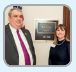
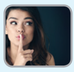
The Kidney Citizen

A publication of Dialysis Patient Citizens
(DPC) Education Center



PRESIDENT'S MESSAGE

Dear friends

As I watch the change of seasons from winter to spring, I also see some exciting things in store for our membership. We still have our two Facebook pages, one for DPC and one for the DPC Education Center. We hope you follow both! And each of the groups still has its own website which we hope you visit frequently as new information continues to be added. We do not want to take away the good things we have going, we just want to add to them!

We are making 2018 special for our members. We want to acknowledge our readers, our webinar and conference call attendees, our advocates and those of you who frequent our websites. We want to learn from you and gather your stories and opinions on a variety of topics. We also will let each of you know what free educational programs we will be presenting as a webinar, conference call, or on Facebook Live so that you can take advantage of these offerings. Finally, you will get information quickly about potential new policies or legislative actions that could affect the care that kidney patients receive. This will enable you to take action as needed.

Next, I want to remind you that DPC also has some new membership benefits that give you access to discounts on products and services you can use- Office Depot, Lenovo, Avis, Budget and UPS! Check them out!

Keeping you up to date on all that is going on in the world of kidney disease is an important part of what DPC offers you. As a member you will receive our patient newsletter "hot off the press." This issue has stories written by patients, a care partner, and professionals in the field, including a psychologist, dietitian, and social worker. Read below to find articles about enhancing a couple's relationship, learning how to handle the potential loss of a kidney transplant, tips on what to expect when first starting dialysis, inflammation, and better eating. Very importantly, you will find an article that shows how I think our DPC membership has impacted Congressional thinking and priorities, including how the Medicare Part B Improvement Act helps kidney patients and how the recent government spending bill includes dialysis needs. The DPC patient voice does make a difference!

I hope that if you are not a member yet, you will become one. It is free, it is easy to join, and we value you and want you to be part of our DPC family. You can join or update your membership at www.dialysispatients.org/tell-us-more-about-yourself. Come grow with us! ●

Sincerely,
Nancy L. Scott
Nancy L. Scott
DPC Education Center
Board President

Dialysis Patients Secure Access to Life Saving Care

By **Megan Beveridge**, Director of Congressional Relations, DPC

We have great news to report for dialysis patients! In early February, Congress passed a short-term funding bill which funded the government through March 23rd. This legislation contained a budget deal which will boost military and nonmilitary funding by billions. At the same time, it includes several provisions which ensure dialysis patients will have access to life saving care.

One provision included in this spending package is from the Medicare Part B Improvement Act of 2017 (H.R. 3178), which was introduced July 7th, 2017 by Reps Kevin Brady (R-Texas) and Richard Neal (D-Mass.), the Chairman and Ranking Member of the House Ways & Means Committee. This provision permits health care providers to utilize data from home dialysis equipment to monitor their patients. Currently, many patients receiving home dialysis treatments have hi-tech equipment in their homes that provide valuable data. This provision would allow nephrologists and dialysis providers to access this important information as well as to provide and bill for services they deliver remotely, also referred to as telemedicine. These technologies can now be leveraged by Medicare providers to help provide better care and reduce overall health care costs, while also increasing access to health care providers.

Another key provision of the Medicare Part B Improvement Act that was included in the funding bill will allow dialysis treatment centers to seek Medicare-approved, outside accreditation to provide dialysis treatments. Currently, facilities that provide care for Medicare beneficiaries face a state survey and certification process along with a Medicare accreditation process to participate in the program. Of these facilities, dialysis facilities are the only ones that are not able to be surveyed and accredited by outside agencies. This has resulted in long delays for the approval of new dialysis facilities as well as extremely high startup costs that discourage new centers from being opened, especially in rural communities where there may be fewer patients making it more difficult to recoup those initial costs. This provision would streamline this process and prevent unnecessary delays in access to care.

Finally, the spending package included a provision which would reauthorize Medicare Special Needs Plans (SNPs) which are Medicare Advantage plans providing care for patients with special needs and chronic diseases, such as End Stage Renal Disease. This provision would reauthorize these plans for 5 years, the longest reauthorization since their creation, and provide patients with more care coordination, including access to health care specialists who can address their specific health care needs. It will also provide them with a more stable and permanent path forward.

As America’s largest patient-led kidney disease organization representing 30,000 dialysis patients and family members, we worked hard at DPC advocating in support of these critical issues and want to applaud Congress for including them in the spending bill. Access to affordable, quality health care is essential for all patients, but especially dialysis patients, and these provisions will not only improve their access to care but also remove barriers which are currently harming that access. ●

Why Advocate?

By **Mike Guffey**, DPC Board Treasurer

After the January Education call, I had a couple of people thank me for my participation and say they could tell I feel passionately about my need to advocate on behalf of ESRD patients. For those of you who were not able to attend the call, let me explain my passion for you.

Like many of you, I crashed into dialysis with no prior planning or education. I got up one morning hoping to take in some sun and warm up on vacation and by noon was hospitalized in the ICU with a diagnosis of End Stage Renal Disease. (No matter how many times they tell you not to worry, that is just a governmental label, End Stage does not sound comforting or reassuring to me.)

My journey living (and working) with the disease led me quickly to the DPC website and soon after that to applying for a position on the DPC Board. To my amazement, I was accepted onto the Board and soon found myself at my first fly-in with no idea what to expect.

Why advocate? To put a human face with an issue. At my first fly in, I learned how important it is to personalize an issue. I could sit with my Senator (or even better his aide) and explain how a proposed bill was either going to improve or worsen my life. It really was not about the facts, although DPC had me prepared with handouts to leave behind with all sorts of facts and figures. It was about the fact that I could explain to them that I was their constituent (a voter they needed to keep their position), and I was willing to come visit them to explain my concerns as well as those of an additional 3,000 dialysis patients and potential voters. (And, I warned them on that first visit, I am persistent. I have been on the DPC Board since 2011, and DPC's representative to Kidney Care Partners

since 2016, and have missed one fly-in when I received my transplant).

Why advocate? It is easy to do. Advocacy does not just mean the Washington fly-in. It means contacting your legislators throughout the year as bills are introduced or being spoken about. It can be a written letter or a telephone call. It can be in person in Washington, D.C. or at an event in your community. It can be as simple as calling into one of their Town Hall calls or going to a Town Hall meeting. Go to their website or the DPC website and sign up for their email list to open the communication channels.

Why advocate? It is rewarding. On the call, I told the story of how after my first fly-in, I was walking through the terminal at Reagan National Airport and noticed an older man walking alongside of me. I was thinking to myself that I felt so much younger and more enthusiastic than that guy before I realized I was walking past a jewelry store with mirrors down its front. Then, I realized that I might not look rejuvenated, but I sure felt it.

Why advocate? We need and deserve their attention. If you and I don't advocate on behalf of ESRD patients, some other group will be there. If we are not communicating to our Senators and Representatives about our needs, somebody else will be about theirs. An available Congressman in an airport is like a homing beacon. Everybody wants a few minutes of his time and a little attention.

