

# The **Kidney** Citizen

A publication of Dialysis Patient Citizens (DPC) Education Center

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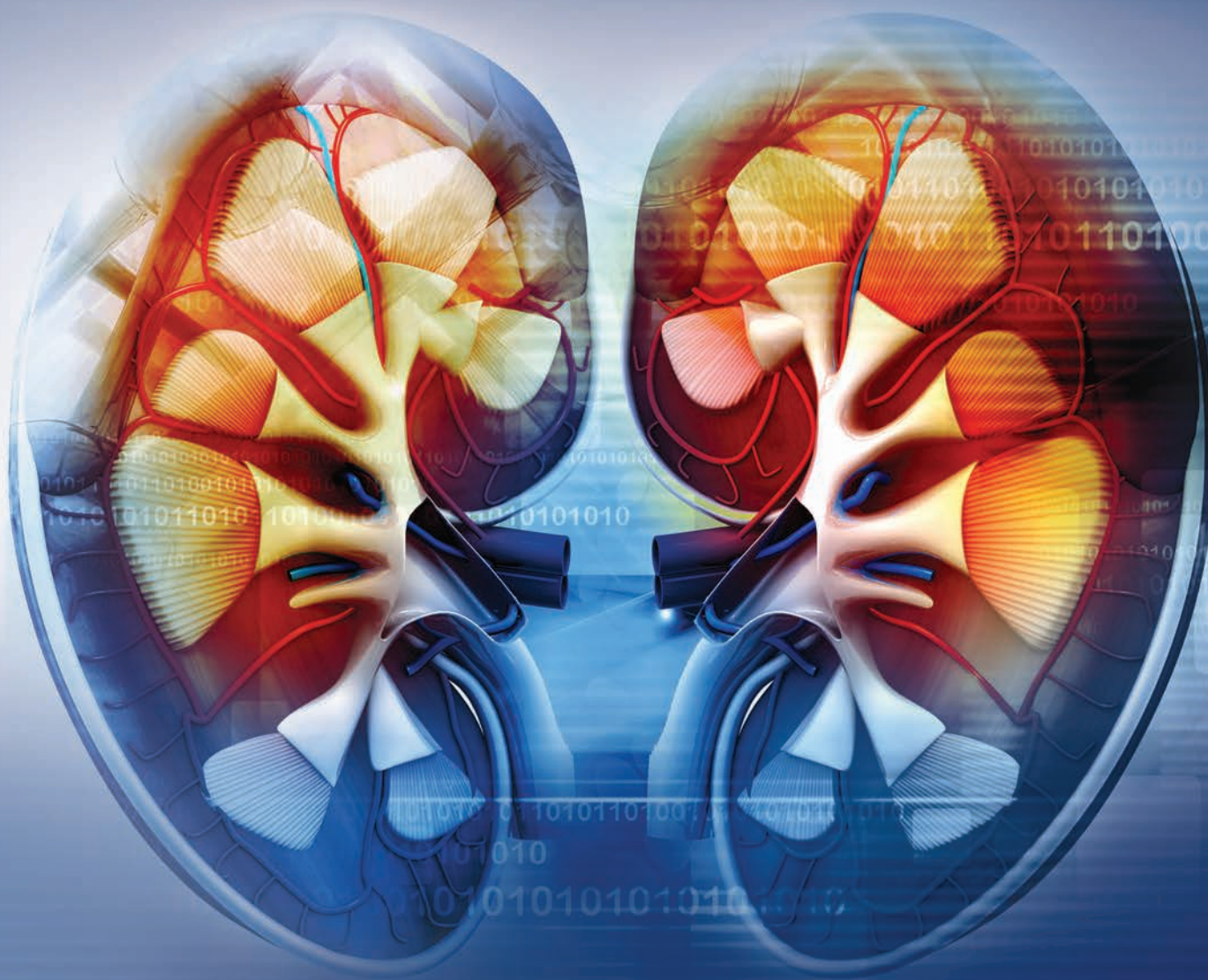


Advance Care Planning

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Work Those Kidneys Out!



# President's Message

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**H**appy New Year! As we start 2019, there is excitement in the air as we make our goals and resolutions for the new year. We are ready to 'brush off the old' and make new habits and positive changes in our lives. Yet according to U.S. News, approximately 80 percent of resolutions fail by the second week of February. Possible reasons include having too many goals, trying to change too many habits at once, getting discouraged and giving up. I have been there too, but last year I focused on one thing, consciously made it a priority and built the habits to ensure my success—you can do it too.

This issue of our newsletter may easily motivate you to add at least one goal for the new year. You will read about the importance of exercise and as a side note, increasing exercise is a goal for most people who make resolutions. It may be better to set fewer and smaller goals that we can achieve and then add new goals as we build new habits and successes. A favorite quote of Charles Duhigg, the author of "The Power of Habit," is "The difference between who you are and who you want to be is what you do."

The new year is also a time for inspiration, hope and connecting with those we love. Studies show that isolation and loneliness increase depression, and we already know that more people who have kidney disease experience some depression. Throughout this newsletter, you will find articles that encourage you to connect with others, communicate more with family and friends, and find ways to give and accept support. As I travel around the country, I often meet renal patients who are experiencing some degree of depression. For some, it may be helpful to seek counseling, which is a sign of personal strength, to understand yourself better and to learn techniques that will improve the quality of your life.

In conclusion, I encourage each of you to live life to the fullest, whether you are a kidney patient, on dialysis or are a care partner or caregiver. One of my many sayings is, "Do dialysis, do not let it do you in." ■

Sincerely



**Nancy L. Scott**  
 DPC Education Center  
 Board President





# Free Monthly Webinars/ Conference Calls



The DPC Education Center invites people living with chronic kidney disease (CKD), end-stage renal disease (ESRD), their families and professional staff to join us for our monthly webinars. You can also join by phone or view the recordings online at a later time. The webinars are planned for the fourth Thursday of the month at 2 p.m. Eastern time zone, except for November and December when they will be held during the third week of the month. You can download monthly webinar fliers to share with others and/or register for webinars at [www.dpcedcenter.org/education-seminars](http://www.dpcedcenter.org/education-seminars). Join by phone by calling 1-877-399-5186 and entering meeting code 433 459 5474.

Although we are still finalizing some of the webinar speakers and topics, you can participate in sessions to understand how exercise affects kidney disease, learn tips from a social worker regarding the transplant process, hear suggestions about caring for a child with kidney disease, learn about diet and nutrition, and expand your knowledge on a variety of other important topics.

Watch some of our past webinars or sign up for our monthly E-News at [www.dpcedcenter.org](http://www.dpcedcenter.org). We hope you will join us for our upcoming educational programs, and let us know what other topics you would like! ■



By **Megan Hashbarger**, Director of Congressional and State Relations, Dialysis Patient Citizens

This past November, America held its 2018 midterm elections. We call it a midterm election because it is held between the four-year cycle of Presidential elections and is often seen as a reflection of the country's temperament towards the President's agenda. This cycle saw big wins for Democrats but also some solid victories for Republicans. While Democrats picked up over 40 seats and retook the majority in the House, Republicans held on to and increased their majority in the Senate. The only thing clear now is that for at least the next two years, we will have a divided government with Republicans controlling the Senate and the Administration, and Democrats controlling the House of Representatives. So, what does this mean for dialysis patients?

# 2018 Midterm Election Wrap-Up



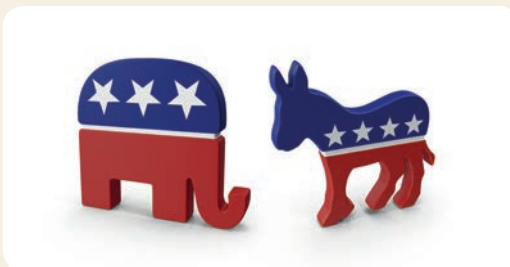


In many ways, this is an opportunity for patients. This election will bring in more than 100 new Representatives, many who have never held elected office. A lot of these new Members are women and minorities. The 116th Congress will easily surpass the current record of 84 women serving, with at least 95 women. Two of these women are also the first Native Americans to be elected to Congress. And many of these newly elected Members ran on a campaign of improving health care. It will be imperative that all Members, not just new Members, hear from dialysis patients and get educated on their stories and priorities to improve their quality of care.

