, MS, RD, CSR, ND, Nutricionista Dietista Licenciada
https://menutritionpr.com

Una de las recomendaciones para llevar una alimentación saludable es que la mitad de los cereales y farináceos que comemos sean integrales. Se ha demostrado que los cereales y farináceos integrales ayudan en la prevención de algunas enfermedades (ej. diabetes, cáncer, alta presión y enfermedades cardiovasculares).[1] Un grano integral tiene las tres partes originales de la semilla: salvado, germen y endospermo.[2]

Salvado: es la parte comestible del exterior de la semilla. Contiene antioxidantes, vitaminas del complejo B y fibra.

Germen: es el embrión de la semilla. Es la parte que tiene el potencial de convertirse en una planta nueva. Contiene vitaminas del complejo B, proteína, minerales y grasas saludables.

Endospermo: es el alimento del germen. Es la parte más abundante de la semilla y le provee energía a la planta para que pueda crecer. Contiene carbohidratos, proteína y poca cantidad de vitaminas y minerales.

A los cereales y farináceo refinado se les remueve el germen y el salvado dejando solamente el endospermo. Esto provoca que pierdan proteína, fibra, potasio y fósforo entre otros nutrientes.

En el pasado, se recomendaba a las personas con enfermedad renal que limitaran los granos integrales porque tenían mayor contenido de fósforo y potasio. Ya sabemos que nuestro cuerpo absorbe en menor proporción el fósforo de las plantas que el fósforo de los animales y que el fósforo añadido en alimentos procesados y bebidas (también conocido como aditivos de fósforo). Un alimento bajo en potasio se puede definir como un alimento con menos de 200 mg de potasio por porción. Las alternativas presentadas a continuación son todas bajas en potasio.

El contenido de fibra de los granos integrales también te puede ayudar a manejar o prevenir el estreñimiento. El estreñimiento es un problema común entre las personas con enfermedad de los riñones. Evitar el estreñimiento también te puede ayudar a manejar el potasio. Las personas con enfermedad renal tienen la habilidad de eliminar más potasio a través de la excreta.

Por último, algunas personas pueden sentir que la dieta renal es muy limitada con pocas opciones. Incluir granos enteros te brindará mayor variedad a tu alimentación. Anímate a intentar alimentos y recetas nuevas. Disfruta de una alimentación variada con estos granos integrales.

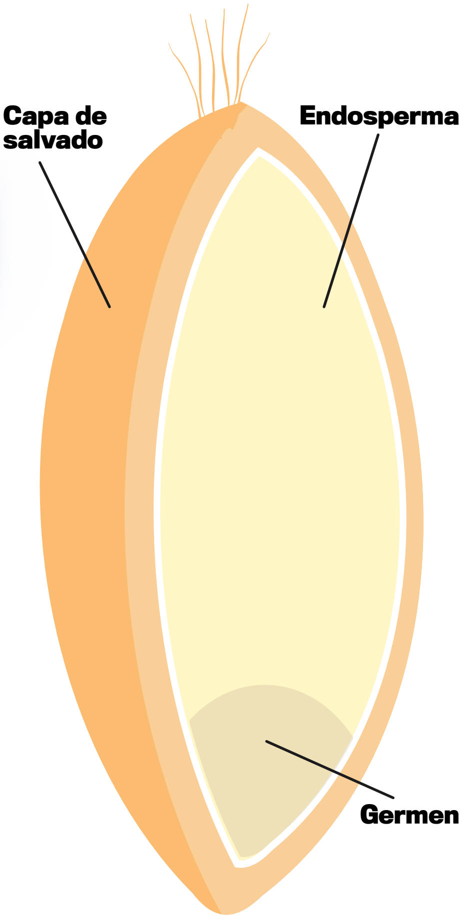
1. Bulgur

Es trigo que se ha precocido y partido en pedazos pequeños. Se utiliza con frecuencia en el este del Mediterráneo. Quizás lo has comido en tabulé (ensalada libanesa) o pilaf.

Para cocinar: Hierve 2 tazas de liquido con 1 taza de bulgur. Cocina a fuego lento por 10 a 12 minutos.