One warning about advocacy. It is generally not an overnight process. I often see people on their first fly-in, or their first visit to the State Capital thinking they are going to go home with the satisfaction of seeing their issue addressed on the spot, with a commitment from their Congressman to do anything in their power to ensure the bill is passed or blocked as you requested.

That usually only happens on TV or at the movies. Not much in DC happens overnight. Medicare Advantage was a discussion topic for several fly-ins before it suddenly received a groundswell of attention and was passed last year, and speeding up the implementation timeframe will still be a topic this year. I spent three years with one Senate aide encouraging him to come visit a local dialysis clinic before he finally took me up on the offer. That was a rewarding experience for everyone involved, including the aide, the clinic patients, the clinic staff, and me.

So again...

Why advocate? If you are able to advocate and not feeling like doing it for yourself, please remember there are others who are physically or financially unable to undertake the effort and are depending on the rest of us to be their voices. If not for me, then for rest of us.

Thank you for giving me this chance to advocate to you. ●

Want to learn more about advocacy?
Visit our newest class on becoming
at advocate at: goo.gl/sdT9cA

Going Home

By anonymous care partner

It was March 29, 2014 and Paul and I were engaged to be married just 7 months later. Our time of engagement bliss was fiercely interrupted with a dash of reality. We were in the emergency room where we discovered that Paul's Chronic Kidney Disease (CKD) had reached its climax. We didn't know it at the time of entry. We just knew that Paul hadn't been feeling well and was experiencing what we thought were flu-like symptoms. I was concerned given his CKD but never thought that the reality of it all would hit him at age 42. I mean, end stage renal failure only happens later in life doesn't it? As I walked towards the restroom, I heard what seemed like the voice of a whisper and the voice into a loudspeaker, at the same time. I'll never forget those words at the nursing station "Oh my God, room 9 has labs that show a creatinine level of 19.0. This can't be right."

This can't be right. As I hesitantly approached my fiancée's room, I saw it. Room 9. Paul was in Room 9. Oh my God. He is in Room 9. I stood there staring at the number 9. I hate you 9. You are the worst number of all 9. This can't be right. Do I tell him what I just heard? Maybe I heard it wrong. Maybe I'll

wait until someone comes in so they can tell him. Maybe it IS just the flu. Should I google creatinine levels of 19.0? Wait, is this really room 9?

On March 29, 2014 my fiancé Paul was diagnosed with renal failure, at age 42. He was to begin dialysis immediately in order to save his life. He would need a temporary port in his chest as access for the dialysis but would soon undergo a procedure to create a fistula in his upper arm for long-term care. He would visit a dialysis clinic three times a week for 4 hours in order to stay alive. This is what needed to be done to stay alive. Stay alive. That's all we needed right? To stay alive? Well, of course. This is the only way, in center dialysis. At least that is what we thought.

Paul traveled "in center" with other individuals on dialysis three times a week for four hours for two years. He worked full-time and tried to maintain his happy life of traveling, spending time with family and friends, and getting married, to me. Paul was lucky to be alive. Despite the way in center treatments made him feel, we were lucky they said. Lucky to be alive. Despite the way Paul could not travel as he once did because of the harsh treatments, we were lucky. Lucky to be alive they said. Despite leaving early and missing out on some family functions, social gatherings, and date nights due to fatigue and low blood pressure, we were lucky. Lucky to be alive they said. But, selfishly I thought, couldn't we be luckier?

Two and half years after Paul was diagnosed with end stage renal failure, we answered our own question. Yes, maybe we could be luckier. It just required some research, self-advocacy, and persistence. While we were happy that Paul was alive and grateful for in center dialysis, we soon learned the modality of Home Hemodialysis. We learned about the modality out of sheer curiosity. It may have been introduced in passing at the start of our scare, but it was never introduced as a viable option until 2.5 years later when we discovered it through our own research. Home hemodialysis is not for everyone. But, it is certainly an option that needs to be explored and discussed between patient, family, and medical team. An option that should be provided so that patient and family can make the final decision, not someone else on behalf of them. This was an option that we didn't really know much about from the start. We connected with NxStage Kidney Care near our home to learn more about the modality and soon began training to do hemodialysis, at home. Why not try to feel better? That was our motto. If it doesn't work, Paul can go back in center. But, what if it does work?

I won't lie, it was absolutely terrifying at first. Sometimes, it can still be for me as his partner. But, "going home" has significantly changed our lives for the better. Paul has never felt better since that terrifying night in the emergency room. We dialyze five times a week in our home and control our own schedule. Paul's blood pressure is no longer a key concern for his illness. When I need to be away from home, Paul can visit in clinic and still receive the home hemodialysis care he needs without going back in center. Home hemodialysis requires patience, commitment, and dedication. There are times when I am exhausted from a long day and think about how I can possibly help dialyze for the next 3.5 hours. But, then I see the difference in my husband. He may still face the challenges of kidney failure but I can honestly say I have him back in my life. And, more importantly, he has full control of his own.

With proper planning and coordination, traveling on home hemodialysis is just as possible as in center dialysis. Paul and I have noticed a huge difference in how he feels while traveling. When he was going in center, he would need at least one day to recover from each treatment and was subject to dialyzing during times that were required in center. Often times this was 6:00 a.m. treatments, on vacation. With home hemodialysis we can treat right before bedtime and he still feels great! Since starting home hemodialysis we have traveled to Myrtle Beach, Hawaii, and Captiva Island, FL all while bringing our machine and medical supplies. Again, home hemodialysis is not for everyone, but shouldn't you find out if it is right for you before dismissing it? You are certainly worth it. ●

Beginning the Dialysis Adventure

By **Thomas Lepetich**, MSW, LCSW

Have you been told you may need to start dialysis soon? Although starting on dialysis can be a very strenuous time in your life, you will also start to feel better. Usually, people who start dialysis are uremic, psychologically stunned, medically compromised and just plain old "out of sorts." And the last thing you want to do is to fill out forms. Perhaps it will be easier to complete forms, read information from your healthcare team and get additional tests or vaccinations if you understand their purpose.

Your dialysis team wants to provide you with the best care possible. To do that, outpatient dialysis units have numerous Medicare standards to meet. Dialysis facilities have to comply with local, State and Federal rules and laws which were developed for your safety and quality of care.

The Federal regulations that govern dialysis clinics are known as the **End Stage Renal Disease** – Conditions for Coverage. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/downloads/SCletter09-01.pdf

In these series of articles, we intend to create a time line for all the information that Medicare wants dialysis units to educate you on. The purpose of this education is to keep you fully informed and "engaged" in decisions about your healthcare. You are an important member of your health care team!

IN THE FIRST WEEK OF DIALYSIS:

A. Tests and Vaccinations

PPD Skin Test: Done initially and only repeated if clinically necessary. It is a test that determines if you have been exposed to tuberculosis (TB). Both patients and staff receive annual PPD Skin Tests.