While the new Congress will be divided, because health care was a central platform of this election cycle, we will see some movement on health care bills. That being said, we are unlikely to see any further efforts to repeal the Affordable Care Act (ACA), but we are equally unlikely to see any efforts to strengthen or improve it. There may be some bipartisan agreement on small fixes to the ACA, but no large efforts to protect the marketplace will pass both chambers. However, this does present an opportunity for other bipartisan health care bills to gain momentum.

For example, we here at DPC have been working on many priorities, but there are three legislative priorities in particular worth reiterating. These three bills all have bipartisan support, and we will again be advocating for them in the 116th Congress. The first is H.R. 4143/S. 2065—The Dialysis PATIENTS Demonstration Act—which would increase access to care coordination for dialysis patients. This bill has 208 bipartisan

cosponsors in both the House and the Senate. Another is H.R. 3976—The Access to Marketplace Insurance Act—this bill would ensure patients are able to use charitable assistance to access private insurance. It has 176 bipartisan cosponsors in the House, and its champion, Rep. Kevin Cramer (R-ND), was just elected to the Senate. Finally, H.R. 2644/S. 1890—commonly referred to as the Kidney bill—contains several provisions to help dialysis patients but would also ensure that all patients, no matter the age, have access to Medigap plans.



All of these bills have broad support and hopefully will be areas of agreement in a divided Congress. If they do not pass before January, however, they will have to be

reintroduced and will have new bill numbers in the new Congress. DPC will be reaching out to our members to encourage them to contact their representatives and ask them to support these priorities. We will keep you all apprised of any updates to these bills, and others, so that you can help us keep your representatives informed. We will also ask you to invite your representatives to come visit your facility. Seeing firsthand what dialysis patients go through will be paramount, especially to all the new Members.

While this has been a bit of a wild election cycle, hopefully, Congress and this Administration will learn to work together to find common ground. When it comes to health care, the patients' best interests should be the priority, and we at DPC will be working tirelessly to elevate that voice for dialysis patients. ■



# Kidney Community Blocks Threats to Charitable Assistance and Dialysis Funding in California

By **Megan Hashbarger**, Director of Congressional and State Relations, Dialysis Patient Citizens

Dialysis Patients Citizen's (DPC) mission is to improve dialysis citizens' quality of life. As a result, we have played an important role in increasing patient access to: health insurance coverage, care coordination, medications and innovative therapies. While we work hard to improve public policies for patients, sometimes we are put on defense to protect our previous hard-fought victories.

One of the most important tools for protecting patient choice and access to insurance coverage is the ability of charities

to provide financial assistance in helping dialysis patients purchase insurance coverage. The American Kidney Fund helps nearly one in four of our members with their health care expenses. Unfortunately, legislation was introduced in California (S.B. 1156) last year, which threatened patients' ability to use charitable assistance, but later was changed to cut the reimbursement rates to dialysis providers. Either version of this bill would have likely led to facility closures and countless patients scrambling to find life-saving care, even if they did not receive charitable assistance themselves. DPC





CEO Hrant Jamgochian and DPC Board Member Danny Iniguez held over 40 meetings with California state legislators during several trips to Sacramento. They were able to raise patient concerns with this flawed legislation, ultimately leading to the Governor's veto of the bill. However, there is now a new Governor and several new state legislators who will need to be educated about the importance of charitable assistance.

Dialysis funding also remains critical to ensuring that patients receive high-quality care. However, voters in California were recently asked to consider a flawed ballot initiative (Proposition 8) that would have limited dialysis reimbursement. Many of the services that are required for the delivery of care were not included in the calculation advanced by this initiative, which could have required virtually all California facilities to dialyze patients at a loss. The good news is that California voters voted down this measure by over 60 percent, avoiding a potentially disastrous situation that would have led to even more facility closures. Both

S.B. 1156 and Proposition 8 were being promoted by the Service Employees International Union, a powerful labor union that wants to unionize the employees at dialysis facilities. While DPC has never gotten involved in labor/management issues, we had to speak out in both instances to ensure that patients did not get caught in the middle.

In 2019, we expect these challenges to resurface and potentially spread to other states. DPC will be working hard to grow our grassroots advocacy network, in order to help educate state legislators over the potential "collateral damage" that such legislation could cause to dialysis patients. As a result, we will be asking for your help in contacting your state and local officials to ensure that before they vote on any legislation, they make certain it passes the critical test of "do no harm." No one knows the challenges that dialysis patients face better than you, so we are counting on your help to protect patient care. ■



# Maintaining Personal Relationships While on Dialysis

By **Alex Purcell**

People with end-stage renal disease (ESRD) who have gone through dialysis can tell you that it is exhausting—and so can their loved ones. Not only does dialysis take a physical toll on the patient, it can also put significant stress on the patient's relationships with their friends and family, right when they need those relationships the most. This dynamic can be especially complicated if the primary caregiver is a spouse or close relative.

If you're in this situation, as either a patient or a loved one, you may be feeling frustrated, sad or lonely. But there's hope: transplant psychologists say that you can learn to maintain and potentially enrich your close relationships while undergoing dialysis.

**It's okay to rely on your family and friends.** Dialysis can make patients feel weak, dehydrated and fatigued. It can also cause

patients to rely on others more than they would normally, according to Jared Skillings, PhD, ABPP, a former transplant psychologist at Spectrum Health System in Grand Rapids, Michigan. "This shift in responsibility might lead patients to feel guilty. They may feel like a burden on family and friends, especially if they are usually not the type of person to receive help," Skillings says. This guilt might also cause patients to push their loved ones away and inadvertently put stress on



relationships. People on dialysis may also feel helpless or hopeless and can become clinically depressed. Adjusting to your new lifestyle changes may take some time, and your relationships with family and friends may change. Be patient with yourself.

**Express yourself.** The stress of treatment can amplify existing issues or yield new disagreements and miscommunications between patients and loved ones. These dynamics can be particularly difficult if the patient is struggling with anxiety or depression, as many people on dialysis do, says Skillings. Furthermore, tension between dialysis patients and their loved ones—especially caregivers—often occurs because all parties involved want to do what’s “right” for the patient, says Jody Jones, PhD, a transplant psychologist with the University of Iowa Hospitals and Clinics in Iowa City. This can lead to a number of other conflicts, she adds. “Communication is tremendously important, but will vary greatly by individual,” she says. “You should discuss practical matters, but ideally, everyone should be able to express their hopes and fears as well. Expressing our darker feelings and thoughts takes the power away from them.”

This kind of open and honest communication knocks down barriers and allows for closer bonds and understandings to form during difficult times. “Talking about things that people are afraid to say out loud can help everyone feel stronger,” says Jones. Additionally, while you’re on dialysis, it might be difficult for your loved ones to anticipate your needs or understand when you don’t want their help. In situations like these, it’s best to be vocal about what you need (or don’t need). “Be assertive. Express what you need or what you want,” says Jones. “In turn, while

caregivers and other helpers shouldn’t be too passive, they should listen to the patient and try not to be overly aggressive about taking charge of the patients’ care.”

**Make space for normalcy**—and for each other. The rigid treatment and medication regimens that dialysis demands can be very isolating. As you adjust your life to fit around this routine, you may crave the normalcy of going to work or maintaining a family life. That may not be







possible, but “you don’t want to let dialysis be the thing that keeps you from living,” says Jones. Having family and friends around to help, share meals and just talk can keep you connected to the world beyond your treatment routines and give you special time to bond. At the same time, you may not always want or need a “cheering squad,” says Jones. Let them know when you need space. “Just trying to cheer up the patient all the time won’t always work,” Jones advises friends and family. “Give them a little space to grieve about what they’re going through, and be able to share in that grief with them.”

**Remember that caregivers are adapting, too.** Undergoing dialysis in the short- or long-term can be exhausting and scary for the patient, but caregivers—especially if they’re the patient’s spouse or close relative—carry heavy emotions and stress as well. They may feel a sense of responsibility for the patient and might feel frustrated by what feels like a lack of recognition or appreciation for their work. “Many frustrations have to do with compliance,” says Jones. “When caretakers see that their patient isn’t doing everything perfectly to maintain a healthy lifestyle during treatment, it creates tension, especially when the caretaker has made sacrifices to take care of their loved one.” While this comes from a place of concern, it can be misconstrued as unfair judgment of the patient, she says.

Likewise, Skillings says that caregivers should try to honor the wishes of the person in treatment, even if they disagree.

