

The **Kadney** Citizen

A publication of Dialysis Patient Citizens (DPC) Education Center



Dialysis, Caregiving and Emotional Health

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Keep Your Funny Side Up: Discover the Humor Perspective

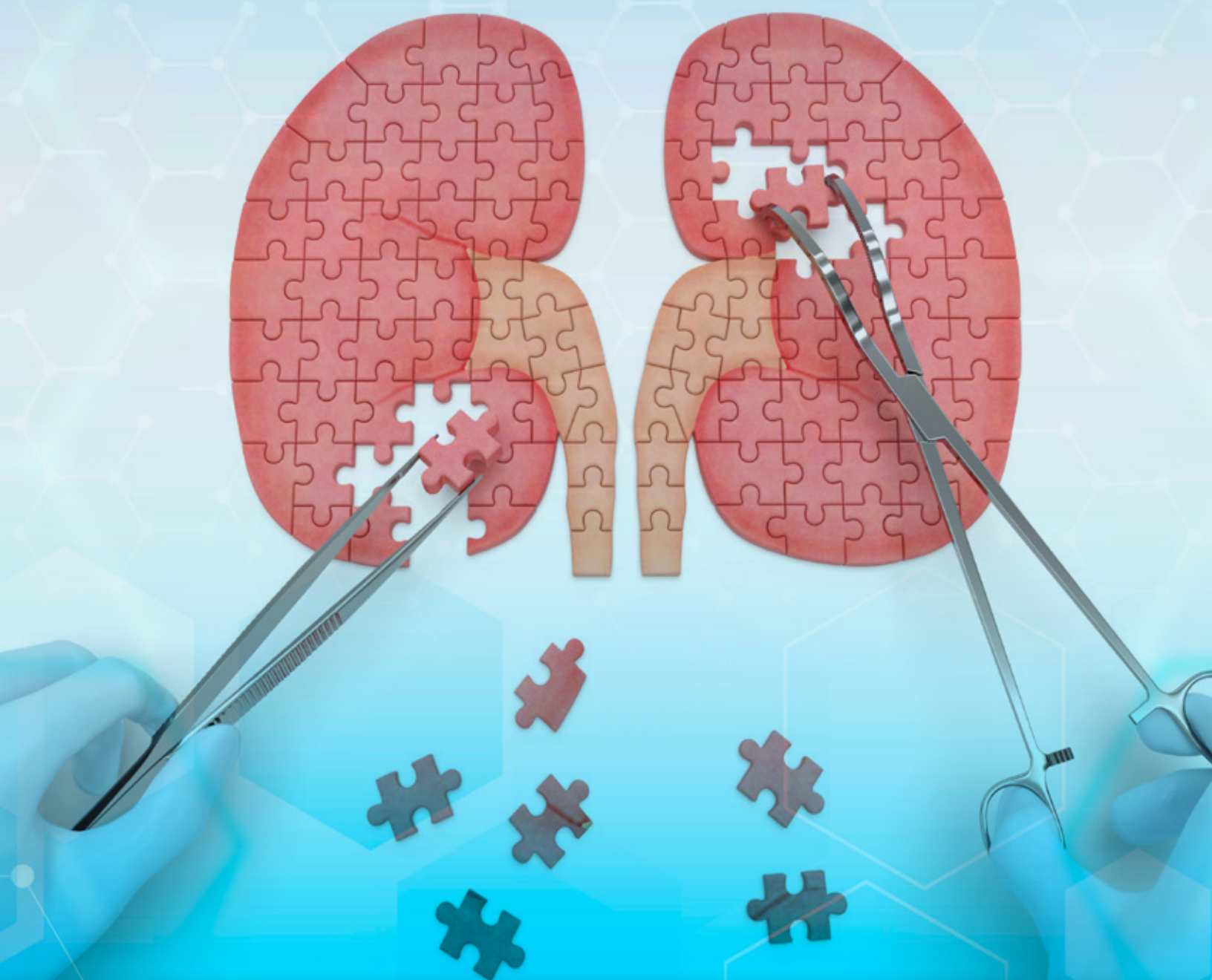
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*Also available in Spanish!



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President's Message

History was made on July 10, 2019! The President of the United States of America signed an executive order to improve kidney healthcare in the United States. The executive order requires our government to take meaningful steps for: preventing and reducing the number of patients developing kidney disease; providing more options for the treatment of kidney disease; and increasing the availability of organs for transplant.

In the words of Hrant Jamgochian, our DPC Chief Executive Officer, "kidney disease advocacy transcends politics." Although the President and many other politicians attended the announcement, this was not a political event. In my opinion, this effort will make life better for potential and present renal patients for many years to come. I remain honored and humbled that the Administration asked me to speak at the July 10th event. I spoke from the heart and shared my story to a "packed auditorium" at an event which was carried live by most of our national news networks. Hopefully, my words encouraged those listening to become

more proactive in their healthcare and address any potential health issues. It is crucial to get physicals, keep provider appointments, and address any health issues that one may be experiencing. There are too many individuals WHO HAVE renal disease and do not know it. By focusing on your health, this can help to prevent and/or delay illnesses.

I will never forget my participation in this event. My focus was solely on the renal patient. I will continue to advocate for us because there is still a tremendous amount of work to do. We must monitor the implementation of the executive order and address any concerns or unintended consequences that may occur. As advocates and concerned citizens, it is our responsibility to focus on ensuring the best quality of life for all patients. Be encouraged, stay involved, and remember that you are not alone on this journey!

Sincerely,

Nancy L. Scott

DPC Education Center
Board President

DPC's 2019 Washington, D.C. Patient Fly-In





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

On June 10-11, Dialysis Patient Citizens (DPC) held its annual patient fly-in where we bring dialysis patients, caregivers and health care professionals to Washington, D.C. to advocate with their Congressional Members on issues impacting them. This year we had 38 patients and 16 health care professionals participate, who met with more than 100 Congressional offices.

The two-day fly in began on Monday with a day of training for our advocates. This year we were delighted to welcome two special guests to speak to our patients. The first was Nick Uehlecke who is an advisor at the U.S. Department of Health and Human Services and is heavily involved in the Department's work on kidney issues. He spoke about the Administration's work to expand access to home dialysis and develop alternative treatments for end-stage renal disease (ESRD).

The second speaker was U.S. Congressman Donald J. Payne, Jr. who represents the 10th District of New





Jersey. Representative Payne started dialysis earlier this year, and he spoke to our patients about his treatment experience and the work he is doing to improve access to quality care. He was also kind enough to join us as our Special Guest during the evening reception.