PNEUMOCOCCAL VACCINE: CDC recommends initial vaccines and then revaccination five years later, until the age of 65 years old. Pneumococcal Disease can lead to pneumonia, meningitis and sepsis.

HEPATITIS B VACCINATION: A vaccination for those who are not immune to Hepatitis B. Admission blood work will determine if you will need the vaccine. Hepatitis is a virus infection that causes liver disease. It is spread by contact with the blood of an infected person.

B. Be informed of Your Patient Rights

This Condition requires your dialysis unit to provide respect, privacy, information, and appropriate services for their patients. You will also receive information about how to file a complaint/ grievance either at your unit or with an outside agency.

The dialysis facility must inform patients (or their representatives) of their rights (including their privacy rights) and responsibilities when they begin their treatment (within 6 treatments) and must protect and provide for the exercise of those rights. This is often repeated annually in many facilities.

Standard: Patients' rights. The patient has the right to:

1. Respect, dignity, and recognition of his or her individuality and personal needs, and sensitivity to his or her psychological needs and ability to cope with ESRD;
2. Receive all information in a way that he or she can understand;
3. Privacy and confidentiality in all aspects of treatment;
4. Privacy and confidentiality in personal medical records;
5. Be informed about and participate, if desired, in all aspects of his or her care, and be informed of the right to refuse treatment, to discontinue treatment, and to refuse to participate in research;
6. Be informed about his or her right to execute advance directives, and the facility's policy regarding advance directives;
7. Be informed about all treatment modalities and settings, including but not limited to, transplantation, home dialysis modalities (home hemodialysis, intermittent peritoneal dialysis, continuous ambulatory peritoneal dialysis, continuous cycling peritoneal dialysis), and in-facility hemodialysis. The patient has the right to receive resource information for dialysis modalities not offered by the facility, including information about alternative scheduling options for working patients;
8. Be informed of facility policies regarding patient care, including, but not limited to, isolation of patients;
9. Be informed of facility policies regarding the reuse of dialysis supplies, including hemodialyzers;
10. Be informed by the physician, nurse practitioner, clinical nurse specialist, or physician's assistant treating the patient for ESRD of his or her own medical status as documented in the patient's medical record, unless the medical record contains a documented contraindication;
11. Be informed of services available in the facility and charges for services not covered under Medicare;
12. Receive the necessary services outlined in the patient plan of care described in § 494.90;
13. Be informed of the rules and expectations of the facility regarding patient conduct and responsibilities;
14. Be informed of the facility's internal grievance process;
15. Be informed of external grievance mechanisms and processes, including how to contact the ESRD Network and the State survey agency;
16. Be informed of his or her right to file internal grievances or external grievances or both without reprisal or denial of services;
17. Be informed that he or she may file internal or external grievances, personally, anonymously or through a representative of the patient's choosing.

Standard: Right to be informed regarding the facility's discharge and transfer policies. The patient has the right to –

1. Be informed of the facility's policies for transfer, routine or involuntary discharge, and discontinuation of services to patients; and
2. Receive written notice 30 days in advance of an involuntary discharge, after the facility follows the involuntary discharge procedures described in § 494.180(f)(4). In the case of immediate threats to the health and safety of others, an abbreviated discharge procedure may be allowed.

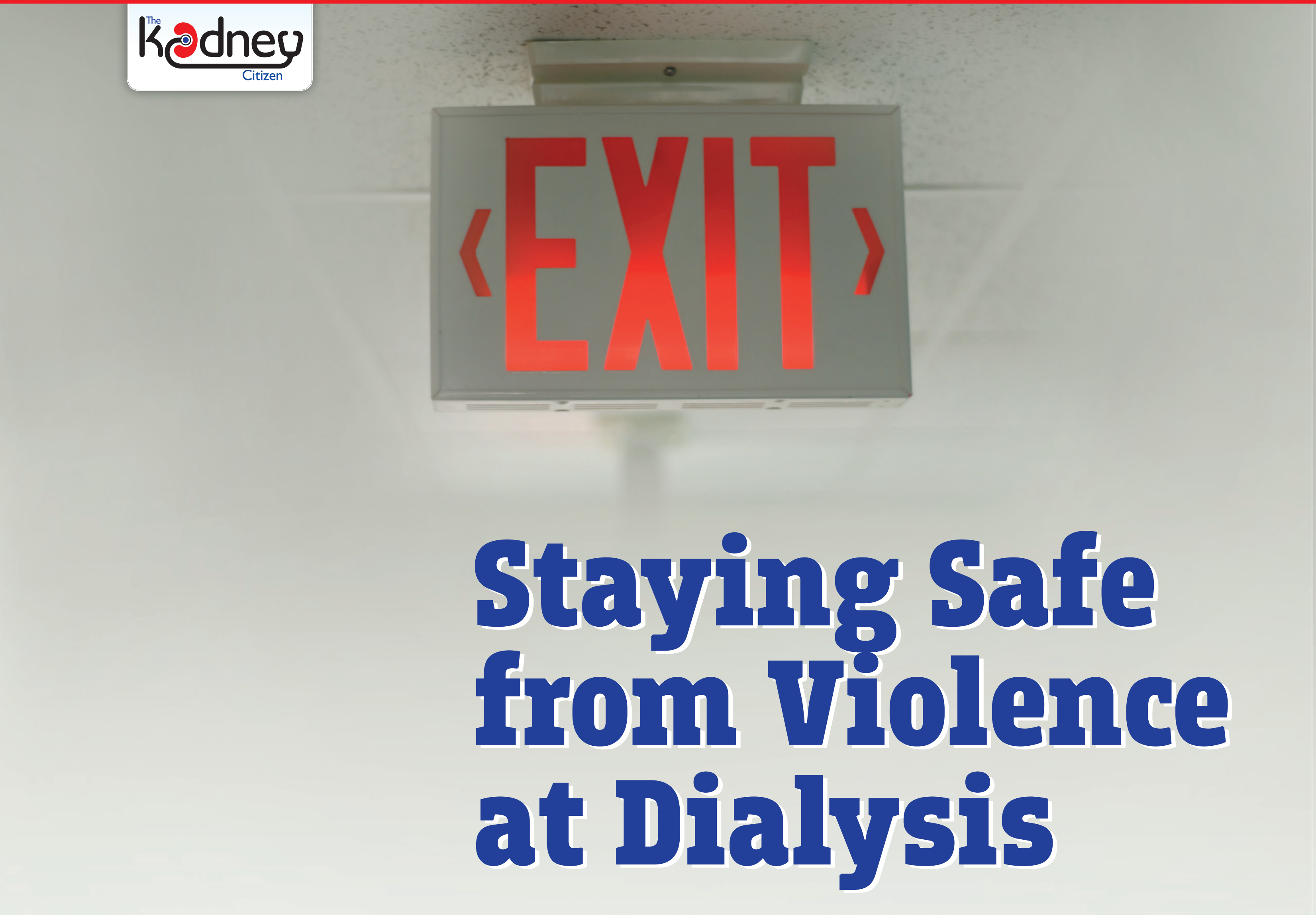
Standard: Posting of Rights. The dialysis facility must prominently display a copy of the patient's rights in the facility, including the current State agency and ESRD Network mailing addresses and telephone complaint numbers, where it can be easily seen and read by patients.