“It’s important to put them first,” he says, although caregivers should talk with the treatment team if they’re concerned about the patient’s physical and emotional state. In this situation, Jones encourages compassion. “It’s hard enough to be on dialysis—it’s even harder to make healthy choices all the time,” she says.

**Compromise.** Jones says negotiating compromises is a healthy way for anyone involved to express what they’re feeling and prevent discord. “The best compromises usually end with both sides getting a little and giving a little of what they want,” Jones says. “Approach the conversation by asking, how can everybody here give a little?” Ultimately, though, you may not be able to resolve all conflicts on your own, says Skillings. And that’s okay.

If you’re really struggling with depression or anxiety, or the conflicts are becoming overwhelming, you (and your family) may benefit from counseling. Your treatment team should be able to connect you and your family with someone who can help.

*Alex Purcell is a former intern of the American Psychological Association and a recent graduate of American University. 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. ■*





# Advance Care Planning

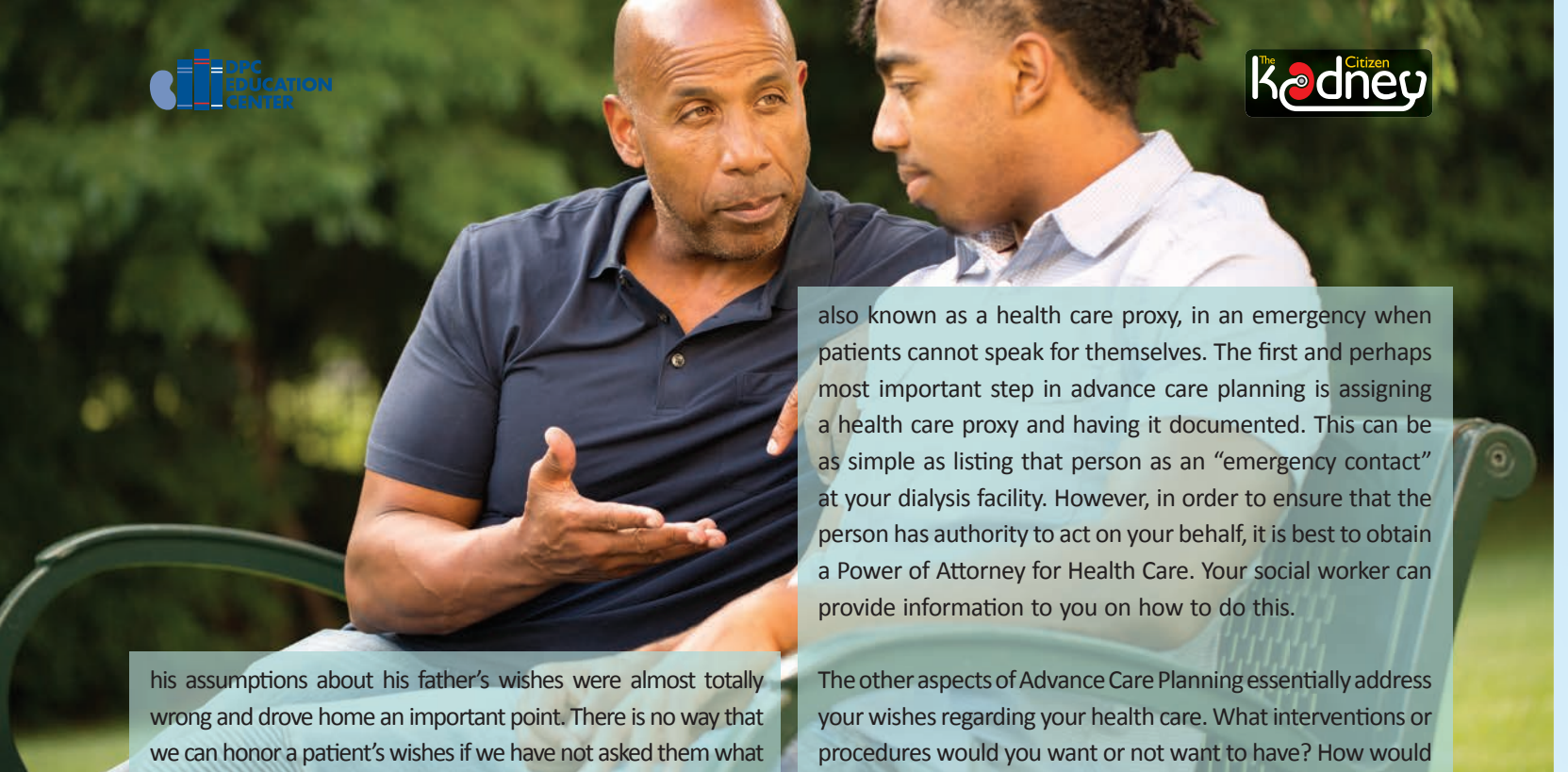
By **David Mahoney, MD**

As a member of Dialysis Patient Citizens, you have chosen to become involved, speak up for what is important to you and take charge of the management of your health. Dialysis modality, diet, medications, exercise, management of your other health-related issues, all require your informed decision-making and action. But despite this high level of involvement in their health care, few dialysis patients have addressed the issue of advance care planning. “I don’t want to talk about that now.” “That’s for sick people, and I am doing well.” “That really scares me.” “I am NOT ready to talk about THAT!” Such reactions and comments are normal and expected. To be honest, most health care professionals are very uncomfortable talking about advance care planning as well. It is when we address such questions in a systematic and well-timed manner that an uncomfortable issue is probably the one that addresses comfort, dignity and autonomy above all else.

I once attended an excellent presentation on Advance Care Planning given at a local hospital. The presenter was charismatic, engaged, and above all, an expert on the topic. “How many of you in this room have life insurance?” Every hand went up. “How many of you are going to live forever and won’t need life insurance?” Of course, not a single hand went up amid a fair amount of laughter. “How many of you have a

will?” About three quarters of the hands went up. “How many of you have a living will?” About ten percent of the hands went up. “If you care so much about what happens to your stuff after you’re gone, you should care about what happens to you before you get there.” Not much laughter, lots of nods.

We plan for many things in life. We plan for retirement. Where will we live? How long will we work? What will we do with our time? And so forth. As we plan to be well and enjoy life, and while we are well, it is the best time to plan for that day when we will have to make a lot of decisions. Having been in medicine for 35 years, I can tell you with authority that the worst time to make a decision is when you are faced with a stressful emergency. What we also tend to forget is that sometimes there are circumstances where we cannot speak for ourselves and our loved ones must make the difficult decisions, often with no idea what our wishes might be. I can think of no better illustration of this than the beautiful book written by Dr. Atul Gawande, entitled, “Being Mortal.” Dr. Gawande writes of his father, also a doctor, who was diagnosed with a rare type of brain tumor. Dr. Gawande, the son, a well-respected and talented physician, thought he knew exactly how his father would want to approach the management of his disease and the choices he would make. To his great surprise, when he spoke with his father,



his assumptions about his father's wishes were almost totally wrong and drove home an important point. There is no way that we can honor a patient's wishes if we have not asked them what they are. Therein lies the essence of advance care planning.

Perhaps the best way to frame this discussion is to say that there is no "one size fits all." You are unique, as are your circumstances, relationships, beliefs, values and wishes. But, what is common to all are a few basic tenets. First, you need to understand your health and the diseases which affect it. You are not a statistic, but knowing what to expect with your health concerns may guide your thinking. Second, ask yourself what your expectations are about your health, what you will or will not be able to do, and how your health conditions will affect your quality of life. Third, understand that this is a dynamic process. As our circumstances change, so will our goals and wishes. Perhaps one of the most important tenets of advance care planning is to reassess plans after a major health event and make appropriate changes. Fourth, this is an activity that requires a team approach, to include yourself, your family, your caregivers, and for many, their clergy or other religious/spiritual leader. Finally, there are no right or wrong answers. Advance care planning is simply your opportunity to express your wishes in case that "what if" happens.