On Tuesday, patients, caregivers and health care professionals all went to Capitol Hill to meet with their legislators. They had 103 meetings with Congressional offices from 32 states. During these meetings, they shared their personal dialysis stories and

treatment experiences and educated lawmakers on specific issues impacting patients—such as the need to preserve access to Charitable Assistance and ensure access to Medigap for all ESRD patients.

These two issues were timely for our fly-in because the Trump Administration recently announced they are currently considering a rule regarding Charitable Assistance. Patients discussed with legislators and their staff how charitable assistance has helped them, whether it was by accessing private insurance or by being



able to pay for Medigap. There has been strong Congressional support for charitable assistance, and hopefully that will continue to be the case in the 116th Congress.

Also, earlier in June, Senators Ben Cardin (D-MD) and Roy Blunt (R-MO) introduced S. 1676 – The Chronic Kidney Disease Improvement in Research and Treatment Act of 2019. This bill has provisions in it that improve patient quality of care, as well as ensure access to Medigap for ESRD patients under the age of 65. Right now, all ESRD patients over the age of 65 have access to Medigap, but only 28 states provide patients under the age of 65 with guaranteed access to Medigap. This bill would fix that at the federal level, and our patients educated Members of Congress about this issue and the recently introduced legislation.

This year's fly-in was a huge success, and we look forward to continuing the momentum from it until our next one in 2020. If you are an ESRD patient, family member, or caregiver we encourage you to get involved. Reach out to your legislators, become an advocate, apply for our fly-in next year – because if you don't, who will?

Dialysis, Caregiving and Emotional Health

By Hannah Calkins

Dialysis is life-changing in many ways. It may be what makes your life possible, for one. But it may also significantly impact your daily routine, your sense of self and your relationships—and it may impact all three if your significant other or another close relative has taken on a caregiving role.

You and your caregiver may be new to this situation or coping with it long-term. Either way, psychologists and social workers who work with people with kidney disease and other chronic illnesses can help you both manage your routines, navigate conflicts and maintain—or even enrich—your relationship through this experience.

First, expect a period of adjustment to your new roles. Immediately

following a diagnosis of a chronic disease, patients and caregivers may “focus on logistics—what needs to be taken care of,” says Jessica Geller, PhD, a clinical health psychologist at Birch Psychology in Denver, CO. “The emotional adjustment to the situation doesn’t always set in right away.”

That may be especially true for people on dialysis. Regardless of whether you’re undergoing it at home or in a treatment center, it involves a great deal of planning, coordination and time. Additionally, caregivers may need to take over new tasks in addition to supporting your treatment regimen.



All patients face different issues. Dialysis treatments may be a breeze for some, but others may have more challenges. “Some people on dialysis may be limited or fatigued, and some may not be able to pick up the kids from school or perform other role functions,” says Audrey Krause, PhD, a transplant psychologist with the Indiana University School of Medicine and IU Health in Indianapolis. “If they’re unable to work, the caregiver might also be the breadwinner.”

You may both struggle during the period of transition until you find what Geller says her patients often call “the new normal.”

“Resistance to this huge life change can actually create more distress,” she says. “While it can be a challenging process to get there, being open to and accepting of what’s taking place can be helpful.”

Over the long term, find complementary ways to cope and support each other. Receiving a kidney transplant is the ultimate goal for many people who experience kidney failure, however, for some patients, dialysis is an indefinite reality. If that’s the case for you, it can be helpful for you and your caregiver to develop ways to collaboratively cope.

This means viewing the management of your health as a shared responsibility and engaging in joint problem-solving.

“If there’s a mismatch between the kind of support a patient wants and the kind [he/she is] given, this can cause increased distress and at times negatively impact their ability to cope,” says Geller. But, if you work together, you may have better outcomes in your health *and* in your relationship.

If your caregiver is also your spouse or partner, you may have some unique challenges in attaining these good outcomes. “While being married can provide a source of support and solace when one person has a chronic illness, some couples may have pre-existing patterns and interactions in the relationship that aren’t healthy,” Geller says. A psychologist or other counselor

can help you work toward a healthier, more productive dynamic.

Communication is key (and it’s okay if you need help with it). No matter what your pre-existing relationship is like, you and your caregiver need “open, clear, and quite intimate communication on both sides,” Krause says. Remember that you’re in it together, especially during times of stress or conflict.

“If there’s a disagreement, the first thing to do is have a conversation and really listen to each other. Try not to blame,” says Krause. “Do a lot of listening and reflecting back: ‘If I heard you correctly, this is what I’m hearing, is that right?’ And then, you can problem-solve effectively as a team.”

If you’re struggling to do this on your own, psychologists, social workers, and other mediators can clarify the problem and identify a resolution. Your psychologist or social worker may be especially helpful if disagreement involves adherence to your prescribed treatment regimen, which is a frequent source of conflict among people on dialysis and their loved ones.

“If noncompliance is an issue, as a psychologist, I want to know the context,” Krause says. “Aspects of dialysis may be uncomfortable, painful, expensive, inconvenient, or sad, but these things can often be ameliorated. Together, we can all identify the source of the problem, and then find a way to resolve it.”

For caregivers, feeling overwhelmed and having feelings such as guilt or frustration are understandable and normal, says Geller.

“It’s a big change to take on an unexpected role,” she says. “It can be helpful for them to know it is common for caregivers to feel this way. It can also be helpful to encourage them to have open communication to express these feelings.”

Geller also suggests that caregivers rely on the medical team, other family members and friends for support. “If the caregiver takes sole responsibility for everything, [he/she will] get burned out,” she cautions.

Other ways to prevent caregiver burnout include active self-care—like eating well, getting enough sleep and exercising—and keeping a consistent schedule, according to Krause.

“When your lives are routinized, you know what to expect and there’s less stress of the unknown,” Krause says. “Remember to make time for yourself—and find reasons to laugh.”

She also suggests that caregivers learn “as much as possible about the medical situation and what dialysis is like, and write it down so you can refer to it when you’re feeling overwhelmed,” she says.