For a full explanation of these rights you can click the link below and review pages 175 – 185.

https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/downloads/SCletter09-01.pdf

WOW! That is a lot of information to absorb in the first two weeks of being on dialysis. However, don't panic. Take your time and review the material that has been provided to you by your dialysis unit. Feel free to ask them questions to get a better understanding of the information. Once again, the purpose of all this information is to make sure you are an educated consumer who can participate in their treatment planning.

Next issue we will cover: **IN THE FIRST 90 DAYS OF DIALYSIS**! ●



Staying Safe from Violence at Dialysis

By **Jane Kwatcher**, MSW, LCSW

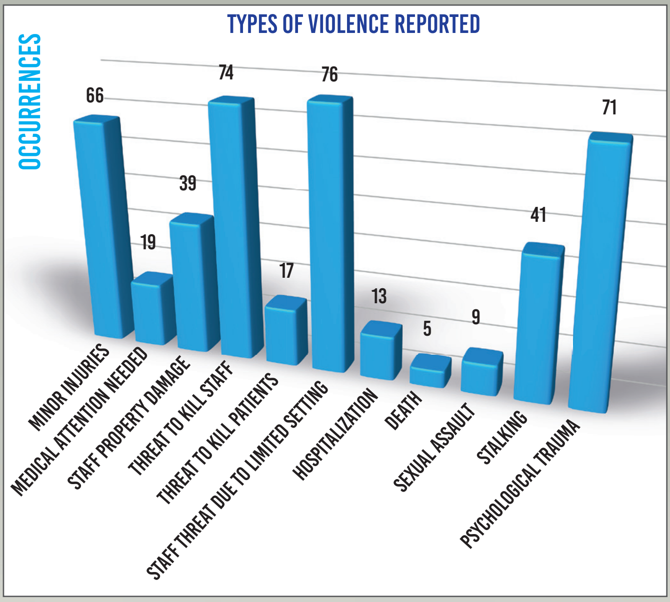
I write and reflect on the eve of yet another school shooting with fatalities. In my youth, and likely yours, the biggest threat at school may have been cruel bullies. Now we need to acknowledge the fact that schools are no longer safe havens. A quick Google search indicates there have been more than 200 school shootings since Sandy Hook in 2012. But what about our safety in healthcare settings, specifically in dialysis centers? These are places you may be for hours at a time, multiple days each week. Can you take your safety for granted?

There are no publicly available statistics for violence in dialysis centers. Everything we know of these events come from events reported in the news or anecdotal reports. Beginning in 2013, my colleague, Mathias Stricherz, Ed.D. started to research the extent and types of violence in dialysis centers. Initially, we administered a survey to dialysis social workers, and received 274 responses. Since then, we have continued to collect narratives from dialysis staff and from news sources.

Some of the incidents reported:

- Florida: woman shot man in the abdomen while he was undergoing dialysis in a spillover of domestic violence.
- New York: an involuntarily discharged patient walked into clinic and opened fire, critically wounding a nurse.
- Kansas: a bomb threat at a clinic required patients undergoing dialysis to be evacuated.
- Kentucky: two 70 year old men had a fist fight in a dialysis clinic.
- Patient’s Delusion Results in Threat of Murder in Dialysis Clinic
- Man on Dialysis for 40 Years Threatens to Shoot Dialysis Center CEO
- Veteran with PTSD Threatens to Bring Gun to Dialysis Clinic
- Dialysis Patient Threatens Violence Against Technician
- Spouse of Dialysis Center Manager Uses Racial Slurs to Clinic Patient

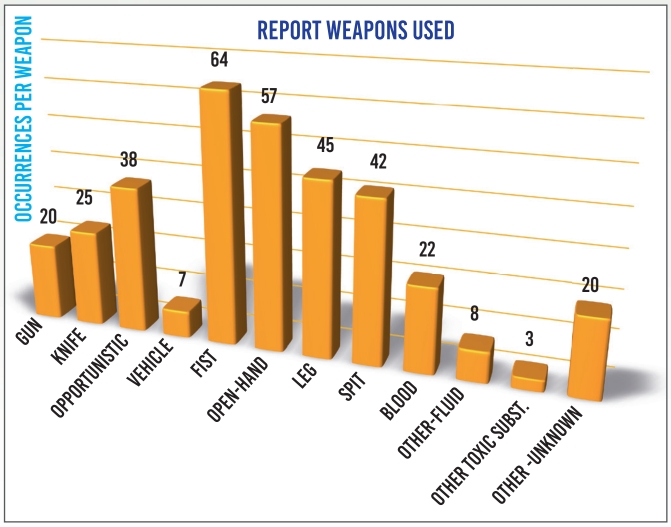
Types of violence reported in our survey data are shown in the table below, ranging from threats, property damage, sexual assault, to death.



Of all the incidents reported, 50% were carried out by patients, largely in response to staff setting limits. Consider the types of things that commonly occur:

- A patient is upset that they are not put on at the expected time.
- A patient is offended by another patient's behavior, dress, politics, sexuality, etc.
- Staff does not respond to patient's need in a timely manner.

A variety of weapons used was also reported. Some were used to do physical harm, others were used to threaten harm.

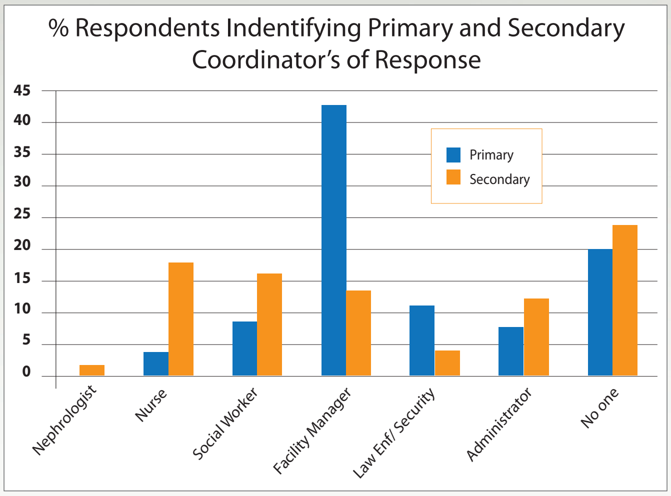


There are three main risk factors for threats of violence in dialysis centers: people suffering from mental illness, substance abuse, or an inability to cope with the changes presented by life. These can afflict patients, staff, or family members. Additionally, the characteristics of the neighborhood need to be taken into consideration. Is there gang activity, shelters or soup kitchens, or homeless people in the area?