One of the most common causes of confusion or delay in delivering health care is deciding who is the decision-maker. Many times it is obvious, such as the parent of a minor. What about a widow with several children who are unable to agree on what to do? The way that I like to present this to my patients is to ask, "If you were in a bad car accident and were brought to the hospital unconscious, whom would you choose to speak for you and make your medical decisions?" This approach conveys the need to have a decision-maker,

also known as a health care proxy, in an emergency when patients cannot speak for themselves. The first and perhaps most important step in advance care planning is assigning a health care proxy and having it documented. This can be as simple as listing that person as an "emergency contact" at your dialysis facility. However, in order to ensure that the person has authority to act on your behalf, it is best to obtain a Power of Attorney for Health Care. Your social worker can provide information to you on how to do this.

The other aspects of Advance Care Planning essentially address your wishes regarding your health care. What interventions or procedures would you want or not want to have? How would you like to address potential comfort issues? What would you like to ensure regarding your treatment? What information do you wish to have communicated to others, especially family? There are several excellent publications addressing the process of advance care planning. Your social worker can help you learn more about them.

I ask your indulgence in looking at this issue from a doctor's point of view. No physician wants to say the following:

1. I have no idea what he would want me to do. I never asked.
2. I should have asked him about his wishes after he had the heart attack, before the stroke, when he could still speak.
3. I would never have done that to him, had I known he never wanted it.
4. You know, we talked about it but never put it on paper.
5. Huge family, really torn, can't agree about what to do. I should have asked him who would make decisions for him "just in case."

In summary, Advance Care Planning is nothing more than planning ahead. If I were to give it a slogan, it would be, "My life, my decisions." It is an opportunity to express your wishes in a formal manner. Help your care team to know your wishes. We can't honor them if we never asked. ■

*Dr. Mahoney is the Chief Medical Officer for Lifeline Vascular Care and has recently joined the DPC Advisory Board. He has been a practicing nephrologist for 25 years.*



# Growing Up On Dialysis



By **Julie Crandall**, CBCS, CMAA, Patient Ambassador, DPC Education Center Board Member

How was it to grow up with end-stage renal disease (ESRD)? Since I didn't know any other way; for me, it was normal. I can tell you that in my case, my family was the most important people that helped me navigate childhood. It helped that they didn't treat me like the 'sick kid' of the family; I was a daughter and a little sister. I didn't know what to focus on for this article. It was difficult to narrow down my childhood with ESRD and dialysis to write this article. I hope that what I chose to focus on will help others.

I was diagnosed with ESRD when I was seven years old. I vividly remember my parents sitting me down in the spare room of my grandparents' house to tell me I had to go to the hospital. I didn't know anything was wrong with me. My parents noticed signs that something was wrong. My small size wasn't a red flag; I had a genealogy of small-stature family members in my extended family. My

mom has told me that two of the red flags were: 1) I was walking like "an old man," and 2) I was getting bloody noses. My official diagnoses are one kidney with hypoplasia (normal kidney but does not grow as I grow) and one kidney with dysplasia (short version: kidney did not develop properly). They were both birth defects that were not discovered until I was seven.

I am very grateful I wasn't diagnosed earlier. We would have lived waiting for the day I would get sick; waiting for the day I would have to start dialysis. I got to be a normal little kid, without worrying about what the future held.

After I had my first peritoneal dialysis (PD) catheter implanted at eight years old, I was up playing volleyball with a blown-up latex glove with my roommate's siblings. I honestly don't remember it being a traumatic thing, starting on dialysis. It was a new way of life for

me, and I do remember having to miss out on slumber parties with friends because I had to be home to dialyze at night on my machine. I didn't want to be different from other kids. I remember one incident in PE class in probably fifth or sixth grade. I was on continuous ambulatory peritoneal dialysis (CAPD) at that point. I would fill with dialysate in the morning, and the empty bag would be rolled up and held to my lower back with gauze fish-net. (Sorry, I can't remember what it was called.) We were walking off the court and a classmate saw my empty dialysate bag on my lower back. I was so embarrassed, I changed the subject fast and ran away.



A couple years later at age 13, I had to change to hemodialysis after multiple bouts with peritonitis. I was terrified—more specifically of having two large needles stuck in me three times a week. There was one patient in particular, John that helped me with the transition. While I did have fantastic doctors, nurses and technicians at the pediatric unit, it was having another kid my age to talk to, who could relate what I was going through, that made it a little less scary. I don't remember exactly what he did to make the transition easier, but I remember we played poker a few times. He was 15, so it was cool to beat him, repeatedly.

Because there was not a unit close to my home in Proctor, Colorado, my family moved to Ft. Collins so I could have a unit where I could do dialysis. It was a difficult time; my dad was going back and forth between our new and old home for work. It was a sacrifice for my older brother, who had to move during his senior year of high school. It was difficult for me to move from a school with 28 kids in my class to a school where there were over 300. I didn't make many friends because I was never in two classes with the same kids. It was difficult to make friends when I had to miss so much to go to dialysis three afternoons a week, and I couldn't do some things that other kids could. I did make a very good friend at church who would visit me at dialysis, or we would talk on the phone while I was at dialysis. Keep in mind, this was long before cell

phones. The staff would have to bring a phone and stretch the cord to be able to reach my chair.

Fortunately, my parents found a nurse back in my hometown that trained to be my home dialysis nurse. We got to move back to my childhood home; back to all my friends I had grown up with, in time to start my eight-grade year.

Near the end of my eight-grade year, my dialysis graft got infected, and it had to be literally dug out of my arm. I had a huge hole in my arm because they couldn't stitch it up. It had to heal from the inside out since the hole was so big. I wanted to try out for the high school cheerleading

squad. Unfortunately, because of my wound, I was not able to try out during my freshman year. Also, due to the size of the wound, when it did heal, it gave me my biggest scar at that time. I did whatever I could do to hide that scar. My friends and I would tell people I got in a knife fight to explain the huge scar. It was difficult for me to let people know I had a chronic illness. I wanted to cover up my illness no matter what.

When I was 15, I decided I wanted to get on the transplant list. My mom reminded me a few years ago why I decided it was the right time. I am a member of the Church of Jesus Christ of Latter-day Saints. I was going to get to start dating at age 16, and I didn't want to date and still be on dialysis. Another patient close to my age was there for me to talk to prior to getting on the list and to answer questions on what I could expect. Her name was Tracy; she was a huge help to me.

I was paged for a transplant at about 3:00 a.m. on June 13, 1987. One of my best friends was staying overnight with me, so we dragged her to the hospital, which was three hours away. I remember being rolled down the hallway, my mom and friend crying, and my telling them to quit crying because I was trying to check out the anesthesiologist. (He looked like Mike Horton on "Days of Our Lives.")



I was able to start high school as a “normal” teenager, not having to worry about dialysis. I did gain about 40 pounds after my transplant because nobody told me that I would gain so much water weight due to the large doses of prednisone. Teachers that had known me for years did not recognize me. I was very blessed to grow up in a small community, with friends I’d known for most of my life. I didn’t have to worry about being bullied. I was teased, but I had been teased my entire life (three older brothers). It was never mean, and no one ever made me feel bad about myself.

At the end of my freshman year, I made a dream come true when I tried out for the cheerleading team. I made the cheerleading squad for my sophomore year of high school. I felt like a ‘normal’ teenager, doing everything teenagers could do.

Then, about a year and a half later, my kidney went through rejection. I went back on the transplant list during my junior year of high school. The morning of my high school’s junior/senior prom, April 21, 1990, I was paged for a transplant. I called my best friend to let her know I was going to miss the prom. I didn’t have any way to reach my prom date; he didn’t have a home phone. Once again, this was before cell phones were commonplace.

This kidney was a great match. I was out of the hospital in three days and able to attend a class movie a week after. I remember walking down the hall, and two of my classmates turned the corner and saw me. One of them asked me, “Didn’t you just have a transplant?” They were shocked to see

me back at school already. The mistake I made was thinking I was ‘healed.’ I was feeling the best I had felt since I was seven years old. I took advantage of how I was feeling. I didn’t take my medications as I should have; I didn’t get a monthly blood test as I should have. I ended up losing the kidney after about two and a half years. It was a difficult lesson to learn; it almost cost me my life. It did cost me my kidney. I chose to wait a few years before I even thought about going back on the transplant list. I knew I had some maturing to do. I needed to know I was ready to do all that was necessary to stay healthy and take care of myself.