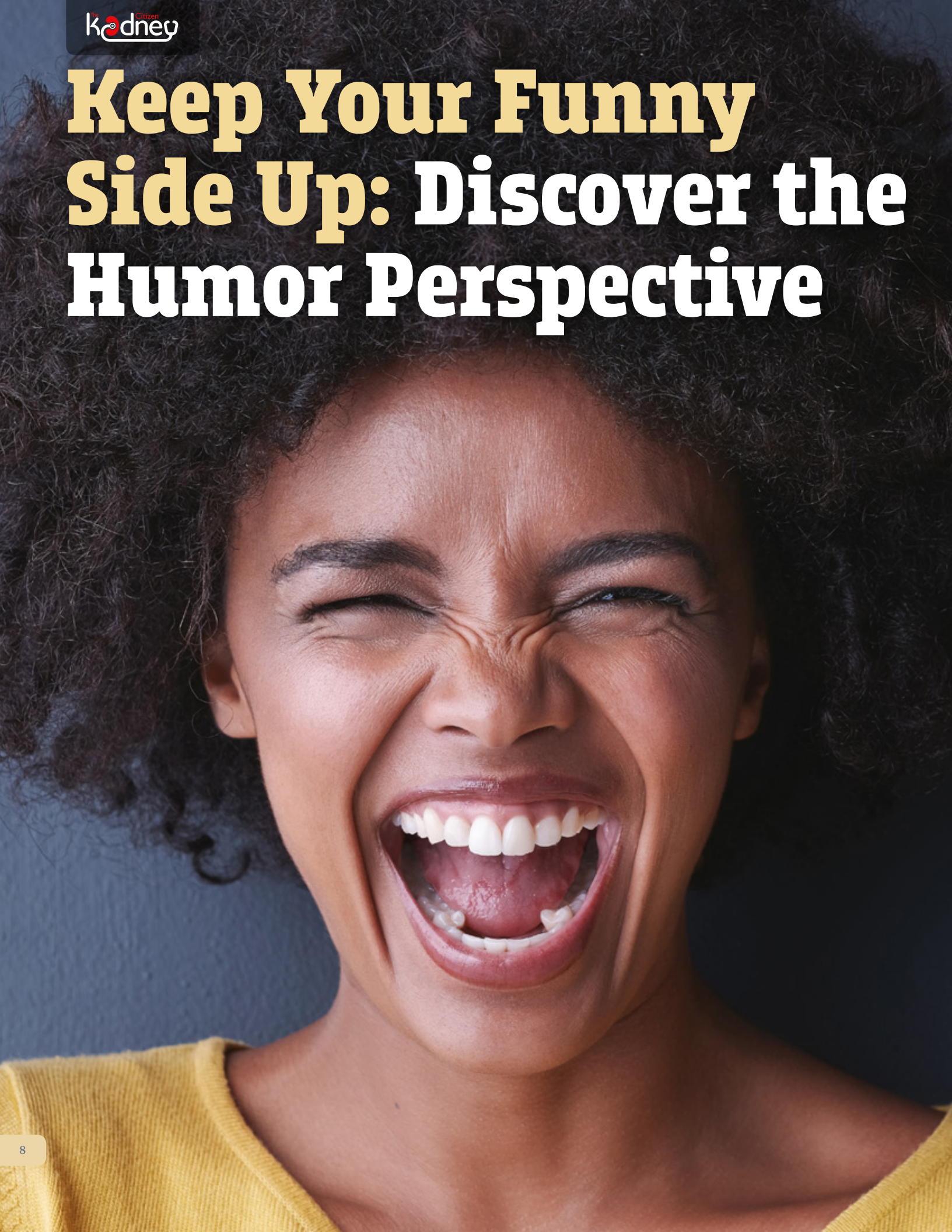


Your relationship may grow even stronger. You will undoubtedly face both physical and emotional challenges while on dialysis, no matter your prognosis. But patients and caregivers often become deeply bonded, and Krause and Geller say that you have the opportunity for growth and even joy through this ordeal.

“These challenging situations can actually bring people closer together,” says Geller. “Patients and caregivers may experience a shift in values after both evaluating what’s truly important in their lives, they may prioritize things in a new way together.”

Hannah Calkins is a writer and editor at the American Psychological Association. This resource was developed jointly by the American Psychological Association and Dialysis Patient Citizens Education Center as part of a partnership to educate dialysis patients and their families on the psychological and emotional aspects of managing kidney disease.

Keep Your Funny Side Up: Discover the Humor Perspective



**By Steve Wilson, Psychologist,
Joyologist, DPC Education
Center Advisory Council Member**

Here's a sobering prediction I came across not too long ago: 52 percent of American executives will die of stress-related illnesses. As a psychologist I know that the emotional tension and stress experienced by those executives will not be caused by the events in their lives. Rather, the stress will be caused by their *perceptions* of those events. It is not *what* is happening to us that hurts; it's *how* we think about what is happening to us.

When you received the diagnosis of chronic kidney disease (CKD), it was a lot to learn about and a lot to take in. Yet, when you attended training to do home dialysis or you received your first in-center dialysis treatment, you probably saw other people with kidney disease laughing and smiling—enjoying their lives. Their perception of living with kidney disease and its treatment helps them to be happy to be alive and to have treatment. You also may have seen people who looked angry that they have kidney disease and have to do dialysis treatments. Their perception may be that life is over, they are worse off than anyone else, and they dread every day. Which perception do you have?

Good News/Bad News

How would you react if you received notice that the post office was trying to deliver an unexpected certified letter to you? If you thought it was *bad news*, like another hospital bill, you would probably react with anxiety: trembling, butterflies or knots in your stomach, increased heart rate and blood pressure, perspiration; in other words, worry and stress. But imagine the letter says that you have inherited a fortune and all your troubles are over. No anxiety. No knots, no trembling, no skyrocketing blood pressure, no worry, no stress. You might even giggle. It all depends on what you *think* (imagine) is going to happen.

You can't control events, but you can learn to control your thoughts and reactions to events.

Control your reactions (keep anxiety manageable) by remembering that every event or situation has many sides, and the sides are not all equally serious. Develop the habit of looking for the less serious sides. Look at all sides of a situation, and you will eventually come to the side that is absurd, ludicrous, zany, or ironic. Find the laughable side of a situation and you will reduce the emotional tension, which is part of your stress.

Humor is a perspective that provides *psychological distance*. It allows you to step back and take a second (or third) look at things. From that psychological distance, troubles don't seem as large, and you can see more of the resources to help solve the problem. Alan Cohen encourages us, commenting that "laughter lifts us over high ridges and lights up dark valleys in a way that makes life look so much better." What are some ways that you make life better even though you have kidney disease?

What Are You Laughing At?

You might try your hand at making up fun descriptions as one way of coping with the tougher parts of dialysis. Some people name their dialysis machine (sometimes as their sidekick) or dress it up. And some people put up funny posters in their "home dialysis room" or watch funny movies while doing dialysis. Here are some "funnies:"

"Why is it called baby-sitting when all you do is run after them?"

"How come the windshield wiper always works better on the passenger side?"

And the Los Angeles Times Syndicate poses this metaphorical question, "Do you ever feel that life is a car wash and you're going through it on a bicycle?"

Do you have additional ones you can share? Send them to us at kniccum@dialysispatients.org.



My Sense of Humor?