Personal Safety:

There are things you can do to stay safe. It starts with being aware. When you are coming to a facility for dialysis, you are naturally thinking of your own care, your own day. But a dialysis facility is no different from another public place. You want to be aware of your surroundings; who is there, what's going on, where are the exits? Are exists blocked or accessible? Is the security door to the treatment area propped open? Is the parking area well lit? Do you know how to safely disconnect from your machine in an emergency?

It would be a tremendous relief to believe that staff will take care of any potentially violent situation, but staff have varying levels of training, experience, and communication skills. At certain times, there is only a "bare bones" staff. In our research, we asked about the primary and secondary coordinators of a response to violence. The most frequently identified person was the dialysis facility manager, followed by "no one."



Further, staff may not have the training and practice to feel they can respond competently. Sixty percent of respondents reported they had on-line training, but fewer than half reported any other kinds of training.

If you hear someone making threats or see an action that tells you danger is present, report it immediately. A lot of times people will say "I don't want to get involved," but it is your involvement, and everyone else's that create a culture of safety by working together. You may be able

Required Training Reported by Respondents

Stricherz, Kwatcher, Kretzner 2015

to de-escalate a situation by speaking calmly, and not arguing, threatening, challenging or shaming. “Hey John, you seem pretty upset. What’s going on?” or “Tell me what happened; I will try to help you.” And then listen with your full attention. We all may experience times when the frustration and stress seem to be overwhelming. Having someone to calmly listen and acknowledge our pain and frustration helps to diminish it; we feel heard. If the person continues to escalate their behavior, you need to call for help; make sure facility staff are aware if possible, have someone call 911, or pull a fire alarm.

In light of current events, it is important to have a discussion of what to do in the case of an active shooter in a dialysis facility. Conventional wisdom is to run, hide, or fight; all of which may be difficult for a patient connected to a machine. This is the why everyone needs to be a part of prevention; immediately reporting concerns, making sure security doors are not wedged open, or perhaps helping to de-escalate a situation. Based on our research, we have identified several risk factors at the organizational level:

1. Lack of facility policies and staff training for recognizing and managing escalating hostile and assaultive behaviors.
2. Working when understaffed.
3. High staff turnover.
4. Inadequate numbers of and inadequate training of security and mental health personnel in violence responses on site.

The staff responding to our survey indicated they are generally not well prepared or supported, and are bound by limited training in preparation, response, and post-event response to violent acts. Only 3% reported having on-site law-enforcement, and 23% reported having security officers with responsibility for checking patients in. Training for personal responses or defensive strategies for safety are not generally available to employees and certainly not for patients.

Generally, we found a lack of prevention plans for responding to threats of violence. Prevention and training require time and financial resources that do not contribute to clinical outcomes or profits. What will you need to do to feel safe? We encourage you to develop your own protection plan and develop the responses you could or should do.

Finding Answers Through Research

Andrea Knob, MS, Genetic Counselor, Clinical Research Coordinator
Beth Israel Deaconess Medical Center

Why do I have kidney disease? Why does my kidney disease not respond to the standard treatments? Will I get recurrence of my kidney disease if I get a transplant? Does kidney disease run in families?

There are many different kidney diagnoses and reasons that individuals can end up on dialysis, and these answers are not the same for everyone. Some forms of kidney disease may result as part of an underlying condition such as diabetes or hypertension, while others may be part of a known genetic syndrome such as polycystic kidney disease. However, for many individuals with kidney diseases such as FSGS, nephrotic syndrome, unexplained proteinuria, and unexplained kidney failure, the cause is unknown, and there may be many unanswered questions. Most of these types of cases are likely due to a combination of genetic, environmental, and lifestyle factors, but how do we understand what these factors are and how they add up to cause someone's experience of kidney disease?

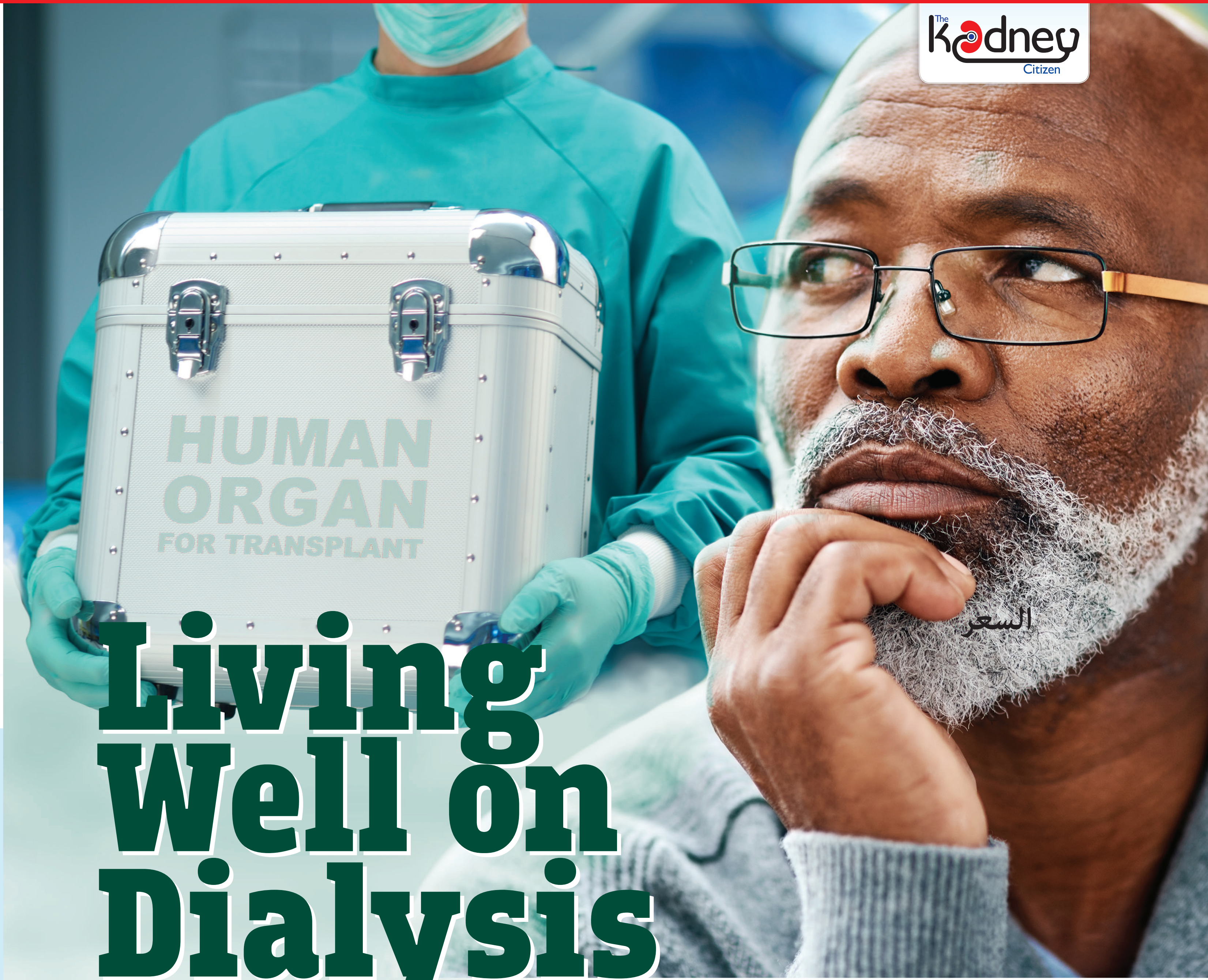
At the Pollak lab in the Renal Division of Beth Israel Deaconess Medical Center, we are trying to learn more about the cause of kidney diseases such as FSGS, Nephrotic syndrome, unexplained proteinuria, and unexplained kidney failure by studying genetics. Genes (which we can think of as the "words" within DNA) contain the instructions for the body to carry out its functions and give rise to traits. We look at genes related to the kidney in order to see if the instructions are what we expect or if there is variation. From there we want to know whether a genetic variant is a normal part of the diversity from person to person or whether the genetic

variant might be giving inadequate instructions for the kidney to function as it should.