I want to share a couple of things I have come to realize over this childhood filled with challenges and victories. 1) I learned to keep going after my dreams. Never give up on what you want to accomplish. You can do it. 2) I learned to be proud of every scar I have. I earned every scar by surviving. Each scar tells a story of how strong I am and of how much I have survived. Never be embarrassed about any scar you have. 3) Transplant is NOT a cure, but it is a new way of life. It is important to follow what your doctors tell you: go to your doctor appointments, get monthly blood tests and take your medications as prescribed. 4) There are others out there who have gone through what you are going through. Talk to others. Please know that you are not alone.

This is a brief chapter in my life with ESRD. I hope it can help at least one person. I am here to help if you have questions or need to talk about dealing with ESRD. ■



Who is ready for a weekend to unwind? These versatile fleece joggers are great for lounging around the house while relaxing and for also helping you achieve your fitness goals by keeping your legs warm on those brisk, outdoor jogs. You can choose from light grey, navy, black and dark grey.

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# Work Those Kidneys Out!

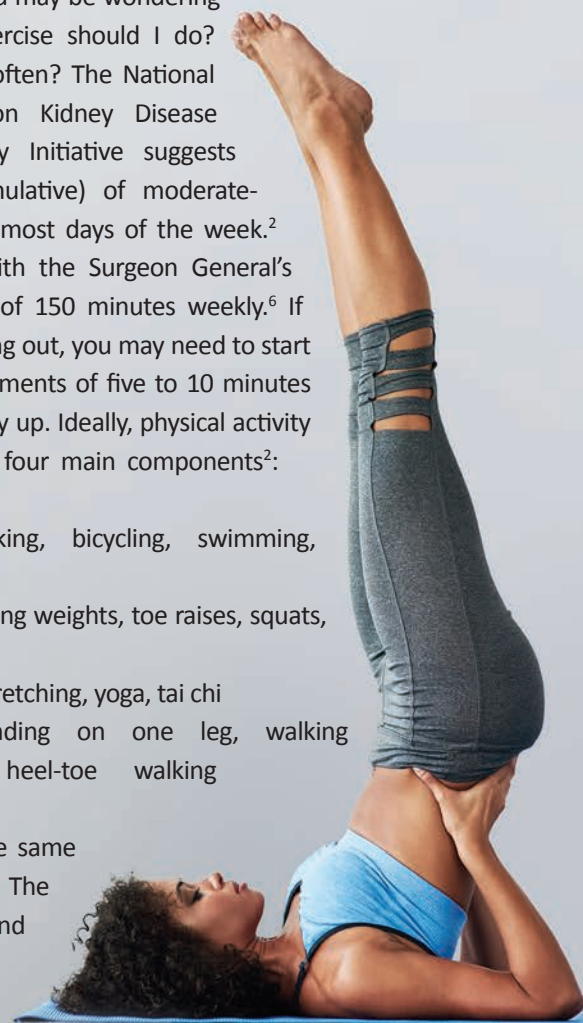
By **Collette Powers**, MA, RDN, LDN, ACSM EP-C

We have all heard it, and we all know it. We have been told from our doctor, a friend or a loved one. Whether it is for controlling high cholesterol, managing weight, reducing blood sugar or keeping our bodies healthy overall, we have all been told at some point we should exercise. But did you know exercise may help protect your kidneys too? Fatigue is a common struggle that many patients with chronic kidney disease (CKD) face. When we are tired, our instinct is to rest. However, over time, that “rest” can lead to a very sedentary lifestyle, which has many downsides when it comes to kidney health. As one becomes less active, they may experience increased muscle loss, decreased heart function and further worsening of their kidneys. Research has shown that one of the best ways to combat fatigue is to get up and move! Increasing your activity level has several benefits, including improved muscle strength, decreased anxiety and stress, and increased energy.<sup>1, 2</sup> With additional research emerging, studies now also suggest that incorporating regular physical activity into your daily routine can help stabilize kidney function too!<sup>3</sup> Exercise has been proven to reduce blood pressure and better manage blood sugar levels, which are the leading causes of CKD.<sup>4</sup> Hypertension and diabetes cause damage to your blood vessels that supply blood to and from the kidney. Experts state that having good blood pressure and blood sugar control leads to increased blood flow and stronger blood vessels.<sup>5</sup> Blood can then flow more naturally without the kidney and heart having to work as hard. This, in turn, helps protect your kidney function.

All right, all right, all right, we know exercise is important. But you may be wondering what type of exercise should I do? How long? How often? The National Kidney Foundation Kidney Disease Outcomes Quality Initiative suggests 30 minutes (cumulative) of moderate-intensity exercise most days of the week.<sup>2</sup> This correlates with the Surgeon General’s recommendation of 150 minutes weekly.<sup>6</sup> If you are just starting out, you may need to start with smaller increments of five to 10 minutes and build your way up. Ideally, physical activity should consist of four main components<sup>2</sup>:

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

Exercise is not the same for everyone. The main idea is to find





an activity you enjoy that is safe and fits into your lifestyle. So, before you get your sweat on, consider these two recommendations:

1. **Consult your doctor.** There are instances where it is recommended not to exercise. If you have a fever, are short of breath, experience chest pain or become lightheaded/dizzy, DO NOT EXERCISE, and consult your doctor. You should speak with your doctor before starting a new exercise routine to assess the need for any activity limitations.
2. **Make and write down a SMART goal.** Pick an activity that is specific, measurable, attainable, realistic and timely. For example, which would you say is a true goal?
  - a. I will ride my bike
  - b. I will ride my bike for 15 minutes three times a week

You chose correctly if you picked choice B. Setting specific goals gives you a starting point. You can better track your progress and assess if and when you need to change your goal.

So you may be wondering, “Well how do I get started?” or “I want to protect my kidneys, but I HATE working out. What will work for me?” “How do I progress?” These are all terrific questions! Join me on March 28, 2019 at 2 p.m. EST as I talk more about ways to fit physical activity into your daily regime. I will discuss more about why exercise should be a part of your CKD management and share my triple P’s for success! ■

*Collette Powers is a renal dietitian with Dialysis Clinic, Inc, <https://www.dciinc.org> and a chronic kidney disease dietitian with Reach Kidney Care, <http://www.reachkidneycare.org>.*

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# My Personal Experience with a Rare Condition

By **Mark Scirocco**, Patient Ambassador

I have been on in-center hemodialysis for three years. It was a rough start, as I went through 11 chest catheters in a little over a year. Two of them just fell out while I was sitting at home; the others got clogged. The last one almost killed me, stopping fluid in my upper body and head. My fistula was barely ready when they took that one out and placed a stent in my chest to allow fluid past my upper body.

Three months after starting my fistula, I needed a fistulogram to open it up. For those of you who have not heard of a fistulogram, it is a common test that looks for issues with the fistula that could be causing problems with dialysis. It is a specific x-ray process that uses dye to look at the fistula's blood flow to primarily check if it is blocked or if there is any narrowing.

I started having issues with my fistula every four to six months after August 2016. After my fourth fistulogram, I came down with a rash that didn't feel like a regular rash. It burned and later peeled like a sunburn. I had a change in steroids for my prostate cancer, and I had a bone scan and CT scan at the same time. I could not tell which one caused the problem. Then in January 2018 came the fifth fistulogram, and the rash was much worse. My dermatologist took a couple of samples that came back showing it was a reaction to something that was put in my system. The fistulogram was the only suspect this time. So the questions were: 1) was it the dye, 2) was it latex gloves or 3) was it the "tent"? The "tent" during a fistulogram when the fistula is in the arm, is where aluminum braces are put in place around the upper body and a fabric is stretched across it. The



fabric, which covered my face and torso while my fistula arm was extended out, caused itching where it touched the skin, thus adding the tent as a suspect.

My labs had been great for over a year, and my time had been cut 15 minutes per session until my time had been reduced from five hours to four and a quarter hours. The day before the last 15 mins were cut, I got a call from the hospital to confirm an appointment for a fistulogram. I was not happy to hear this and complained to the center that I got a horrible rash from something during the procedure. They said my dialysis machine reported, “ineffective access flow testing, unable to run HD at prescribed BFR.” I was told to stop baby aspirin five days prior and to take medications 12 and two hours prior to the fistulogram. I was scared, but I put my trust in the people at my clinic and signed the papers authorizing them to do the procedure. I dialyzed for the next three treatments (when I got 15 minutes cut from my time) with no alarms, beeps or buzzes.

After being prepped for this last fistulogram, when the nurse asked what I was allergic to, I told her I get a horrible rash every time I have this procedure done. As soon as the dye went into my system, I told them I was itching all over my body. I was then given prednisone and Benadryl. In the recovery room, the rash began to appear and started spreading.