To have a terrific sense of humor, you also need a sensitivity about humor. The best comedians make us laugh because they realize that, with the right perspective, almost everything can be funny. You and I need to be sensitive to the fact that laughter can be completely out of place if the timing is wrong. But, the next time life's little foul ups are getting to me, I'm going to see if I can find the comic's perspective and use my wittiness to outwit the dimwits and the nitwits and...RELAX. Humor—getting a joke or figuring out a riddle—involves problem-solving. It puts your brain in gear to make better decisions. After a few chuckles about the less serious side, I can turn my attention more successfully to serious concerns. You can do it, too!

Tell us about a time when humor and laughter helped you through a tough situation, and we'll share them in a future newsletter! Send to kniccum@dialysispatients.org.

Steve Wilson is a psychologist, author, speaker, workshop leader and consultant who helps people and organizations get the absolute most out of themselves while they love every minute of it. He is the Cheerman of The Bored of World Laughter Tour, Inc.

Cooking with Latin Flavors

By **María Eugenia Rodríguez,**
MS, RD, CSR, LND,
Licensed Dietitian Nutritionist

You have probably heard about the importance of eating a low sodium diet. The general recommendation for people with kidney disease is to consume less than 2,000 mg of sodium per day. According to statistics from NHANES 2007-2010, the adult man in the United States consumes 4,240 mg of sodium and the adult woman consumes 2,980 mg.¹ In some South American countries such

as Argentina, Brazil and Costa Rica sodium intakes have been reported between 4,400 and 4,700 mg per day.²

One of the sources of sodium in our diet are the condiments we use for cooking. Many common condiments in Latin American and Caribbean cuisine can be high in sodium. In a study published in February of this year, the amount of sodium in 12 categories of packaged products sold in 14 countries in Latin America and the Caribbean was examined.² The researchers evaluated 16,357 products. The study reported that condiments (n = 1083) was the group with the





highest sodium content among the 12 product categories (median: 7,778 mg/100 g; average: 684 mg/serving). In Puerto Rico, an island in the Caribbean, it is common to use all-purpose seasoning, bouillons, and “sazón” to prepare meats, rice dishes, stews and soups. These condiments are high in sodium.

Reading the nutritional label of the condiments you use for cooking is essential to select the lowest in sodium. A product that has more than 140 mg of sodium per serving is considered high in sodium. In addition to looking at the sodium content on the nutrition label, it is important that you look at the serving size. If you use a portion larger than the nutrition label indicates, you will be using more sodium in the preparation of your food.

One teaspoon of salt has 2,300 mg of sodium. Therefore, use it in moderation. Avoid using salt substitutes because they contain potassium. If you look at the list of ingredients, you will see that the salt substitutes have potassium chloride. Some brands of these substitutes can provide up to 600 mg of potassium in a ¼ teaspoon serving.

There is a great variety of herbs and spices. You can buy fresh or dried herbs in the supermarket or grow them fresh in your home. The spices you will always find dry. Store dry herbs and spices sealed in a dark, dry place in the kitchen. Fresh cut herbs can be stored in paper towel inside a sealable bag in the refrigerator. Dry herbs have a more powerful and concentrated flavor than



Some alternatives without salt or low sodium are:

- Garlic and onion powder • Garlic, onion and fresh peppers • Lemon, lime • Bay leaves
- Cumin • Oregano • Cilantro • Long Coriander • Jalapeño chilis • Hot sauces • Chili powder, cayenne pepper • Paprika, annatto, turmeric • Black pepper • Cinnamon, cloves, nutmeg, vanilla • Ginger • Rosemary, thyme, basil • Vinegar: white, apple, red or white wine, sherry, balsamic • Sofrito: cooking base prepared with cilantro, long coriander, sweet chili pepper • Chimichurri: green sauce prepared with cilantro, parsley, oregano • Garlic sauce: oil and garlic

fresh herbs. Therefore, use a smaller portion of dry herbs than of fresh herbs when cooking.

Once you have them in your home, mix different herbs and spices to create different flavor profiles. Initially, it can be intimidating to use new seasonings, but with practice you will gradually achieve better results in your foods. In addition to adding aroma, smell and flavor to our meals, herbs and spices provide antioxidants, vitamins and minerals to our diet. Dare to use them!

Tell us, what are your favorite condiments? Send to kniceum@dialysispatients.org.

References

1. U.S. Department of Health and Human Services and U.S. Department of Agriculture. 2015 – 2020 *Dietary Guidelines for Americans*. 8th Edition. December 2015. Available online: <https://health.gov/dietaryguidelines/2015/guidelines/chapter-2/a-closer-look-at-current-intakes-and-recommended-shifts/>
2. Arcand, J; Blanco-Metzler, A; Benavides-Aguilar K et al. Sodium Levels in Packaged Foods Sold in 14 Latin American and Caribbean Countries: A Food Label Analysis. *Nutrients* 2019, 11, 369

Cocinando CON SABOR LATINO

Por **María Eugenia Rodríguez,**
MS, RD, CSR, LND,
Nutricionista Dietista Licenciada

Probablemente, ha escuchado sobre la importancia de llevar una alimentación baja en sodio. La recomendación general para personas con enfermedad renal es consumir menos de 2,000 mg de sodio al día. Según estadísticas de NHANES 2007-2010, el hombre adulto en Estados Unidos consume 4,240 mg de sodio y la mujer adulta

consume 2,980 mg.¹ En algunos países de Sur América como Argentina, Brasil y Costa Rica se han reportado ingestas de sodio entre 4,400 y 4,700 mg al día.²

Una de las fuentes de sodio en nuestra alimentación son los condimentos que usamos para cocinar. Muchos condimentos comunes en la cocina latinoamericana y caribeña pueden ser altos en sodio. En un estudio publicado en febrero de este año, se examinó la cantidad de sodio en 12 categorías de productos empacados vendidos en 14 países de Latinoamérica y el Caribe.²





Los investigadores evaluaron 16,357 productos. El estudio reportó que los condimentos (n=1083) fue el grupo con el mayor contenido de sodio entre las 12 categorías de productos (mediana: 7,778 mg/100 g; promedio: 684 mg/porción). En Puerto Rico, una isla del Caribe, es común usar adobo, cubitos y sazón para preparar carnes, arroces, guisos y sopas. Estos condimentos son altos en sodio.

Leer la etiqueta nutricional de los condimentos que usa para cocinar es esencial para poder seleccionar los más bajos en sodio. Un producto que tenga más de 140 mg de sodio por porción se considera alto en sodio. Además de mirar el contenido de sodio en la etiqueta nutricional es importante que mire el tamaño de la porción. Si usa una porción mayor de la que indica la etiqueta nutricional estará usando más sodio en la preparación de sus alimentos.