Here at the Pollak lab, we have identified genetic variants (mutations) that we know are associated with kidney diseases such as FSGS, nephrotic syndrome, and related conditions. Although FSGS and nephrotic syndrome don't usually run in families, approximately 10% of cases do appear to have a larger inherited genetic component. We have done a lot of work with genes such as ACTN4, NPHS2, TRPC6, INF2, and APOL1 for example. We want to know more about these genes and how they work, and we think that there are important genetic mutations that we still need to discover. We also want to learn more about why kidney disease, and particularly end stage kidney disease is more prevalent in certain populations.

We hope that by learning more about the genetic factors that may be involved in these kidney conditions we can eventually find more answers for patients and families with kidney disease. By studying genetics we hope to identify clues as to why and how some people develop kidney disease. We can also better understand differences in the way that people may respond to treatments. We can learn why some people experience recurrence of kidney disease in their transplanted kidneys, and why kidney disease can sometimes run in families. We also hope to identify information that can lead scientists to better treatments with less side effects in the future.

We invite patients with FSGS, nephrotic syndrome, unexplained proteinuria, and/or kidney failure as well as their family members to participate in our ongoing research. We also hope to collaborate with providers who care for these individuals and/or families in communities nationwide. Participation in our study can be coordinated by phone/email/mail and can be completed from home. It typically involves a one-time saliva sample (or blood sample if that is your preference), and a questionnaire. There is no cost to participate. Testing is performed on a research basis, with the option of electing to learn any relevant results that might come out of the study. (Some people prefer not to know but still want to contribute to the research effort.) To learn more about us and our study you can contact Dr. Martin Pollak and/or our research coordinator, Andrea Knob, by phone at 617-667-0467 or by email at aknob@bidmc.harvard.edu. You can also visit our website at https://sites.google.com/site/pollakfsgs for more information about our research.



Living Well on Dialysis

When a Kidney Transplant Fails

By **Jewel Edwards-Ashman**

After years, maybe a decade or even longer, of living with chronic kidney disease you finally get the call from your doctor letting you know that you'll receive a kidney transplant. If it's successful, you'll be able to quit your dialysis treatments. You'll have enough energy to run a marathon, or maybe just walk up a flight of stairs. You'll be able to do whatever you've been putting on hold because of your health. You're not even thinking about another round of kidney failure in the future, and most transplant recipients aren't. Organ failure, however, is something most transplant recipients will likely face more than once in their lifetime.

I had very few complications in the first few years following my own kidney transplant. Then I became pregnant, miscarried in my second trimester, and ended up undergoing treatment for an acute episode of organ rejection. All of those events left me with decreased kidney function, and I soon learned that my transplanted kidney would likely fail after about five to seven years. My initial reaction: This is not how things were supposed to go. Since then, I've been trying to mentally and emotionally prepare myself for a second round of kidney failure.

Data show that I'm not alone. "The average lifespan of a kidney transplant is 12 years for a deceased donor, and 15 years if you have a living donor who is related", according to Jared L. Skillings, PhD, a transplant psychologist and Chief of Psychology for the Spectrum Health System in Grand Rapids, Michigan.

If you receive a kidney transplant, you'll likely be monitored closely for years by your nephrologists (i.e. kidney doctors) and transplant team, so any news of decreasing function shouldn't come as a surprise. "Patients I have talked to who have had a transplanted kidney for a long time, say 'I kind of knew it was coming'," says Kristin Kuntz, PhD, a transplant psychologist at The Ohio State University Wexner Medical Center.

However, some patients become acutely ill, or contract a virus or infection that leads to kidney failure. "For these patients, the failure of the kidney may seem out of the blue. It's sudden. The patient is not prepared for it. It's a very difficult adjustment. You had planned out your life and all of a sudden you're facing a return to dialysis," Kuntz says.

No matter what camp you fall in—prepared for the worst, or completely shocked—kidney failure is hard. Here are some tips for adjusting to the news.

Keep doing the things you enjoy doing and taking care of yourself.

After receiving a kidney transplant, you might go several years without feeling sick. Many of the symptoms of kidney failure will likely disappear and you'll find yourself doing things you wouldn't have done before your transplant. But finding out that your transplant is failing could put you in such a funk that having fun and pursuing new interests seem like a waste of time. Your second instinct might be to withdraw from your friends and family.

Try to keep doing things that you enjoy and spending time with people you care about. "Don't let feeling discouraged keep you from doing the things you like. You'll end up feeling worse, if you stop doing those things," Skillings says.

Also, don't slack off on good health behaviors, Kuntz advises. Do what you can to stay healthy—eating right, exercising and taking your medications.

Take a step back and reflect on how you're feeling.

You might start worrying about the future or stressing about the next steps after hearing that you'll have kidney failure again. You may even start thinking ahead to your next transplant. While it might seem like a good idea to start preparing immediately for dialysis or another transplant, Kuntz advises patients to hold off on creating an action plan. Take some time to think about how you're feeling.

You'll probably experience a range of emotions, according to Skillings. "Feeling afraid is really normal. Knowing that your transplanted kidney is failing makes you nervous. You might go through a period of grief where you're mourning the loss of your kidney function. There is a grief process of realizing that you are not well," Skillings say. Some patients also respond to the news with anger or avoidance, or they feel guilty thinking about all the things they could have done wrong.

Some transplant centers require patients to have a period of reflection before starting another transplant process. "The transplant team will probably ask about what you did well with your last transplant, what are some areas for improvement, what worked for you and what didn't work," Kuntz says.

Whether taking time for reflection is a requirement or not, understand that it's OK if you need some time to process everything that's happened. Let your transplant team know if you're taking a breather to prepare for what comes next, whether that's returning to dialysis or pursuing another transplant.

"If you decide to go on dialysis, there is always a chance to go back and do a transplant later, even if you're not ready right now," Skillings says.

Consider who you might tell and when.