Just a few days later, my neck was getting tight, and blisters were forming around my neck and left eye. I already have asthma, so I went to the emergency room (ER) as I feared breathing problems would be accelerated. The ER doctor diagnosed my ailment as Stevens-Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN) by my external symptoms—the rash was burning and hurting rather than itching. Being unfamiliar with SJS/TEN, they sent me by ambulance to another

hospital where health care workers were familiar with this rare disorder. During this hospital stay, the staff helped care for my lips, which were swollen and oozing blood, the rash spots, which were peeling like a severe sunburn, and my short stints of chills and difficulty breathing. I was lucky I did not get sepsis while fighting this infection, and I am happy to say I am well on the road to recovery from SJS/TEN.

I also think there were great gaps in communication among those involved in my care—the dialysis clinic, my primary physician and my dermatologist. I needed everyone on my team to understand my condition, know what had happened and to have a plan to prevent future episodes. If they had shared this information, I believe my last bout that was so dangerous could have been prevented.

According to the US National Library of Medicine, “Stevens-Johnson syndrome/toxic epidermal necrolysis (SJS/TEN) is a severe skin reaction most often triggered by particular medications. Although Stevens-Johnson syndrome and toxic epidermal necrolysis were once thought to be separate conditions, they are now considered part of a continuum. Stevens-Johnson syndrome represents the less severe end of the disease spectrum, and toxic epidermal necrolysis represents the more severe end.” Although the symptoms for SJS/TEN often start with a fever and flu-like symptoms, the painful skin conditions of blistering and peeling start within a few days.

My goal in sharing my story is to help others avoid this experience by learning about SJS/TEN. It is a life-threatening disease and for me, a repeat case of SJS/TEN can be very serious or even fatal. Although it is hard to know about every rare condition out there, the more we can learn from each other, the more we can protect ourselves in the future. ■



# Insights from the Dialysis Patient Citizens 2018 Patient Survey: Patients' Priorities for Quality Measures and New Innovations in ESRD Care

By **Jackson Williams**, Director of Regulatory Affairs and General Counsel, Dialysis Patient Citizens

Dialysis Patient Citizens (DPC) thanks everyone who completed its 2018 Patient Survey. It is another way to make your voices heard. We use our patient survey to get your input on current issues and to convey your opinions to policymakers in Washington, DC.

This year, our survey included questions on two recent developments in Washington:

- **Medicare's "Meaningful Measures" Initiative:** In early 2018, Medicare officials announced plans to reduce the number of quality measures it uses to hold health care providers accountable. This meant that for dialysis care, the

ESRD Quality Incentive Program (QIP) was due to undergo changes. We surveyed patients on which elements of quality of care were most important to you.

- **The Kidney Innovation Accelerator ("KidneyX") Initiative:** KidneyX is a public-private partnership to accelerate innovation in the prevention, diagnosis and treatment of kidney diseases. In collaboration with the American Society of Nephrology, we surveyed patients on which burdens of kidney disease and dialysis care you most want to see addressed by new technology.

## Patients' Priorities for Quality Measurement

Table 1 displays the results of a survey question that listed 20





areas of quality or patient experience and asked patients to choose no more than five measurement priorities. This list was not comprehensive but was intended to sound out patients on a variety of dimensions of their care, as well as specific issues contained in the 2018 proposed QIP changes.

Five of the top seven areas relate to patients' experience of care that are asked about in the ICH-CAHPS survey of in-center dialysis patients. Currently, the responses to the ICH-CAHPS questions about facility staff respect, listening, and professionalism, and physical comfort during dialysis, are rolled into composite measures. After the response to the survey questions indicating the importance of these qualities, DPC urged Medicare to break these out and report each one individually.

The large amount of patient interest in measures of satisfaction with their care highlights the current crisis in survey response rates and its impact on the ICH-CAHPS. Because of a longtime, nationwide trend in fewer Americans taking time to answer surveys, measures go unreported for half of U.S. dialysis facilities that do not receive the minimum 30 returned surveys. DPC has urged Medicare to urgently step-up efforts to find ways to obtain and report ICH-CAHPS scores for a greater proportion of facilities; they tell us that changes may be coming in the next few years.

Both our membership and volunteer leadership agree that the following areas should be given priority in the Quality Incentive Program:

- Dialysis Adequacy
- Safety/Bloodstream Infections
- Depression Management
- Medication Management
- Experience/Satisfaction with Care (ICH-CAHPS)
- Patient-Reported Outcomes

We urged Medicare to reduce the QIP measure set from 11 to a smaller set with greater weights, to focus providers' attention and resources on improvement or maintenance of quality in areas of importance to patients.

Patients continue to prioritize dialysis adequacy (Kt/V) as an important measure. Many kidney care experts think this measure is "topped out," meaning that nearly all facilities perform well, and the measure no longer distinguishes among them. In light of the survey results, DPC urged Medicare to keep this measure in the QIP due to its importance to patients.

This year, Medicare removed the Serum Phosphorus and Pain Assessment measures from the QIP. The results of our survey found that these dimensions of care areas were not that important to patients. Thus, we did not object when CMS wanted to remove them as areas for which dialysis clinics should be held accountable.

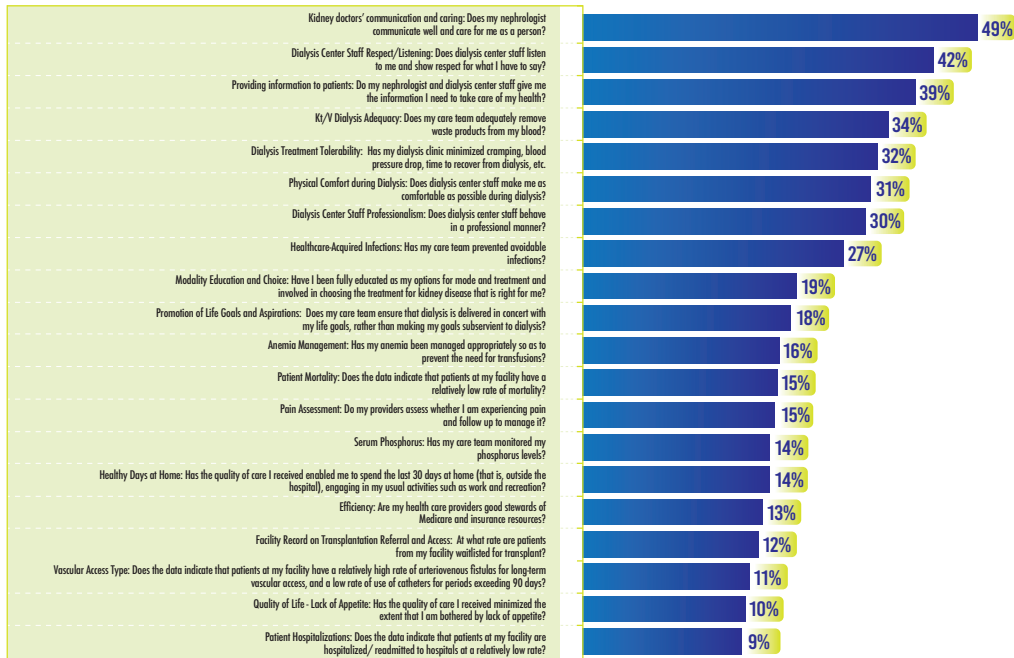
In addition, Medicare added a Transplant Waitlisted measure to the QIP. It appears from our survey that patients do not think this is an outcome for which dialysis clinics should be held accountable, so we urged that this measure continue to be reported on the Dialysis Facility Compare website, but we did not urge its inclusion in the QIP.