Una cucharadita de sal tiene 2,300 mg de sodio. Por esto, úsela en moderación. Evite usar los sustitutos de sal ya que contienen potasio. Si mira la lista de ingredientes verá que los sustitutos de sal tienen cloruro de potasio. Algunas marcas de estos sustitutos pueden aportar hasta 600 mg de potasio en una porción de 1/4 cucharadita.

Existe una gran variedad de hierbas y especias. Puede comprar hierbas frescas o secas en el supermercado o cultivarlas frescas en su hogar. Las especias siempre las consigue secas. Almacene las hierbas secas y las especias selladas en un lugar oscuro y seco dentro de la cocina. Las hierbas frescas cortadas las puede



Algunas alternativas sin sal o bajas en sodio son:

- Ajo y cebolla en polvo • Ajo, cebolla y pimientos frescos • Lima, limón • Hojas de laurel • Comino • Orégano • Cilantro • Ecao
- Chiles, jalapeño • Salsas picantes, pique
- Chile en polvo, pimienta roja • Pimentón, achiote, cúrcuma • Pimienta negra • Canela, clavos, nuez moscada, vainilla • Jengibre • Romero, tomillo, albahaca • Vinagre: blanco, manzana, vino tinto o blanco, jerez, balsámico
- Sofrito: base para cocinar preparado con cilantro, recaó y ají dulce • Chimichurri: salsa verde preparada con cilantro, perejil, orégano
- Salsa al ajillo: aceite y ajo

almacenar en papel toalla dentro de una bolsa sellable en la nevera. Las hierbas secas tienen un sabor más potente y concentrado que las hierbas frescas. Por esto, use menos cantidad de la hierba seca que de la hierba fresca al momento de cocinar.

Una vez las tenga en su hogar, mezcla diferentes hierbas y especias para crear diferentes perfiles de sabor. Inicialmente, puede ser intimidante usar condimentos nuevos, pero con la práctica logrará cada vez mejores resultados en sus comidas. Además de añadir aroma, olor y sabor a nuestras comidas, las hierbas y especias aportan antioxidantes, vitaminas y minerales a nuestra alimentación. ¡Anímese a usarlos!

Cuénteme, ¿cuáles son sus condimentos favoritos? Envía a kniccum@dialysispatients.org.



Referencias

1. U.S. Department of Health and Human Services and U.S. Department of Agriculture. 2015 – 2020 *Dietary Guidelines for Americans*. 8th Edition. December 2015. Available online: <https://health.gov/dietaryguidelines/2015/guidelines/chapter-2/a-closer-look-at-current-intakes-and-recommended-shifts/>
2. Arcand, J; Blanco-Metzler, A; Benavides-Aguilar K et al. Sodium Levels in Packaged Foods Sold in 14 Latin American and Caribbean Countries: A Food Label Analysis. *Nutrients* 2019, 11, 369



CALCIPHYLAXIS:

A Rare Disorder That Can Be Deadly for Kidney Patients

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

Calciphylaxis is a rare disorder that affects the smallest of arteries that supply blood to the skin. These vessels, called arterioles, become blocked by deposits of calcium, fibrous tissue and blood clot, leading to a loss of



delivery of oxygen to the skin. As a result, the skin becomes necrotic (dead, black) and may develop ulceration (open sores). Many of these areas of compromised skin then become infected, which can be life-threatening and difficult to treat. Although the process of calciphylaxis is poorly understood, there are risk factors that appear to be common to its development.

Factors that are believed to contribute to the development of calciphylaxis include kidney failure with the associated calcium and phosphorous abnormalities of MBD, elevated PTH levels, treatment with certain preparations of vitamin D, treatment with warfarin (a blood thinning drug), certain inflammatory conditions and high body fat content. Other risk factors include number of years on dialysis, diabetes mellitus, and low blood albumin (protein) levels. Unfortunately, there are very few studies that define the degree to which each of these may increase the risk of developing calciphylaxis.

Dr. Mahoney is the Chief Medical Officer for Lifeline Vascular Care and a member of the DPC Education Center Advisory Council.

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POTASSIUM AND HYPERKALEMIA

By Jessiana Saville,
MS, RD, CSR, LD

Potassium is an important element within the body. For people WITHOUT kidney failure, it helps regulate fluid balance, muscle contractions and nerve signals. When people eat more potassium than their body needs, the kidneys dutifully filter and excrete out any extra through the urine. However, when the kidneys don't work, extra potassium in the blood can build up and lead to a very serious problem called hyperkalemia, or high potassium.

This is why many people on the renal diet receive education about high potassium foods. While they can eat some high potassium foods, eating them in excess or large quantities can be very dangerous.

What Happens If I Get Hyperkalemia?

Years ago as a new dietitian, I remember my first patient with a hyperkalemic episode. After she got out of the hospital, we talked during her dialysis session about what happened. She said that she had woken up one morning and was fully aware she was awake but could not move. Her eyes were open, and she was able to think, but she could not move her mouth to talk, her arms or her legs. She saw her fiancée and family members panicking, calling 911, and taking her to the hospital, but she could not do anything about it.

She was able to recover from the episode and after some dietary sleuthing, we discovered she had been drinking a large quantity of coconut water, which is what had thrown her potassium past a level that her body could handle.

With high potassium levels, people may experience a growing weakness, a feeling of numbness or tingling, nausea, vomiting, trouble breathing, chest pain, palpitations, irregular heartbeats, and in more extreme cases paralysis (like my patient), heart failure, or death.

What Causes High Potassium?

There are many causes of high potassium, although diet is the most commonly one discussed. Other things that can lead to high potassium include excessively high blood sugar levels, certain medications (such as some blood pressure medications), herbs, and some conditions (such as Addison's disease). The following herbs can contribute to high potassium as well and should be avoided by people on dialysis: herbal

supplements, including milkweed, lily of the valley, Siberian ginseng, or Hawthorn berries.