Valor Nutricional (½ taza cocido)

- 76 calorías
- 3 g Proteína
- 17 g Carbohidratos
- 4 g Fibra
- 62 mg Potasio
- 36 mg Fósforo



3. Arroz integral

El arroz es común en muchas culturas, incluyendo la dieta latinoamericana. No contiene gluten. Sin embargo, el arroz blanco no es buena fuente de fibra porque es un grano refinado. El arroz integral se puede sustituir fácilmente en cualquier receta que lleve arroz blanco. El arroz integral puede ser de varios colores como, por ejemplo, marrón, negro y rojo.

Para cocinar: Hierve 2 a 2 ½ tazas de líquido con 1 taza de arroz integral. Cocina a fuego lento por 35 a 45 minutos.

Valor Nutricional (½ taza cocido)

Arroz integral vs	**Arroz blanco**
• 109 calorías	• 121 calorías
• 2 g Proteína	• 2 g Proteína
• 23 g Carbohidratos	• 27 g Carbohidratos
• 1.8 g Fibra	• 0.3 g Fibra
• 77 mg Potasio	• 27 mg Potasio
• 75 mg Fósforo	• 34 mg Fósforo

2. Cebada

Tiene un exterior muy duro y es difícil de remover sin que pierda un poco del salvado. Podemos conseguir con facilidad la cebada perlada que se le remueve parte del salvado. Aunque no es completamente integral sigue siendo un grano rico en fibra. Se puede usar en risotto, ensaladas y sopas.

Para cocinar: Hierve 2 tazas de liquido con 1 taza de cebada perlada. Cocina a fuego lento por 30 a 40 minutos.

Valor Nutricional (½ taza cocido)

- 97 calorías
- 2 g Proteína
- 22 g Carbohidratos
- 3 g Fibra
- 73 mg Potasio
- 42 mg Fósforo

4. Avena

La avena es un desayuno común entre los latinos. En Puerto Rico, se prepara con leche en vez de agua. Al prepararse con leche, la avena cocida tendrá más fosforo y potasio que si se prepara con agua o con otros sustitutos de leche bajos en fosforo y potasio.

Las hojuelas de avena vienen en diferentes formas: copo tradicional y hojuelas cortadas al acero. Depende cual compres será la cantidad de líquido y tiempo de cocción que necesitas para cocinarla.

Para el desayuno, puedes prepara la avena cocida caliente, pero también hay otras maneras de prepararla como avena fría (la dejas en la nevera desde la noche antes) o avena horneada. También, puedes usar las hojuelas de avena en diferentes recetas como granola, albóndigas, galletas, batidos o barritas.

Valor Nutricional (1/2 taza avena cruda)

- 154 calorías
- 5 g proteína
- 28 g carbohidratos
- 4.1 g fibra
- 147 mg potasio
- 166 mg fósforo

Alimento	Fóforo (mg)	Potasio (mg)
½ taza avena cruda (o preparada en agua)	166	146
Avena preparada con ½ taza de avena cruda y 8 onzas leche de vaca	398	512
Avena preparada con ½ taza avena cruda, 4 onzas leche de vaca y 4 onzas agua	282	329
Avena preparada con ½ taza avena cruda y 8 onzas leche de almendra (Silk)	186	176
Avena preparada con ½ taza de avena cruda y 8 onzas leche de arroz (Rice Dream Classic)	196	176

Referencias

1. Sparks, Brittany. Is there room for more than white rice in the renal diet? A new look at ancient grains. J Ren Nutr. 2018;28:e15-e18.
2. Oldways Whole Grains Council. Whole Grains A to Z. Available at: https://wholegrainscouncil.org/whole-grains-101/whole-grains-z

Spoon-Saving Strategies

By Sara Naveed

Raise your hand if getting out of bed feels like an accomplishment to you, if you have ever felt the need to nap after taking a shower or if being tired feels like it's a part of your personality now! How about constantly finding yourself in a push/crash cycle—pushing way past your limit one day and then paying the price for it in the form of heightened symptoms and having to rest several days in order to recover? Don't worry—you're not the only one!

