

# kidney living<sup>®</sup>

Fall 2016

Issue 16

**BE THE MVP  
OF YOUR  
HEALTHCARE TEAM**

PUT YOUR  
**BEST FOOT**  
FORWARD

**REDEFINING  
NORMAL**



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# kidney living®

A MAGAZINE FOR PEOPLE ON DIALYSIS

## GOODBYE SUMMER! HELLO HOLIDAYS!

Eight years ago my husband and I started dialysis. Since that time, I've been home raising our two children, but haven't worked outside of the house. This year, I decided that I needed to get back into the workforce and prepare myself for a new kidney (I'm finally on the transplant list) and a new way of life. Going back to work has been great for me! My new job consists of teaching young kids the importance of eating healthy and how they can accomplish this on a budget. With both my husband and I being kidney patients, I know how important nutrition is. Not only has this been a great professional opportunity, but it's also been very personally rewarding.

In this issue, you will learn courage and strength from others who face what we face every day. This issue also talks about the importance of eating healthier around the holidays, taking care of your feet, and preventing falls this winter.

Have an awesome end of your year! I hope you enjoy a wonderful holiday season as well!



*Candria Denzmore*

Candria Denzmore, Patient Editor

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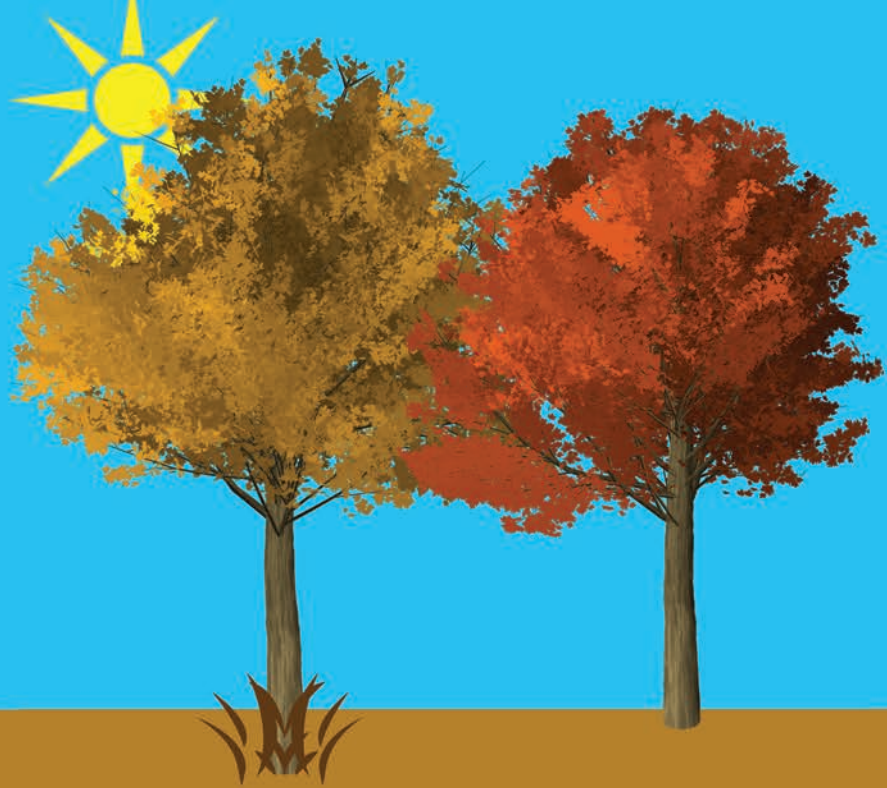
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# WHEN FALL COMES

By Frances L. Carey

When fall comes it brings with it a lovely scene  
That I admire more than in the spring  
Trees do lose their leaves of a green monotone  
But find a sense of color all their own  
A prism of colors on display  
A work of fine art in every way



## in this issue

4

### Putting out fires.

Patients often have more than one battle to fight. Kidney patient, Shawn Booker, is putting out fires while fighting his own kidney disease.



5

### Step up!

Let's talk feet. Tips for keeping your feet healthy.



9

### Kidney Kitchen

Fall favorites and healthy Thanksgiving tips!