Diet and Hyperkalemia

Food is an important consideration when it comes to keeping potassium levels in line for people on dialysis. There are a couple of different strategies that can help keep potassium intake at a safe level:

1. Avoid bingeing or large portions of high potassium foods and learn what portion sizes will work for you. Lists of “high potassium foods” can vary on the internet, widely because some categorize high potassium as >250 mg, while others categorize high potassium as >150 mg.
2. List of high/med/low potassium foods:

Low Potassium (<150 mg)	Medium Potassium (151-250 mg)	High Potassium (>250 mg)
Applesauce ½ c - 92 mg	Pear 1 med - 227 mg	Milk 1 c - 371 mg
Blueberries ½ c - 65 mg	Orange, 1 med - 237 mg	Black Beans (½ c) - 306 mg
Grapes ½ c - 88 mg	Peach, 1 med - 193 mg	Avocado ½ med - 549 mg
Pineapple ½ c - 88 mg	Peaches, canned ½ c - 160 mg	Banana, 1 med - 467 mg
Raspberries ½ c - 94 mg	Green Beans, ½ c - 187 mg	Nectarine, 1 med - 288 mg
Cauliflower ½ c - 88 mg	Broccoli, boiled ½ c - 165 mg	Pomegranate, 1 med - 399 mg
Onions, raw ½ c - 126 mg	Collards, boiled ½ c - 214 mg	Potato, baked med, 610 mg
Rice, cooked, 1 c - 17 mg	Pepper, 1 whole - 211 mg	Spinach, boiled from raw, ½ c - 420 mg
Lettuce, romaine 1 c - 81 mg	Carrots, boiled ½ c - 177 mg	Peanuts, roasted ½ c - 491 mg
Baby carrots, 5 - 140 mg	Chickpeas, boiled ½ c - 238 mg	Sweet potato, peeled and boiled, ½ c - 302 mg

3. Digging into the details can assist people with making knowledgeable choices. If you are curious about a specific food, you can always look up the actual potassium content by using an app like cronometer.com, the USDA nutrient database, or even in some cases MyFitnessPal. If using an app to look up potassium content, remember that sometimes potassium may be unlisted and show up as “0.” This doesn’t mean the food lacks potassium, it just means that it wasn’t put in the database chart of high, med, low potassium foods.
4. At this time, reading labels for potassium content of food is confusing at best for clients. Due to government guidelines, potassium is required to be listed at this time. However, there are lots of inaccuracies on labels, so be aware that labels listing potassium as “0 mg” may be inaccurate at this time.

What If My Favorite Food Is High in Potassium?

Many people have wiggle room to include at least one serving of a high potassium food in their diet. Your dietitian can be a helpful guide in helping you

figure out how your favorite high potassium foods can fit in your diet.

Another strategy for including some high potassium foods in the diet is to demineralize them. The best way to do that is to double boil them. This primarily only works for starchy vegetables such as potatoes, winter squashes, or sweet potatoes. Soaking removes very little potassium, so if you plan to demineralize your vegetables, double boiling is best.¹

When You Need to Be Especially Careful

There are two situations where people should be especially careful with potassium intake.

1. If you have to miss dialysis for some reason, you should absolutely be especially careful with your potassium intake until you are able to get back to dialysis. Dialysis helps remove some potassium from the blood, so missing dialysis can lead to a buildup of potassium and hyperkalemia.
2. If there is an emergency situation and you do not know when you will be able to dialyze next. In some situations, patients who have been caught in a natural disaster situation (e.g., flood, hurricane, etc.) and are unable to get to dialysis. Or their dialysis center may even be damaged or closed temporarily. If you are in an emergency situation and are uncertain when you will be able to dialyze next, it is wise to stick to only the lowest potassium foods until you have a scheduled treatment.

In summary, hyperkalemia can be dangerous. Becoming familiar with the potassium in foods, learning strategies to remove potassium, and being aware of other contributing factors can help prevent an unpleasant trip to the emergency room or worse. Gaining an understanding of potassium in your diet can also give you more flexibility to enjoy some limited amounts of high potassium foods.

How to leach Potatoes



Jessianna Saville is a registered dietitian, speaker, and blogger about renal nutrition at [kidneyrd.com](https://www.kidneyrd.com). Her practice is built on helping people preserve kidney function and understand the often confusing renal diet.

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By *Daniel Cukor, PhD and
Rajnish Mehrotra, MD, MS*

Many patients find coping with the challenges of hemodialysis (HD) treatment to be demanding, but about one third of patients with end-stage renal disease (ESRD) who are undergoing maintenance dialysis meet criteria for depression. Despite the high rates of depression, many ESRD patients are not receiving treatment for it. One reason that might contribute to the low rate of treatment is the lack of clarity on which treatments for depression are safe and effective for ESRD patients. In the general populations, both cognitive behavioral therapy (CBT) (a form of talk therapy that helps patients learn problem-solving skills and behavioral modification strategies) and antidepressant medicines have been shown to reduce depression. We undertook a study¹ with the primary goal being to compare the effectiveness of CBT and sertraline (an antidepressant medicine) in depressed patients receiving maintenance dialysis. The study was done in patients older than 21 years with ESRD and major depression or dysthymia who were receiving maintenance dialysis at one of 41 dialysis facilities in Dallas, TX; Albuquerque, NM; or Seattle, WA. There were 120 participants in the treatment component of the study.

Patients who were depressed and agreed to take part in the study were randomly assigned to receive either CBT or sertraline. People assigned to CBT had 10 one-hour sessions with a trained therapist over 12 weeks. Standard CBT intervention for depression was modified for the unique challenges of ESRD patients on HD treatment to include education about mental health considerations, adherence with the dialysis prescription, adapting advice about behavioral activation to life on dialysis, and identification and challenging maladaptive thought patterns that may be specific to patients living with kidney failure. The sessions were recorded, and some of them were reviewed to make sure the therapists were doing the treatment as it was intended. CBT treatment was delivered by master's-level study therapists. The therapy was delivered in-person face-to-

**Summary and Discussion
of “Comparative Efficacy of**

Therapies for Treatment of Depression

**for Patients Undergoing Maintenance
Hemodialysis: A Randomized Clinical Trial”**

face while the patient was undergoing his/her hemodialysis treatment. Patients were given a choice to receive therapy at another time, but virtually all chose to receive therapy while undergoing hemodialysis.

Those in the sertraline group were prescribed a dosage of 25 mg per day to start. It was increased gradually to a stable dosage over six weeks, which was maintained for another six weeks. Patients in both groups completed questionnaires to measure depression symptoms as well as other outcomes of interest at baseline and at six and 12 weeks.

After comparing the groups at 12 weeks, depression scores had improved in both the CBT and sertraline groups, with improvement being slightly greater among the patients who received sertraline. However, side effects were more frequent in the sertraline than in the CBT group.

For patients receiving dialysis who are depressed, both sertraline and CBT seem like reasonable treatment options, as they both reduced depression scores. Patients and providers need to discuss the relative advantages and disadvantages of each approach, including patient's preference for treatment and the availability of resources, but either treatment could be the best one for a patient.

Some really important questions about depression treatment still remain. We are not sure if patients had the ability to choose the treatment they wanted (like in regular clinical care), the results would be any different. We also don't know the effect of combining both treatments together. Would more patients benefit from a combined approach? Would depression scores improve even more? Also, we don't know how long the treatment effects will last. As depression normally waxes and wanes, it is difficult to know if these treatments have fundamentally altered depression's course. Finally, the study did not examine how to practically implement these treatment strategies into usual dialysis care.