We currently live in an era where we are constantly fed the narrative that our self-worth is based on our productivity. So it's only natural to want to push ourselves when our bodies are being nice to us on the "good days." The temptation to cross off all the items on that to-do list is REAL! However, it's important to remember and accept that with fatigue being such a prevalent symptom, especially following dialysis, you can't do everything you want. The question then is how do we get things done with the limited number of *spoons* we have, without pushing ourselves? Confused about why I used the word spoons there? Don't worry—let me explain!

Chronic illness warriors use the word spoons to describe the idea of limited energy. The premise of The Spoon Theory is that we have a "spoonful" of energy available for each task, each day. With every activity, we remove one or more spoons. In comparison to healthy people who have an unlimited supply of spoons, we start each day with fewer spoons and use more spoons for each task. Because we have a limited number of spoons, we need to be more cautious of when and where we use them. This can be accomplished through the art of pacing and adapting various spoon-saving strategies.

Here are some spoon saving strategies I use daily that you should give a try:

Plan Your Day

Use a planner or smart phone to have your days planned in advance and lower the amount of stress in meeting your personal, as well as professional deadlines. An ideal first step is separating your needs from your wants in order to help prioritize and focus your energy on the right things. Spread activities throughout the day and schedule hard tasks during the time of the day when you have the most energy. Remember not to multitask. Switching back and forth between various tasks requires a lot of refocusing, thereby, exhausting you even more! In addition,

make sure not to schedule multiple energy-consuming events close together.

Stay Organized

Keep common household items on every floor and possibly in every room of your house in order to prevent unnecessary trips between different floors and/or rooms. Arrange your work environment for easy access to commonly used equipment and supplies.

Reduce Unnecessary Energy Use

Take a seat during the simplest of tasks like taking a shower, grooming, dressing, folding laundry and ironing. Better yet, buy clothes that don't require ironing. Use electric or automatic appliances such as a dishwasher, electric mixer and robotic vacuum to simplify everyday tasks. Use a disability parking tag to park closer to entrances, and shop at less busy times in order to decrease the amount of walking required and time spent waiting in lines. If possible, shop online.

Do things slowly and avoid rushing so you don't end up using all your energy at once. Just like your car uses more gas to get to your destination faster, we expend more energy when we are rushing. On the other hand, if you are more laid back, you'll find that you have more energy to accomplish your tasks and goals because you are no longer expending any energy on the panic and stress that comes with rushing. And most importantly, don't give yourself permission to do a lot!

Rest

Rest is very important in the successful management of any illness; however, many people tend to push themselves beyond their limit most days. While remaining active is important, pacing yourself by scheduling frequent breaks throughout the day between various tasks is even more crucial for us since resting allows our muscles to refuel for more activity. Become attuned to your body. Give your body rest *before* it gets to a point where you've done too much and will need to "pay for it" later. Listen to it at the first sign it gives you to stop the task at hand. And make sure to keep your naps short (less than 30 minutes) in order to avoid messing up your nighttime routine.

Sleep

A good night's sleep maximizes energy levels, so good sleep hygiene can get your day started with more spoons. Aim to get at least seven to eight hours of sleep. Follow a bedtime ritual that signals to your body that it's time to go to sleep. Go to bed and get up at about the same time every day. And as hard as it can be, try staying away from your phone, laptop and TV. These simple tips can maximize the number of spoons you wake up with each day.

Delegate

Know your body's limits, and don't be afraid to ask for help from your loved ones. Certain tasks that are difficult for you might be super easy for them.

If there is anything my health journey has taught me so far, it's that we need to love our bodies and treat them right. Not only do we need to honor our limits, but we also must make sure we live within those limits. Adapting these simple spoon-saving strategies will not only help you live within those limits, but also control your symptoms, bring more stability into your life and improve your overall quality of life. This is because each saved spoon is a gift of healing you're giving yourself and your body.

Most importantly, I've come to realize that my worth is not based on my productivity. My worth just is! It's inherent…and yours is too!