### **Patients' Priorities for Innovation**

DPC also surveyed our members to seek your priorities for innovation. We asked patients what conditions they would most like to see addressed by innovative technologies. As Table 2 indicates, nearly 60 percent of patients cited the fatigue and low energy level that results from ESRD as a condition they hope could be alleviated by new technology. Generally, patients cited three categories of conditions that merit improvement from new technology:

**TABLE 1. OVERALL QUALITY OF DIALYSIS CENTER**

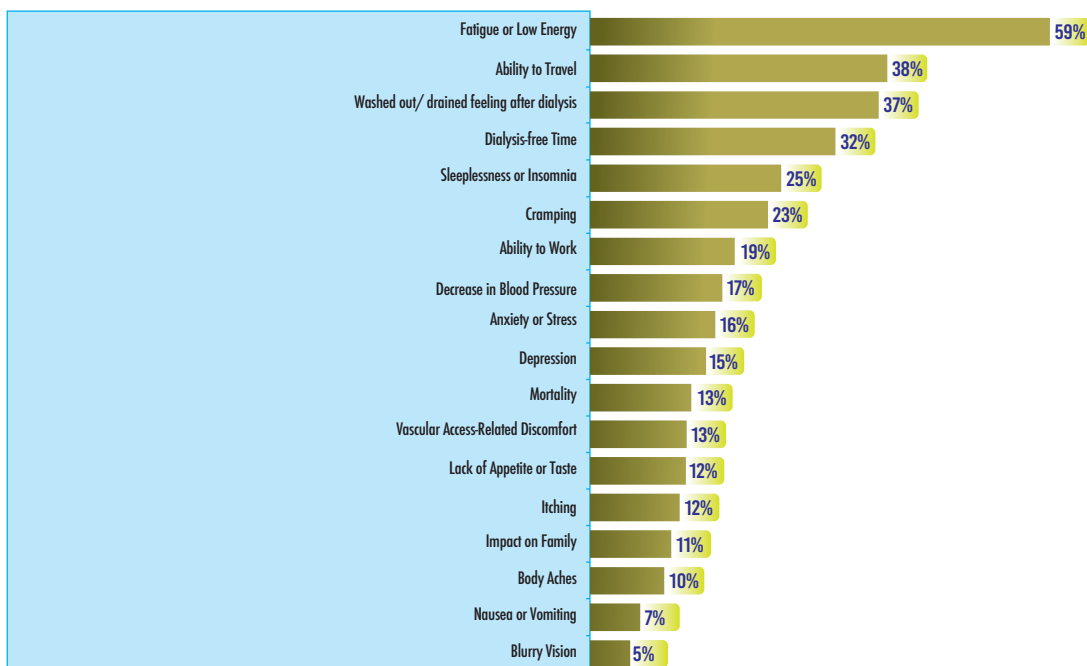
**IMPORTANT MEASURES FACILITY SHOULD BE ACCOUNTABLE FOR**  
CARING, RESPECTFUL STAFF AND COMMUNICATION ARE THE MOST IMPORTANT MEASURES OF A QUALITY DIALYSIS CENTER FOR PATIENTS. HOSPITALIZATION OR VASCULAR ACCESS RATES ARE RELATIVELY LOW.



**TABLE 2. NEW PRODUCT DEVELOPMENT**

**CONDITIONS WOULD MOST LIKE TO SEE ADDRESSED**

**3 OUT OF 5 PATIENTS WOULD LIKE TO SEE FATIGUE/LOW ENERGY ADDRESSED VIA NEW PRODUCT DEVELOPMENT.**





- **The effects of dialysis treatment.** Current dialysis technology, which has scarcely improved since its inception, leaves patients feeling drained after the treatment and generally fatigued most of the time. As one of our board members observed, it is this fatigue that prevents most patients from remaining employed. For patients, relief from other side effects of dialysis, such as cramping and the drop in blood pressure sometimes called “crashing” would also be welcomed.
- **The physical constraints of dialysis.** One of our board members referred to the burden of the time and location commitment to treatments as “the shackles of dialysis.” Patients would be

grateful for relief from these constraints through an implantable or wearable artificial kidney.

- **The symptoms of ESRD.** Dialysis cannot fully replace the body’s kidneys; any new technology that can ease ESRD symptoms like insomnia, nausea, lack of appetite and itching—conditions that dialysis can’t eliminate—would have considerable value to patients.

DPC will continue to seek your ideas and opinions in the coming year. We will continue to share what is important to you with lawmakers as well as with other organizations that can benefit from knowing both your needs and concerns. We hope that you will complete our 2019 Annual Survey, which will be available later this year. ■



The **DPC Education Center** just launched a new and fully-responsive website, making it easier than ever for dialysis patients, family members and healthcare professionals to get informed and lead healthier lives.

Check out the website today at:  
[www.dpcedcenter.org](http://www.dpcedcenter.org)

**Education Through Empowerment**



# The 30-90 Day Period of Dialysis

By **Thomas Lepetich**, MSW, LCSW

Now that you have been a dialysis patient for 30 days, there are more requirements that you and the dialysis facility must fulfill, as stated by the federal government. The Centers for Medicare & Medicaid Services (CMS) guides both the facility and you, the patient, in what must happen to keep you safe and to help you have the best quality of life. This is done through a process called Conditions for Coverage (<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/downloads/SCletter09-01.pdf>).

Within the first 30 days or 13 treatments of you initiating outpatient dialysis, the interdisciplinary team (treating physician, registered nurse, dietician, social worker, and yourself or a designee) does an “individual” assessment of your medical, dialysis, nutritional, emotional and situational needs.

Compliance with this Condition is determined by observation of practices; interviews of patients, personnel and medical staff; and review of medical records.

**INITIAL ASSESSMENT AND PLAN OF CARE:** To be completed within 30 days of first treatment in unit.

**90 DAY ASSESSMENT AND PLAN OF CARE:** To be completed 90 days after Initial Assessment.

**KDQOL:** Quality of Life (QOL) survey due with 90 Day Assessment, then, completed yearly after that.

Dialysis is both life-saving and life-altering. It changes patients’ eating, sleeping, medication use and daily activities at home and in the community. Dialysis and associated symptoms can reduce the ability to work (50 percent of new patients each year are working-age). The degree of lifestyle change needed—following prescribed diet/fluid limits and medications and managing symptom burdens—depends considerably on the modality chosen and affects patients’ day-to-day health-related quality of life. Per the Centers for Disease Control and Prevention, health-related quality of life is the impact of a chronic disease and its treatment on patients’ perceptions of their own physical and mental function. Amongst people on dialysis, Kidney Dialysis Quality of Life scores are both a critical outcome and a predictor of hospitalization and death.

**DEPRESSION SCREENING:** Done after 90 days from first treatment in unit, then, completed yearly after that.

Depression is the most common psychiatric illness in patients with end-stage renal disease (ESRD). The reported prevalence of depression in dialysis population varied from 22.8 percent (interview-based diagnosis) to 39.3 percent (self- or clinician-



administered rating scales). Such differences were attributed to the overlapping symptoms of uremia and depression. Systemic review and meta-analysis of observational studies showed that depression was a significant predictor of mortality in dialysis population.

**PAIN ASSESSMENT:** Done after 90 days from first treatment in unit, and then, completed semi-annually after that.

Pain is one of the most common symptoms in patients with ESRD. Based on this fact, and the findings of other clinical studies, CMS identified a need to incorporate a measure that determines whether facilities regularly assess their patients' pain and whether they develop follow-up plans as necessary. CMS believes that a measure such as this offers the possibility of improving the health and well-being of patients with ESRD.

**QOL/Depression/Pain:** Together with your care team, your dialysis social worker uses the results of these instruments to form your Plan of Care. The goal of the plan is to address any negative responses that you have had to your dialysis regimen, as indicated by these surveys. Research has shown that patients with high Quality of Life scores and low depression/pain scores are more active and involved in their lives and medical treatments and stay out of the hospital more and live longer.

#### **V500 § 494.80 Condition: Patient Assessment.**

**V501** The facility's interdisciplinary team, consists of, at a minimum, the patient or the patient's designee (if the patient chooses), a registered nurse, a physician treating the patient for ESRD, a social worker and a dietitian. The interdisciplinary team is responsible for providing each patient with an individualized and comprehensive assessment of his or her needs. The comprehensive assessment must be used to develop the patient's treatment plan and expectations for care.

("Interdisciplinary teams" work collaboratively with regular meetings to discuss patient status and the evolving plan of care. Working as a team allows for working toward common goals, pooling of expertise and a forum for problem solving.)

("Individualized" means each assessment is unique to a particular patient and addresses that patient's needs. "Comprehensive" means the assessment covers and addresses all issues that are

actionable by the dialysis facility; this could include referrals to specialists for assessments that are beyond the capacity of a dialysis facility.)

**V502** (a) *Standard: Assessment criteria.* The patient's comprehensive assessment must include, but is not limited to, the following: (1) Evaluation of current health status and medical condition, including co-morbid conditions.