It's not always easy to talk to friends, family members and other people you know about your health status. They might not understand why your transplant is failing, which can lead to lots of invasive questions. It's best to share this information with people who have been supportive of you in the past. Talking about your kidney transplant may even be helpful for your close friends' and family members' emotional adjustment to the news, Kuntz says. If you do tell friends and family, and they are supportive, you'll be able to lean on them when you need help.

You might decide to tell your donor, assuming they are supportive, that the kidney is failing. These conversations can be emotional and difficult, so Skillings recommends writing a short "speech" or memorizing what you want to say beforehand.

You don't have to share the news with people who are toxic or have been unsupportive in the past. "It's OK to not tell someone, even if you're related to them, if you don't feel like it's safe," Skillings says.

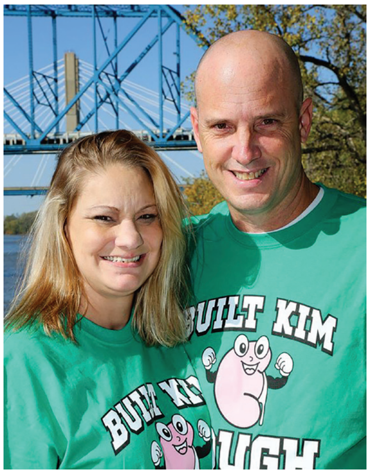
Try counseling or get professional help if you need it.

For those of us with a chronic illness, some aspects of our health are out of our control. If the likelihood of kidney failure is on the horizon, you may feel like there's no point in keeping up with your favorite activities or continuing to take your medications. Some people become depressed.

Seek help if you start feeling hopeless, depressed or are unable to cope with the news. Consider seeing a licensed psychologist, therapist or other mental health professional. Your transplant team or nephrologist will likely be able to refer you to a provider who can help you through this tough time.

Jewel Edwards-Ashman is the member communications manager in the Practice Directorate at the American Psychological Association. She was diagnosed with kidney disease (FSGS) in 2003 and received a kidney transplant in 2013.

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 ●



Choosing a Partner with Kidney Disease

By **Deron Johnson**

Let's not sugarcoat it. Kidney disease is not fun.

There are approximately 739,000 Americans currently dealing with end stage renal disease, according to the U.S. Renal Data System. Factor in countless family members and other loved ones who are affected by the disease, and you soon realize you are not alone in the fight.

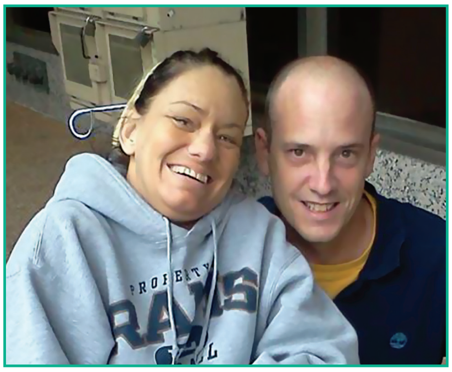
For every victim of this horrible disease, there are almost always at least one or two primary caregivers. I am not talking about the wonderful doctors, nurses, and other health professionals. Their expertise and caring ways are unmatched. I am referring to the lay person caregiver; usually a spouse, a parent, or other family member. I know a little bit about this because I am one of them. If you are reading this as a caregiver of a loved one with kidney disease and hoping to get all the answers to every question you might have, you are going to be disappointed.

But, I will tell you this. As daunting as this is, it can be very rewarding. My wife, Kim, was born with focal segmental glomerulosclerosis – FSGS. That is a mouthful, I know. So, we are going to keep the technical terms to a minimum. Just know this – through no fault of her own, she was dealt bad cards and born with kidney disease. Sometimes kidney disease is known as the "hidden disease" and, for Kim, kidney failure was not diagnosed until age nine.

She struggled gaining weight and was sick often during her childhood, but she still managed to live a normal life, that is, until her kidneys began to completely shut down. By age 16, it was time for dialysis. Her brother, Kurt, stepped up and, while not a perfect match, was a good enough match to donate one of his kidneys. After a few years, however, Kim's body began rejecting the kidney. After getting back on the transplant list, Kim's second transplant happened in 1998. That kidney lasted a remarkable 13 years.

That is where I come in. I met Kim in 2010. We were introduced at a social event by a mutual friend. We hit it off immediately. The night I met her, Kim told me about her disease. She never hesitated. She told me almost matter-of-factly, as if she felt I needed to know and just got it out in the open right away. I knew what kidney disease was, of course, but did I ever have a lot to learn.

Within a couple of days of us meeting, casual lunch plans were discussed. It was difficult to arrange, however, because Kim was doing in-clinic hemodialysis at the local DaVita Center. She said I could come visit her there, if I wanted to. I thought about it and decided to bring lunch to her. This was my first eye-opening experience. I had no clue. I knew she was getting dialysis but I had no idea what that enormous machine was doing.



It was then I decided I was going to have to buckle down and learn as much as I could, if this new relationship was going to go anywhere. Kim needed a third transplant. But there was a checklist of items we had to do to get her there. Within a few months, we had made it on the transplant list at Barnes Hospital in St. Louis. By April of 2012, Kim was very sick and doing home peritoneal dialysis. That is when we got the call. A kidney was available! Immediately you go from elation, to sadness for the person who had passed away but made a critical life choice to be a donor, and on to nervousness.

The surgery was successful. By 2015, Kim was working full-time and leading a relatively normal life. We had married in 2013 and were raising kids. Sure, there were the follow-up doctor visits, the numerous blood draws and hospitalizations. But, we were leading a relatively normal life. Hospitalizations are frequent. Remember, the immune system is shot, especially in Kim's situation, having had three transplants.

Things had been fine. Her labs were normal – or at least normal for someone in Kim's situation. That all changed in the summer of 2016. Kim had been feeling abnormally ill, extra fatigued, and nauseous. We were making the two-hour drive from our hometown in Quincy, IL to St. Louis to see the doctors there. On the trip, Kim was very quiet. I asked her what was wrong, and she said she knew her kidney was failing. Ever the optimist, I tried to pep talk her. "You'll be fine," I said. "Everything will check out." Kim, the realist who has been fighting this her whole life, disagreed. Once in St. Louis, doctors did a biopsy. Waiting for the results was excruciating. Sadly, Kim was right. The doctors came in. You could see by the look on their faces that the news was not good. The lead doctor came right out with it. There is no easy way to say it. "The kidney is in bad shape," he said. "It's failing." They left the room and Kim and I sat quietly for a minute. I hugged her. I sat back down, and I did something I rarely do. I started bawling. The emotions flowed out of me.

As a caregiver, I sometimes feel like I do not make a good husband. Conversely, as a husband, I sometimes feel like I do not make a good caregiver. It is a constant struggle. But I am learning every single day. Kim is back on dialysis. She does not like it, but the alternative is ... well, there is no alternative. So, we wait. We are back on the transplant list in St. Louis. We have now made two trips to Chicago to try and get listed there. We figure the more options, the better the odds. If nothing else, we are getting great advice and talking to some of the smartest people in the world about Kim's condition.