Check out Sara's website at:
https://fabulousandfatigued.com

Managing Chronic Pain in Dialysis Patients

By Amanda Nelli, MD
and Padma Gulur, MD

Pain is a complex symptom and a common concern for all patients with a chronic illness. In particular, end-stage renal disease (ESRD) poses unique challenges. It has been found that 37-50 percent of patients with ESRD on hemodialysis experience chronic pain, and more than 80 percent of these patients experience moderate to severe pain.[1] Pain in dialysis patients often goes undertreated, which may be because it is often caused by multiple problems. The pain experienced in dialysis patients is often a combination of physical, social and psychological influences.[2]

There are multiple medical causes of pain in the dialysis population, including complications related to diabetes, underlying arthritis, deposition of b2 macroglobulin causing carpel tunnel syndrome or those directly related to dialysis (such as cramping). Understanding the cause of the pain is the first step in helping patients manage it appropriately. Proper pain management is extremely important because unmanaged pain can lead to depression, which may result in patients withdrawing from their dialysis treatments.[3]

Pain is rarely managed with only one type of therapy. It is best addressed by using a combination of treatments—this approach is called "multimodal" pain management. This may include the use of medications, injection therapies, massage, physical therapy, acupuncture and more. Because there are so many different pain medications available, when managing pain with medication it is important to determine the correct type for the presenting pain symptoms. It is also important to use medications that are safe for the kidneys. Other medications, in the form of creams or sprays, may be used in certain areas, such as pain caused by the dialysis access.

Multimodal Pain Management

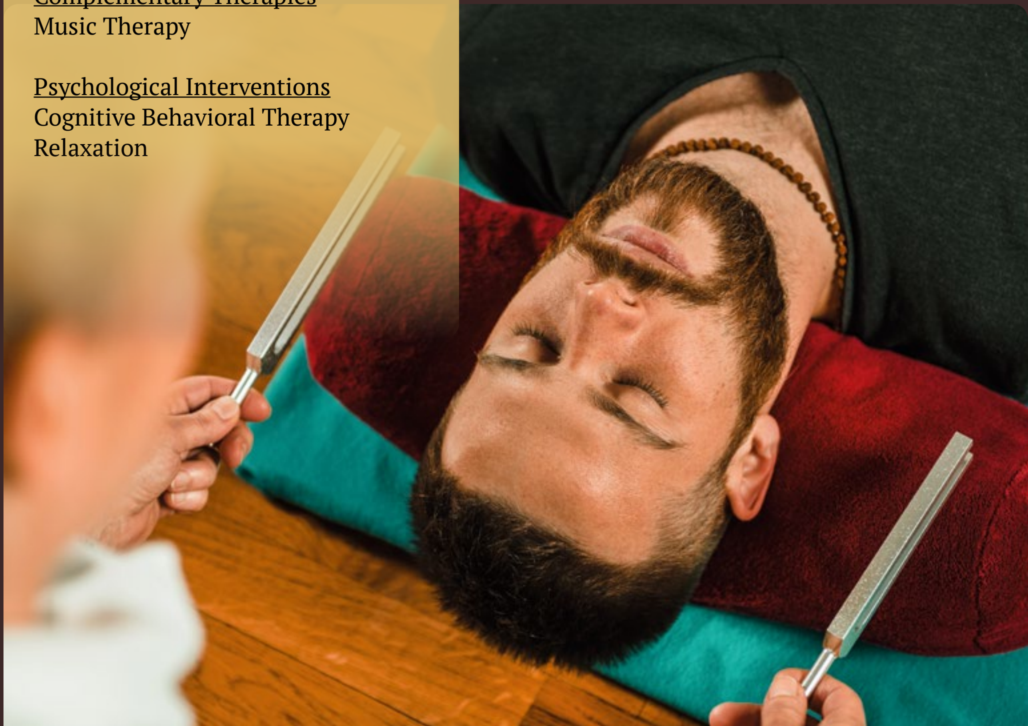
Pharmacological approaches
Medications
Injections
Creams and Sprays

Interventions
Injection therapies
Spinal cord stimulators

Kinesiotherapy
Physical Therapy
Occupational Therapy

Complementary Therapies
Music Therapy

Psychological Interventions
Cognitive Behavioral Therapy
Relaxation



There are multiple injection therapies that can be used, especially if the pain is in the back, neck or joints.