**V503** (2) Evaluation of the appropriateness of the dialysis prescription,

(A hemodialysis (HD) prescription includes the number of treatments per week, length of treatment time, the dialyzer, specific parameters of the dialysis delivery system (e.g., electrolyte composition of the dialysate, blood flow rate, dialysate flow rate), anticoagulation and the patient's target weight. An appropriate HD prescription is individualized to meet the dialysis needs of the patient.)

(A peritoneal dialysis (PD) prescription must take into consideration the peritoneal transport rate determined by peritoneal equilibration testing [PET], residual renal function, total body surface area, certain medical conditions and personal preference. The PD prescription includes the number of exchanges or cycles to be done each day, the volume of fluid to be used with each exchange, whether fluid is always present in the peritoneal cavity (except for brief periods between draining and reinfusion of dialysate), and the concentration of glucose or other osmotic agent to be used for fluid removal (which may vary according to a prescribed sliding scale).)

**V504** Blood pressure, and fluid management needs.

Because of the adverse effects of ESRD, many patients experience dramatic changes of blood pressure and fluid management, the management of which may require reassessment of medication needs, adjustments in target weight and changes to the plan of care (POC).

**V505** (3) Laboratory profile.

Laboratory work-up should include, but not be limited to, comprehensive metabolic testing, dialysis adequacy, complete blood count, iron studies and screening for the Hepatitis B virus.

**V506** Immunization history and medication history.

“Immunization history” should include whether the patient has received standard immunizations (pneumococcal, hepatitis and influenza) and has been screened for tuberculosis. The immunization record is expected to include at least the patient’s immunization history as of the effective date of this regulation.

**V507 (4)** Evaluation of factors associated with anemia, such as hematocrit, hemoglobin, iron stores and potential treatment plans for anemia, including administration of erythropoiesis-stimulating agent(s).

**V508 (5)** Evaluation of factors associated with renal bone disease.

(Disturbances in mineral and bone metabolism are common in patients with ESRD, often resulting in hyperparathyroidism and chronic kidney disease (CKD) mineral and bone disorder if not managed effectively.)

**V509 (6)** Evaluation of nutritional status by a dietitian.

**V510 (7)** Evaluation of psychosocial needs by a social worker.

**V511 (8)** Evaluation of dialysis access type and maintenance (for example, arteriovenous fistulas, arteriovenous grafts and peritoneal catheters).

The efficacy of the HD patient’s vascular access and the PD patient’s peritoneal catheter correlates to the quality (adequacy) of their dialysis treatments and is of vital importance to their overall health status.

**V512 (9)** Evaluation of the patient’s abilities, interests, preferences and goals. This includes the desired level of participation in the dialysis care process, the preferred modality (hemodialysis or peritoneal dialysis) and setting (e.g., home dialysis), and the patient’s expectations for care outcomes.

**V513 (10)** Evaluation of suitability for a transplantation referral, based on criteria developed by the prospective transplantation center and its surgeon(s). If the patient is not suitable for transplantation referral, the basis for non-referral must be documented in the patient’s medical record.

**V514 (11)** Evaluation of family and other support systems.

**V515 (12)** Evaluation of current patient physical activity level.

**V515 (13)** Evaluation for referral to vocational and physical rehabilitation services.

Vocational rehabilitation referrals may be appropriate for older youth and adult patients who desire to return to work and/or improve independent living skills.

**V516 (b) Standard: Frequency of assessment for patients admitted to the dialysis facility.** (1) An initial comprehensive assessment must be conducted on all new patients (that is, all admissions to a dialysis facility), within the latter of 30 calendar days or 13 hemodialysis sessions beginning with the first dialysis session.

**V517 (2)** A follow-up comprehensive reassessment must occur within three months after the completion of the initial assessment to provide information to adjust the patient’s plan of care specified in § 494.90.

Patients new to dialysis and/or a new dialysis setting frequently need time to adjust and adapt to the treatment. The three-month comprehensive reassessment enables the interdisciplinary team (IDT) to re-evaluate how well patients follow their treatment plan; their educational, psychosocial, rehabilitation and nutritional needs; their current adjustment to the dialysis regimen and coping; and the accuracy and appropriateness of patients’ plans of care.

**V518 (c) Standard: Assessment of treatment prescription.** The adequacy of the patient’s dialysis prescription, as described in § 494.90(a)(1), must be assessed on an ongoing basis as follows: (1) Hemodialysis patients. At least monthly by calculating delivered Kt/V or an equivalent measure. (2) Peritoneal dialysis patients. At least every four months by calculating delivered weekly Kt/V or an equivalent measure.

**V519 (d) Standard: Patient reassessment.** In accordance with the standards specified in paragraphs (a)(1) through (a)(13) of this section, a comprehensive reassessment of each patient and a revision of the plan of care must be conducted—(1) At least annually for stable patients; and



**V520 (2)** At least monthly for unstable patients including, but not limited to, patients with the following: (i) Extended or frequent hospitalizations; (ii) Marked deterioration in health status; (iii) Significant change in psychosocial needs; or (iv) Concurrent poor nutritional status, unmanaged anemia and inadequate dialysis.

**V540 § 494.90 Condition: Patient plan of care.**

The Condition is directly related to the Condition for Patient assessment, as the plan of care is built upon the patient assessment. The individual plan of care is revised after each patient assessment, and portions of the plan of care must be updated if the target goals for each area are not achieved or not sustained.

The concept of patient-centered care has gained increasing prominence in recent years as a key aim of the U.S. health care system. Patient and family engagement offers a promising pathway toward better quality health care, more efficient care and improved population health.

YOU know how you feel and what you need better than anyone else. Attending Plan of Care meetings empowers YOU and your family to help make decisions about your care. When you understand all of your choices, YOU have more control over your own health.

**V541** The interdisciplinary team as defined at § 494.80 must develop and implement a written, individualized comprehensive plan of care that specifies the services necessary to address the patient's needs, as identified by the comprehensive assessment and changes in the patient's condition, and must include measurable and expected outcomes and estimated timetables to achieve these outcomes. The outcomes specified in the patient plan of care must be consistent with current evidence-based professionally-accepted clinical practice standards.

**V556 (b)** Standard: Implementation of the patient plan of care. (1) The patient's plan of care must (i) Be completed by the interdisciplinary team, including the patient if the patient desires; and (ii) Be signed by the team members, including the patient or the patient's designee; or, if the patient chooses not to sign the plan of care, this choice must be documented on the plan of care, along with the reason the signature was not provided.

**V557 (2)** Implementation of the initial plan of care must begin within the latter of 30 calendar days after admission to the

dialysis facility or 13 outpatient hemodialysis sessions beginning with the first outpatient dialysis session.

**V558** Implementation of monthly or annual updates of the plan of care must be performed within 15 days of the completion of the additional patient assessments specified in § 494.80(d).

**V560 (4)** The dialysis facility must ensure that all dialysis patients are seen by a physician, nurse practitioner, clinical nurse specialist or physician's assistant providing ESRD care at least monthly, as evidenced by a monthly progress note placed in the medical record, and periodically while the hemodialysis patient is receiving in-facility dialysis.

**V561 (c)** Standard: Transplantation referral tracking. The interdisciplinary team must (1) Track the results of each kidney transplant center referral, (2) Monitor the status of any facility patients who are on the transplant wait list and (3) Communicate with the transplant center regarding patient transplant status at least annually and when there is a change in transplant candidate status.

Requiring the facility to track patients' transplant referrals and their status on the transplant wait list is intended to enhance the communication and coordination between the transplant center and the dialysis facility so that patients do not get "lost" along the way in the transplant referral, work up and waiting period.

**V562 (d)** Standard: Patient education and training. The patient care plan must include, as applicable, education and training for patients and family members or caregivers or both, in aspects of the dialysis experience, dialysis management, infection prevention and personal care, home dialysis and self-care, quality of life, rehabilitation, transplantation, and the benefits and risks of various vascular access types.

The dialysis facility must provide patients and their family members/caregivers with education and training in these listed areas, at a minimum.

Out of all the deaths experienced by patients in the first year of dialysis, 40 percent occur within the first 90 days. You and your family's input and participation are the most important things you can do for your health. With everyone working together on The Assessment and Plan of Care, they can become your roadmap to obtain the most beneficial results from your dialysis regimen. ■



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