13

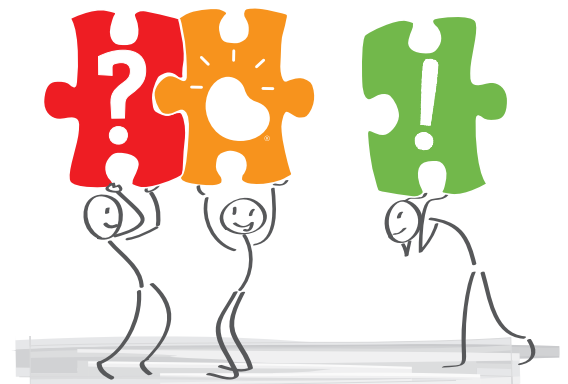
### Ask Your Healthcare Team

I'm nervous about falling. How can I prevent falls?

14

### Kidney Living Voices

Do you feel like you're a part of your healthcare team? Why or why not? What do you find to be the best way to communicate with your healthcare team?





## TEAM LEADER



# Fighting **fires** while on dialysis

As a lieutenant firefighter in Knightstown, Indiana, Shawn Booker knows what it's like to be part of a team—especially in times of crisis. He spends his days leading his crew as they respond to emergencies and work together to fight fires and save lives.



Shawn Booker on duty

Shawn is also a fighter in his personal life as he battles kidney disease. The diagnosis first came as a shock. Shawn was always active and fit. He even served in Desert Storm before heading to college. Despite his excellent physical condition, he was diagnosed with kidney disease at the age

of 21. By 23, he was on dialysis. After 4½ years on dialysis, he was fortunate enough to receive a kidney transplant, which lasted for 16 years.

Shawn, who is now 45 years old, has been back on hemodialysis for the past three years and

goes for treatment three times a week before heading to work at the fire station. Dealing with kidney disease and being on dialysis has shown Shawn that teamwork is just as important when it comes to taking care of his health as it is guiding the fire department. Shawn has a great relationship with his healthcare team and meets with them regularly to let them know how he's feeling – especially if he notices any changes. Since Shawn's job requires so much physical and mental strength he needs to be at his best and his medical team helps keep him there!

Though he admits working after dialysis is not always easy, he knows his limits. On dialysis days, he doesn't fight fires and leans on his crew a little more for help around the firehouse. Shawn continues to be a strong leader and an example for all members of his crew. He makes sure to take care of himself and continues to exercise regularly. As he jokes, he needs to make sure he *"keeps up with the younger guys"*.

# Put your best **FOOT** forward

*By Jay Schnitzer, DPM, FACFAS, FABPM, Associate Professor  
of Podiatric Medicine and Surgery, Temple University;  
Kidney Transplant Recipient*

Unfortunately, poor self-care and over-the-counter remedies have contributed to an increase in infections, delayed healing, and poor outcomes leading to amputations and worse. As a podiatrist (foot doctor), I see a lot of kidney patients. Many people know people with diabetes are at high risk for foot problems, but did you know the risk of developing a foot ulcer is just as high for those on dialysis? If you are diabetic and on dialysis your risk is even higher.

Having a foot ulcer can become a serious problem leading to infection, gangrene, and even the need for an amputation. A major risk factor is peripheral arterial disease which causes poor circulation in the legs. Having heart disease also increases one's risk. Nerve damage (peripheral neuropathy) can result in numbness of the feet which can make it harder to feel a foot injury. The skin of the feet can become dry and more prone to injury. Having a low albumin and high phosphorus levels in the blood can also contribute to one's risk.

As a kidney patient myself, I truly understand the frustrations of dealing with this disease. I hope these tips help you keep your feet healthy so you can continue to stay active and let your feet get you where you need to go—wherever your journey takes you!

Corns, calluses, blisters, and dry skin are all “foot problems” that you may have been able to take care of yourself in the past. If you are on dialysis, you probably realize it's not as easy anymore.

## KEEP YOUR FEET HEALTHY

- ALWAYS wear socks and DON'T walk barefoot, especially outside.
- Buy shoes that fit your foot well.
- Watch out for excessive cold in the winter and hot surfaces in the summer.
- When bathing, test the bath water with your elbow first to make sure it's not too hot.
- For dry skin, apply lotion to the top and bottom of your feet avoiding between the toes.
- Avoid using sharp objects on your feet such as a razor blade to help shave off dry skin or pins to pop blisters.
- Check your feet daily washing them with mild soap and warm water and drying them carefully, especially between the toes.
- Look for changes such as redness, cuts, blisters, and swelling. Be sure to check the bottom of your feet using a mirror if necessary or ask a family member to help.
- Areas of concern should be promptly treated and let your healthcare team know right away of any issues you are having.