Despite all of these still unanswered

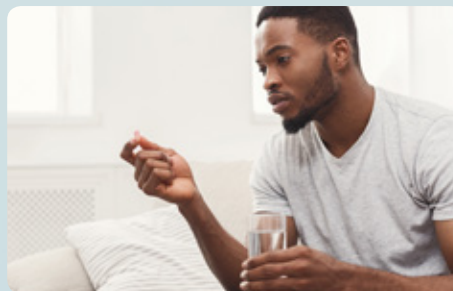


questions, we can offer the following tips to patients:

Get involved in research. We strongly believe that this study benefitted from the significant amount of patient and other stakeholder input that we received over the course of the study. One unique element to this study was the formation of patient and stakeholder councils right at the beginning of our designing the study. We discussed all elements of the study's plans and the study's progress once we got started.

We think that partnerships between patients and the research community are one of the keys to making sure that the most important and relevant questions are being addressed.

Take depression screens. Many dialysis centers have implemented some program to screen for depression. We know you are asked to complete a lot of paperwork, but fill out the questionnaires! Having your center know and document that you are depressed is the first step to getting help.



Consider your care options. Talk with your treatment team about the options for treating your depression. Your social worker can provide counseling and help connect you with local providers. Your nephrologist or primary care doctor may be willing to prescribe an antidepressant or connect you with a specialist.

Don't overthink engaging in treatment. Many folks are not excited to have another doctor appointment, especially if it has to do with mental health. Don't let stigma or bias prevent you from getting the help you need. Pursue treatment—there may be barriers to getting care, but persevere, you will feel so much better once you get help with your depression.

Good feelings tend to spread. While this may seem obvious, people in our studies not only saw improvement in their mood, but both groups also reported reduced anxiety, reduced disability, more energy, improved satisfaction with life and even better sleep.

Daniel Cukor is the Director of Behavioral Health at the Rogosin Institute in Brooklyn, NY. Rajnish Mehrotra is Professor of Medicine at the University of Washington and is section head of Nephrology at the Harborview Medical Center in Seattle.

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Being an Active Member of My Health Care Team

By Reidaone Bourjolly, DPC
Education Center Board Member

When it comes to Chronic Kidney Disease (CKD) and end-stage renal disease (ESRD) there are many reasons to be proactive in your health care. Writing this article is quite therapeutic for me, and I hope it can serve as an eye opener for those who can use it for prevention and for those already living with ESRD.

My newfound knowledge and new love for myself came to me after having to go through what I lived through. *Lived* is the word that stands out to me. Special is the fact that I have the gift of life—my kidney transplant—which also allows me to serve others. My condition taught me how to be a better and educated active member of my health care team. Living through CKD, then ESRD, dialysis, and now a successful kidney transplant has taught me the importance of information. I found myself realizing that I needed to help myself survive this illness because there were so many things I still wanted to do and accomplish, and I wanted to help others.

Being an active member of my health care team took a lot of effort and



support from my family and friends for me to be proactive with my doctors and nutrition choices. The steps I took can help serve as a blueprint for helping ourselves, not only survive, but draw a map on how to move forward. Becoming acquainted and proactive with the path that needs to be taken can lead you toward being blessed with a new road of opportunities toward living and having a quality lifestyle.

We have a chance to work with our doctors in making decisions that work best for our lives. I can't stress enough the importance of keeping records and notes to attack this illness head on. According to science, the chances of survival can be slim without being proactive and having a will to live; arming yourself with information can only add fuel to your courage.

Assembling a binder, titling it, "Beating CKD, ESRD, & Dialysis" and sectioning it off with "Survival Techniques" labels is what I developed for myself to serve as a blueprint to follow. I encourage you to develop your own binder as you go through the journey of this illness.

Section 1: TEAM

After being diagnosed and going through the emotions of denial, shock, heartbreak, and despair, my first section did not come easy. It came after the support, comfort and love poured in from others who were my team. I formed a team. Some members of that team were volunteers, and others were chosen. This section was called *TEAM*, and we all need a support group when trying to advocate for our health. There will be times that you will not have the will power to advocate for yourself. That is when your members will give you that extra push and that occasional reminder that you have more to live for and that you are bigger than your illness.

Section 2: NOTES

Being a good team leader is also admitting to yourself that you may not be as strong as you thought emotionally. I needed to understand what I was dealing with after getting diagnosed. This section is called *NOTES*. I realized after hearing "CKD" come out of my



doctor's mouth that all my listening senses stopped working; it would be like that during my whole process. At times I was able to retain what I heard, and at other times I couldn't remember what had been said to me. That is where section 1 (*TEAM*) came in handy. My brother or my dear friend volunteered to escort me to all my doctor visits, and we both had a notebook to take notes so we could go over what I was told. After each visit, I added these notes to my binder.

Section 3: RECORD KEEPING

I wanted to be a good patient, and I came to the realization that being a good patient meant understanding the course of action my doctor wanted for me. This section of my binder is called *RECORD KEEPING*. In this section I kept a record of all my doctor's information, all the blood work reports, exams, results, and list of medications. Keeping track of these reports is my duty as my own managed care worker. As a good patient, it is not in your best interest to make things difficult for yourself or your specialist. I have learned that not all your doctors will be in communication during your illness, and you will need to bring this information with you to your visits. You will also need to refer to this information for comparison so that you can gain a grasp of what works for

you and what does not. I kept all my report cards given to me by my dialysis nutritionist after blood work was done. By keeping them, I was able to refer to previous months when my numbers were great and months where I received an unhappy face sticker because my phosphorus level was too high. By doing so, I was able to realize where I went wrong with my diet and make the proper adjustments needed.

Section 4: COURSE OF ACTION

COURSE OF ACTION was the name of section 4. With the help of sections 1, 2, and 3 of my binder, I was able to develop a plan. In order to improve the quality of life I had and to not allow ESRD to dictate how long I was going to live, I had to have a strategic plan of attack. There was a war going on against my body, mind and soul. With the course of action I developed in this section, I had faith that I would make it through—even on my most trying days. When developing this section, I realized I needed sub-sections:

Physical Fitness: Prior to CKD, I joined a fitness center and hired a trainer and life coach. With my newfound lifestyle, I lost 50 pounds and was at the best health of my life. I did not know at the time that my fitness trainer prepared me physically and mentally to deal with the news of



having CKD and later ESRD. My healthy lifestyle allowed me to put dialysis on hold for over a year after being diagnosed with CKD and later to easily make adjustments to continue training even on the days I received dialysis. Without this section, I would not be as healthy as I am today.

Nutrition: After my initial diagnosis of CKD, I had to make a few adjustments to my diet. After starting dialysis, there was another set of adjustments that had to be done to have the proper numbers. I needed to get listed on a transplant list with the hospital of my choice. With this section, I was able to insert all the information my nutritionist provided me with along with my own research.