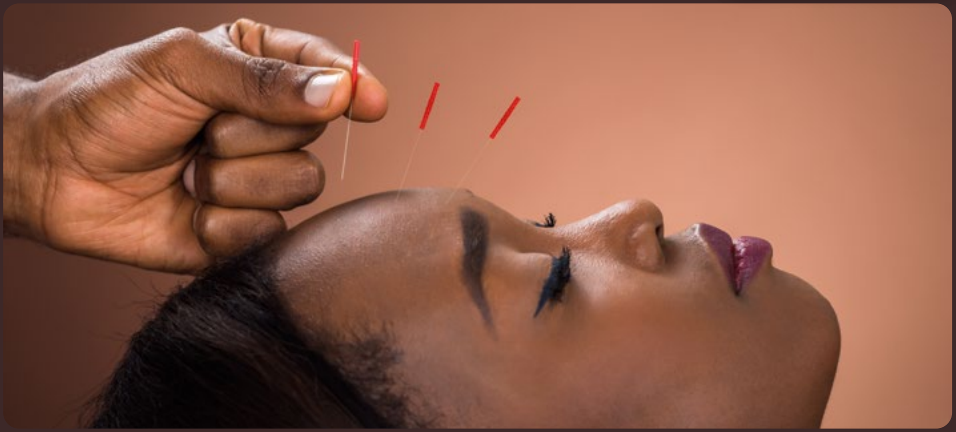
Physical or occupational therapy may also be of benefit. These therapies focus on the source of the pain and can include stretches and exercises to improve function for daily tasks.

Another therapy is cognitive behavioral therapy (CBT). CBT is a psychological treatment that combines multiple approaches to best treat pain and is especially beneficial in patients with high anxiety or other psychologic disabilities. CBT includes relaxation, biofeedback techniques, imagery, setting goals and music therapy.

Relaxation has been shown to benefit both pain and anxiety. It can include breathing exercises, muscle relaxation, and more. Biofeedback is learning to control the body's reactions, such as skin temperature, heart rate and blood pressure. Imagery is a major part of passive relaxation and may have the best results when guided by a therapist. Music therapy is also a useful technique to manage pain. Music therapy can be done in a formal session with a trained music therapist or be done informally while listening to music at home. During music sessions, patients are often asked to participate in choosing the song or playing music. When listening to music at home, the music choice should be calming and relaxing rather than music that is stimulating. Preferably, these techniques should be taught by a trained provider, and then practiced at home for the most successful pain management. Talk with the social worker at your dialysis center about relaxation techniques you could try.

Summary:

The most successful treatment for pain comes from using multiple methods of pain management. Pain medicine specialists, such as physician anesthesiologists, can help you develop these comprehensive plans. Medications may relieve some of the pain, but they may be restricted to avoid kidney damage. Therefore, it is important to consider other therapies such as physical therapy or CBT. CBT can be a valuable pain management option in dialysis patients as multiple pain syndromes are often found in this population.



Amanda Nelli, MD is Postdoctoral Researcher at Duke University in Durham, NC. Padma Gulur is Professor of Anesthesiology and Population Health, Executive Vice Chair of Anesthesiology at Duke University in Durham, NC and a member of the American Society of Anesthesiologists' Committee on Pain Medicine.

References

1. Davison SN. The Prevalence and Management of Chronic Pain in End-Stage Renal Disease. Journal of Palliative Medicine. 2007;10(6):1277-87.
2. Davison SN, Jhangri GS. The Impact of Chronic Pain on Depression, Sleep, and the Desire to Withdraw from Dialysis in Hemodialysis Patients. Journal of Pain and Symptom Management. 2005;30(5):465-73.
3. Davison SN, Jhangri GS. Impact of Pain and Symptom Burden on the Health-Related Quality of Life of Hemodialysis Patients. Journal of Pain and Symptom Management. 2010;39(3):477-85.