*Being proactive and taking care of your feet has been found to reduce the risk of amputation. The skin is an important part of your body's defense. It protects you from infection so keeping your skin healthy is very important.*

# REDEFINING MY NORMAL

## WITH COURAGE AND GRACE

*By Celeste Castillo Lee*



I have been a kidney patient for more than 35 years and have experience with hemodialysis, peritoneal dialysis, and transplant.

I have seen many changes over time in the care of kidney patients. No matter what life has thrown at me, I have always taken it one day at a time and treated each day as an adventure. I was diagnosed with a rare autoimmune disease at 17. From a young age I have been invested in my care. I had the privilege of a team of professionals who partnered with me, some of whom continue to follow my condition to this very day.

Throughout these years, I have had to redefine my “normal.” I have seen the positive impacts of research and new medicine on patient care. I was on dialysis before medicines like erythropoiesis-stimulating agents (ESAs) were available. Many of us suffered from debilitating anemia that made us feel incredibly tired, cold, and drained of energy. Medicines like ESAs were game changers, and greatly enhanced the quality of life of dialysis patients!

When I first started dialysis, I was in high school and faced scary health issues that none of my peers had to face. As my journey with kidney disease continued into college, I was thrilled to have the miraculous gift of a kidney transplant, which lasted for 10 years. It was very difficult to lose the kidney transplant, say goodbye to my donor’s kidney, and face dialysis again. However, with the support of my family and friends, I was able to continue working, creating new memories and experiences, all while being reliant on dialysis once more.

Despite kidney disease being a part of my daily life for almost as long as I can remember, I strive to not let kidney disease define me completely. When I talk with my peers on dialysis, or anyone who lives with chronic illness, I share with them that people with kidney or chronic disease can still lead productive and meaningful lives. Dialysis is time-consuming, but it shouldn’t stop you from living! For the last 35 years, I have fought kidney disease while going to college, getting married, being a step-mom, becoming a dedicated patient centered advocate, and maintaining a successful professional life. I am a health system administrator, and have been responsible for developing and designing patient-centered care for academic medical centers. I work with researchers and health professionals by



helping them to operationalize patient engagement in research, clinical practice and education. This work has been the greatest calling of my life, and provides me with some of my deepest happiness.

In 2006, I was diagnosed with Nephrogenic Systemic Fibrosis (NSF). NSF is a rare disease affecting skin, muscle, and other organs. It has been found in some patients with advanced kidney disease after their exposure to gadolinium-containing contrast dyes used in magnetic resonance imaging (MRI). NSF is very painful and debilitating. It is one of the greatest medical challenges of my life. Symptoms and signs of NSF for me include hardening of the skin, joint stiffness, and muscle weakness. The symptoms have gotten worse over time and affect my hands and legs, making it more and more difficult to walk and move my hands.

Then, this past November I took a very bad fall, breaking my sternum, rib cages, right-shoulder blade, and back. Apparently, the long term side effects of steroids and dialysis had taken their toll on my bones; what once helped me has turned into an enemy. Because of my high antibodies from my previous transplant and numerous blood transfusions, I have been waiting for a second transplant since 1992. A devastating consequence of the fall and injuries is being removed from the transplant list, which I learned about earlier this year. The development deprived me of the hope I was holding onto for 24 years and the news took me some time to process. The hard reality is that I am not eligible for another transplant. The more difficult part is mourning the loss of hope.

As a result of my fall last year and the NSF, my ability to walk, move, or breathe is a constant struggle. Also, my independence and autonomy are in question. My spirit that helped me soar in the face of adversity in the past is now facing the ultimate test. I have always been able to fit dialysis into my life and find its meaning in providing me with a quality life. But now this is becoming a trial



*Despite kidney disease  
being a part of  
my daily life for  
almost  
as long as I can  
remember,  
I strive to not let  
kidney disease  
define me.*


as I begin to depend on others for some of my most basic needs. The independence I have always known is disappearing and I worry I may never gain it back.