Education: In order to survive dialysis, I had to educate myself. This is also where section 1 and 4 came into action. My team, which included my support members and my life coach, demanded that I set my laziness aside, become aware of what was happening to me and figure out what my odds were to surviving this life-threatening disease. I decided after starting dialysis that I would get a better understanding of my illness and the process of dialysis by enrolling in a dialysis technician course. That way, I would be educated on the process of the dialysis machine and the nurse/technician's role in my treatment. I

wanted to be an active, informed and involved participant in my dialysis treatment. This is what helped me make the right decisions. I also dedicated hours of research pertaining to CKD, ESRD, transplantation and nutrition. Without this knowledge and having faith, I would not have been placed in the proper position to be in charge as a member of my health care team.

Faith and Trust: This chapter in my life has showed me the power of believing, staying positive, and keeping faith. This section is a place I had to refer to often. There were days that were tougher than others physically and mentally, and I needed a place to refer to my notes on those topics. I became more spiritual, and I became acquainted with Bible verses that I was able to use for healing. In this section I had a list of people who I knew I could count on for the extra motivation. I needed to look past my pain and sympathy for myself. These people were my *Prayer Warriors* team. These people were my brother, friends and relatives who knew how to pray and knew the meaning of praying together for a greater purpose. There were times I didn't know how to pray for myself, and these teammates knew the meaning of faith—even when my body was discouraging me.

Transplantation: Being a member of my health care team was not easy

because it also included the part of needing a blessing of what I called receiving a transplant. There are many ESRD patients who need a kidney transplant, and there are also many patients ineligible for a transplant who must continue to receive their treatments through dialysis. The only way to find out if you are eligible is to ask your healthcare team about undergoing a transplant evaluation. A member of my health care team helped me to find out the steps required to get listed. When my family and friends found out I was sick, many of them took time out of their schedule to get tested to be donors. There were times that I found it very difficult to spread the word or ask people to consider doing this life-saving gesture. That is where my team and prayer warriors came into play. During the times that I felt weak, they were strong and knew the importance of asking others and strangers to get tested. It was also my job to find ways to get listed in other states. By acquiring this knowledge, additional people volunteered information toward my effort.

Those are the sections of my binder, and it is always within my reach at home. You may want to add or change the titles of your sections and subsections in order to make it work for you. The binder will help you stay organized and knowledgeable. Additionally, you will find you are adding to it as your treatment changes, as you learn new tips and as new people come into your life.

Advocating for my health did not come without a lot of effort on my part. You can only survive this illness by having a full understanding of what steps to take to improve your quality of life. Being a proactive member of your health care team not only benefits you, it also benefits your family, those who support you, and most of all, those you can pay it forward to. After receiving my transplant, I can say that I have been on many different sides of this illness. The effort I have made to learn how to be an advocate for my health allows me to continue to be a leader for my own health and to teach others to advocate for their health.



CONNECTING WITH OTHERS

Through the PKD Connect Center

By Zseraldina Ferenczi

My name is Zseraldina Ferenczi, and I am the Community Outreach Coordinator at the Polycystic Kidney Disease (PKD) Foundation. I also have the privilege to support the PKD community through our new PKD Connect Center, launched in July 2018. Our PKD Connect team is dedicated to providing patients and families with resources, emotional support and an opportunity to get connected with people who have similar experiences. With PKD Connect, no one faces PKD alone. PKD Connect staff understand that patients, family members or friends impacted by PKD sometimes need advice, encouragement or a shoulder to lean on from someone who knows firsthand what you're going through. We offer a variety of services, so no one will ever have to face PKD alone.

One such service is the PKD Connect Mentoring Program. This peer-mentoring program delivers excellent patient-centered support intended to help people manage their conditions by connecting them with mentors from similar life circumstances or with similar health conditions. Whether you or your loved one has just been diagnosed or

is getting ready for dialysis or a kidney transplant, PKD Connect mentors are here to listen to concerns and share their own experiences and perspectives. PKD peer mentors are carefully selected and trained experts who can provide support, guidance, education and ideas for improving and managing their mentees' overall health. PKD Connect mentors are a valuable part of the PKD Connect Team who can empower their mentees to move forward with their lives after being diagnosed with PKD. Mentors also encourage mentees to control and manage their health in a way that will allow them to live a longer and happier life. Risa Simon, one of PKD Connect's outstanding mentors, has had a long battle with PKD. In 2010, she secured her own preemptive living donor transplant, and now she dedicates her life to inspiring others. This is what she wrote: *"My purpose is to give back what my mentor gave to me. I hope to help PKD patients believe in themselves and the possibility of a better tomorrow. I'm here to encourage them to become their own best advocate, bypass dialysis, and execute strategies to find potential donors."*

Our HOPE line offers callers general information about PKD and access to resources to help address concerns. The 800-PKD-HOPE (753-4673) number is

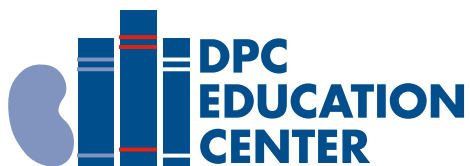
What is PKD?

According to the PKD Foundation, "polycystic kidney disease (PKD) is a genetic disease (passed from an affected parent to their child) causing uncontrolled growth of cysts in the kidney eventually leading to kidney failure. It affects all racial and ethnic groups equally". A geneticist, which is a physician with special training in genetics, can help evaluate, diagnose, and manage PKD. Genetic counseling will be helpful to understand the role of genetics in PKD.

a patient support phone line that anyone affected by PKD can call. Whether people are looking for emotional support, resources, or are seeking help with long-term survivorship, PKD Connect staff is available to help.* The PKD HOPE line is available between 8:00 a.m. and 5:00 p.m. Central time, Monday through Friday.

Through PKD Connect, I hope everyone impacted by PKD will find support and encouragement to fight PKD and live life knowing that you are not alone.

**The PKD Connect is an information and referral line and is not staffed by clinical professionals. It does not provide medical services, diagnosis, treatment recommendations or laboratory test analysis. Its staff can only provide information based upon published materials that have been approved by the PKD Foundation's Scientific Advisory Committee.*



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Apply for DPC's 2020 **Advocacy Day**

We are very fortunate that we are able to bring dialysis patients to Washington, D.C. each year to meet with their elected officials. This provides advocates like you with the unique opportunity to make your voice heard on behalf of dialysis patients from your state in order to improve dialysis care.

Visit dialysispatients.org and apply by 12/13/19 to be considered for DPC's 2020 Advocacy Day. Selections will be made based on application quality, legislative priorities and prior involvement in DPC.