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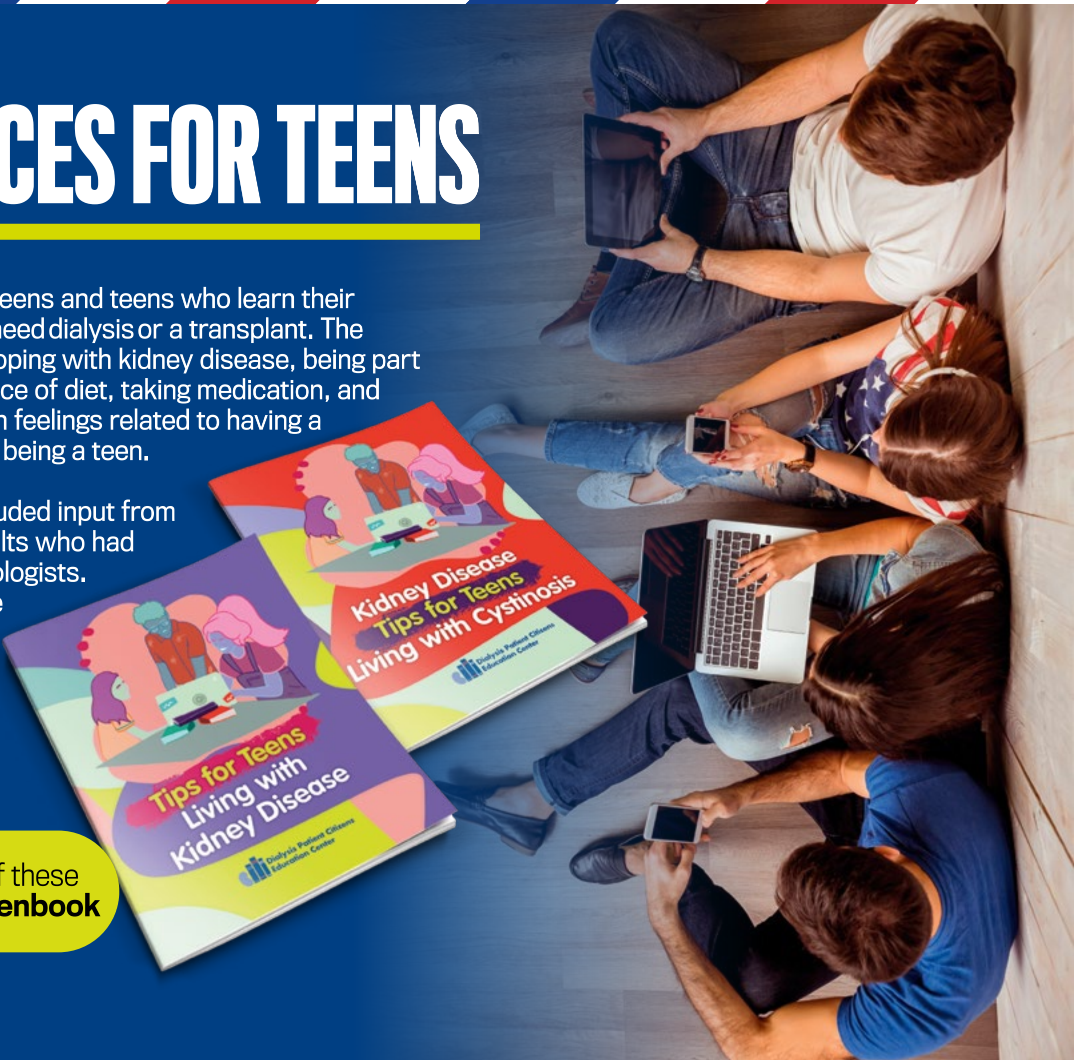
NEW RESOURCES FOR TEENS

These booklets were developed for tweens and teens who learn their kidneys are not working and they will need dialysis or a transplant. The booklets provide a brief overview of coping with kidney disease, being part of their health care team, the importance of diet, taking medication, and treatment methods. They also touch on feelings related to having a chronic illness, family and friends, and being a teen.

The development of both booklets included input from kids currently on dialysis, parents, adults who had kidney disease as children, and nephrologists. Although both booklets are similar, one focuses on teens who learn they have kidney disease and the other is for teens who already have cystinosis and learn they now have kidney disease as well.



Download or order hard copies of these booklets at: **dpcedcenter.org/teenbook**