Because of my professional and personal history, I recently reached out to my doctors and requested a palliative care consult. I know that when some people hear "palliative care" they think of hospice and terminal illness. However, I have learned that palliative care is so much more. It affords me a new team of healthcare professionals dedicated to focusing on alleviating my pain and managing my symptoms. Together, we work with my existing healthcare team to make sure that everyone is on the same page and that I am getting the care I need from my dialysis treatments as well as the pain relief I need to cope with

daily activities. We also set goals together so that every day is not an overwhelming challenge, but rather that I'm able to find joy in each day.

I won't lie. I constantly struggle with my "new normal." Currently, I miss the independence of being able to work full time, travel, drive my car, take a shower alone, and put on clothes. I have come to truly understand the isolation and loneliness severe illness brings, but I have also chosen to focus on all the good things in my life: my husband, my family, my friends, and my calling. I've been able to stay active as an advocate for patients in the kidney community.

In addition to helping address my symptoms and pain, my palliative care team and I have had very real and candid discussions about stopping dialysis. For me, this is an option that I am glad to have if the pain or burden on my life becomes too great. However difficult these discussions are, they also are incredibly valuable to me and my family. They have brought us even closer and I feel that I am not alone as I face whatever it is that lies ahead. I take each day as a blessing – another chance to make a difference. I continue the process of redefining my "normal" and try to focus on the reality with courage and grace.



# BIOLOGIC vs BIOSIMILAR drugs

## What You Need to Know

If you get an erythropoiesis stimulating agent (ESA) to treat anemia (low red blood cell count), then you are getting a biologic drug. This means that the ESA was made from the building blocks of living things like plants and animals (“bio” means “life”). Biologic drugs are very complex and cost a lot to make. This can make it hard for many people who need a biologic drug to get it. But now, the United States Food and Federal Drug Administration (FDA) is allowing drug companies to make biosimilar drugs. “Similar” in the case of biosimilar drugs means that the drug should be so much like the original biologic drug that it is as safe and effective.

Making a copy of an original biologic drug is somewhat like making a copy of a simple drug. But because both biologic and

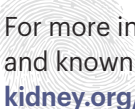
biosimilars are made from living things, there are always some differences in each batch. These differences are small and should not, by law, affect drug safety or efficacy. So, the same way you can buy a cheaper store brand of aspirin (generic drug) instead of a brand name aspirin, you can buy a cheaper biosimilar drug. It should not be cheaper because of less quality, but because costly research on how to make the original drug has already been done.

Biosimilars have been used for many years in Europe and other countries with success. Problems with biosimilars happened most often in countries with poor control over how the drugs were made. However, the FDA has been very careful to ensure that companies follow tough rules for making biosimilar drugs safe and effective.

**The FDA is currently reviewing two new biosimilar ESAs for use in dialysis, so if approved, you may be getting a biosimilar to treat your anemia in the near future. Some questions you should consider asking your healthcare provider:**

- Are there going to be changes in my ESA medicine? Ask your healthcare team to let you know about any planned changes in your drugs before they are made.
- What is the name of the new medicine? Write it down so you can update all your medicine lists at home and for your other medical providers
- Are there any known reactions or side effects?

Just like generic drugs, biosimilar drugs will allow more people to get the care they need. As with any type of drug, however, patients and healthcare teams need to first be aware of safety. This means stopping or fixing reactions and side effects right away. You should always ask what drugs you are getting and why. This is no different when it comes to biosimilar drugs. Be sure to let your healthcare team know how you are feeling after any changes in your medication.



For more info about biosimilars and known side effects visit:  
[kidney.org/kidneyliving](https://www.kidney.org/kidneyliving)



# be thankful this fall for a healthier thanksgiving

*By Heather Shenk*



**Many holiday celebrations focus on food, but none more so than Thanksgiving.** For people whose health situations require them to alter their diet, the holiday can become a source of anxiety. This sentiment could not be truer for the thousands of Americans who are on dialysis. Although some people may choose to take a “holiday” from their diet, the reality is that any time certain foods are eaten in large enough quantities (holiday or not), you could be jeopardizing your health.

There are ways to alter a Thanksgiving feast slightly (or for those who are interested, to a greater degree) so that those on dialysis can partake and not have to fear any repercussions. Whether you are a dialysis patient or have a dialysis patient attending your holiday festivities, the information that follows can help shed some light on how to make the day enjoyable for all.