I do what I can to help Kim. I prepare her machine for dialysis every day. That is about a 20-minute process. I inventory her supplies and stay on top of what is needed. Every out of town doctor appointment she has, I drive her. These are relatively small things, but they are important to Kim. One thing I have learned: work as much fun into this as possible. Kidney disease is not fun. But there is still a life to lead. When we went to Chicago recently, we went to a Cubs game the night before the appointment (even though I am a diehard Cardinals fan). Chicago is a 5-hour drive, so that is a long haul just to go and do doctor appointments. So, it is important to work in fun things to do when possible.

Getting a fourth transplant is going to be hard. The antibodies in Kim's system are very high. But we have two choices. Fight. Or not. We are choosing to fight.

Kim received her fourth transplant on November 17, 2017 at Barnes-Jewish Hospital in St. Louis. Subsequent doctor visits have all been positive. Her kidney is performing great! Her creatinine has been in the low 1's which is remarkable ●

The Sweetest Taboo

By **Charissa Rice**

Shhh...not so loud. This is a topic or subject that not too many want to talk about. That's funny because most of us spend a lifetime trying to do it. So why is sex and anything pertaining to it so taboo? I guess as a patient with a chronic illness that should be the last thing on my mind.

I can remember when visiting my many doctors, hearing them discuss different symptoms and what I might expect with my many illnesses. I have lupus and also kidney failure. There are a lot of things that can cause my libido to be depleted, but it was really never brought up. I learned the hard way that what I was dealing with would affect my sex life.

I've been married for 18 years. Our early years were tough, because I didn't understand why I felt or didn't feel a certain way. I was young, so I didn't think anything physical was wrong. I also thought the doctor had gone through all the possible symptoms I might experience. Well I was on blood pressure meds, dealing

with lupus and kidney failure and at that time my biggest concern was why I had no interest in sex.

It wasn't until I started researching and reading for myself that I began to understand all the things my body was going through. Sometimes as patients we rely on the doctor to tell us everything, but we have to be more proactive. I had to do something, my husband had begun to suspect that I was cheating on him. Totally not the case. Another lesson learned is to talk to your mate and let them know what is going on.

What it all boils down to is that you will experience some changes. Some may not be drastic and others will really be life changing. The question is "How will you handle it?" I've learned to take control of the situation and not sit by and let things just happen. How did I overcome the challenges of changes in my sex life? First I talked about it, put it all on the table of what was going on and what we could do about it. What has helped us is doing the things that made us fall in love with each other when we first met. Dates, phone calls, texts or love notes to each other. When there is extra money to splurge we get away just the two of us and spend time with each other.

Even though it takes a little more planning and fore play than others, spontaneity is key too. Surprises can help reignite or just light that dim light. Know that it's not over or the end of the world. You can still live and enjoy life, it just may take a little more effort to get there. ●

Put Out the Fire! Simple Strategies to Reduce Chronic Inflammation

By **Jessiana Saville**, M.S., R.D., C.S.R., L.D.
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DPC Ed Center Advisory Council Member

What's the big deal about inflammation and kidney disease?

Chronic kidney disease is an inflammatory chronic disease. There are many factors that contribute to this inflammatory state including diet, lifestyle, and environment. In addition, once the kidneys have started declining, decreased ability to filter toxins and a variety of other cascading mechanisms further exacerbate an inflammatory state.[1] For example, uremic toxins also cause oxidative stress and lead to inflammation.[1] Uremic toxins have also been linked to changes in the intestinal microbiome (think of this term as what keeps your gut healthy and protects your body from dangerous pathogens).[1] Intestinal imbalance can then lead to more inflammation because the gut is critical in controlling inflammation. There has also been evidence suggesting that the anti-inflammatory properties of certain foods and supplements, such as omega 3 fatty acids from food, fish oil, or flax seed oil, may help decrease inflammation in kidneys.[5] Decreasing inflammation is valuable for anyone with kidney disease to preserve kidney function, improve quality of life, and maintain a strong immune system.

What foods can I eat to combat inflammation?

High Fiber

Dietary fiber has been shown to lower inflammation and lower mortality risk in the CKD population.[3] High fiber may also decrease acidosis, thus further reducing inflammation.[3] It is uncertain, however, whether it is the actual fiber that decreases

inflammation or rather the nature of foods that are high in fiber. Two possible reasons why fiber intake is so powerful:

1. Dietary fiber sustains and modulates the gut microbiome, as fiber is essentially "fuel" for the good bacteria in the gut.
2. Fiber-rich food groups may contain antioxidant and anti-inflammatory properties.3 Some kidney-friendly sources of dietary fiber include many fruits and vegetables. Legumes and whole grains are also a great source of fiber although may be higher in potassium and phosphorus. They can fit into many renal diet regimens, but patients should discuss adding these with their renal dietitian. The following table is a list of food substances that are good sources of fiber and lower potassium and phosphorus options.

Food Item	Amount	Fiber (g)	Potassium (mg)	Phosphorus (mg)
Apple	1 medium	4	195	20
Blackberries	½ cup	4	117	16
Pear	1 small	5	172	16
Raspberries	½ cup	4	93	18
Green beans	1 cup	4	183	36
Green peas	½ cup	4	88	62
Chickpeas	½ cup	5	83	65
Black beans	¼ cup	5	167	62
Barley	½ cup	4	77	61

Omega 3 fatty acids/fish oil

Supplements of omega 3 fatty acids or fish oil have shown promising anti-inflammatory effects in some recent research.4 These effects on inflammation are likely due to the ability of these fatty acids to combat oxidative stress and downregulate pathways of inflammatory cytokines.4 Both supplements and diet have been shown to be effective. Fatty fish are a great source of dietary omega 3's and include: salmon, mackerel, herring, trout, and tuna.

Prebiotics and Probiotics

Prebiotics and probiotics may have anti-inflammatory effects, according to some studies, presumably due to their actions of modulating the gut microbiome. 1 Prebiotics are the fibers that are food for the good bacteria in your gut. Probiotics consist of supplements containing the actual bacteria that are good for your gut. Currently, there isn't much conclusive evidence of the benefits of prebiotics/probiotics for CKD patients. However, one study has shown reduced inflammation with probiotic supplementation in animal models. This leads us to believe there would be little harm, and possibly some benefit, to supplementing with a probiotic food.1 We need more data!

Physical Activity

Physical activity has a multitude of benefits in healthy and CKD populations. Experts suggest that in patients with pre-dialysis CKD, 6 months of regular walking exercise (30 minutes per day 5 days weekly) has anti-inflammatory effects.1 Therefore, an evening walk around the neighborhood may be a great step toward reducing inflammation and slowing the progression of CKD.

Knock out that Fire!

Taking small steps to reduce inflammation in your lifestyle can pay dividends. Increasing fruit and vegetable intake, eating more fish, and getting exercise can be important lifestyle habits. Talk with your dietitian and physician about ways to incorporate more diet, lifestyle, or supplement approaches to decrease inflammation. ●

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