# SIMPLE WAYS TO change up

## YOUR THANKSGIVING MEAL

The big three things to watch in a kidney diet are SODIUM, POTASSIUM, and PHOSPHORUS. All must be limited in between dialysis sessions to help avoid health issues. An overload of potassium can be very dangerous, and even result in death. There are simple things that can be done to make favorite dishes better options for people on dialysis:

- Use unsalted butter instead of salted. The savings: 90 mg of sodium per tablespoon!
- Make your own chicken stock. The stock can be used to make stuffing, gravy, etc. By making your own stock, you will be saving lots of sodium and possibly potassium and phosphorus, depending on what additives are in the prepared broth that is typically used.

make the stock



A few days ahead, place some chicken in a stock pot or a crock pot with water, some onion, some white wine vinegar and spices (thyme, bay leaf, parsley, rosemary, sage – or any others preferred). Cooking the chicken for a very long time makes for a broth that is dark and flavorful. *Note:* make sure the chicken doesn't have any added sodium in it (or worse yet, sodium phosphate, which equals phosphorus) or the stock will as well.

- Choose fresh turkey over frozen. Frozen turkey has much more sodium than fresh. Depending on other additives used during the brine before the turkey is frozen, there may be sources of unnecessary potassium and phosphorus. If you make your gravy from pan drippings, the gravy will have less sodium as well.
- Watch the sodium content of the bread used to make stuffing. If making bread from scratch without salt is not possible, choose a variety of white bread that has about 100 mg of sodium per slice. If you choose to make the bread from scratch, reduce or omit the salt and add spices you'd typically use in the stuffing to add flavor.
- Use egg whites in stuffing instead of whole eggs. Egg yolks have quite a bit of phosphorus in them. Using the egg whites adds the necessary binding to the stuffing for a good texture and keeps the phosphorus lower.

Green beans are a very good choice for people on dialysis. Add cider vinegar or dill when cooking for extra flavor.



- Serve green beans. Try steaming them and adding a tablespoon of cider vinegar or dill to the water for extra flavor. Green beans are relatively low in potassium and very low in phosphorus. They are a very good choice for people on dialysis. Typical holiday green bean casseroles, however, should only be eaten in very small quantities because of the other ingredients. Other traditional holiday vegetables (such as lima beans, winter squash, and corn) aren't as good of a choice for dialysis patients.
- Consider serving a rice or pasta dish like risotto instead of, or along with, mashed potatoes. Potatoes and sweet potatoes are very high in potassium and should only be eaten by people on dialysis in very small quantities. Potatoes can be leached to remove some potassium, but doing so changes the taste and texture. Mashed potatoes also have cream, milk, or some type of dairy product in them, which is a source of phosphorus. Simmer risotto in home-made chicken stock, unsalted butter, and desired spices (include lemon juice, for a nice kick) for a tasty alternative that everyone can enjoy.

## FALL RECIPES



## Stuffed Pumpkin Meatloaf

Makes 4 servings

## INGREDIENTS

## Meatloaf:

- ¾ cup cooked pureed pumpkin
- ½ cup oats
- ½ cup flour
- 2 tbsp. finely chopped white onion
- Water, as needed

## Filling:

- 1 tsp. olive oil
- 2 tbsp. grated onion
- ½ cup chopped spinach
- 2 tbsp. cooked chickpeas
- 2 tbsp. chopped peeled tomatoes
- 1 tbsp. lemon juice
- ½ tsp. pepper

## DIRECTIONS

1. Preheat the oven to 350°F.
2. In a large bowl, stir the pumpkin, oats, flour, and 2 tbsp. chopped onion. Mix well and set aside for 15 minutes. If the mixture becomes dry, add a few drops of water and knead well.
3. In a large skillet over medium heat, add oil and sauté 2 tbsp. grated onion for 3 minutes.
4. *For filling:* transfer onions to a large mixing bowl and add spinach, chickpeas, tomatoes, lemon juice, and pepper. Using a spatula spoon, mix all the ingredients well.
5. Divide the meatloaf mixture in half. Knead one of the halves to lay flat on the bottom of a 4" deep baking pan, approximately 4" width by 7" length.
6. Lay the filling on top of the meat layer and spread evenly with a spatula spoon.
7. Knead the second half of the meatloaf to cover the filling and mold evenly.
8. Bake 15-25 minutes or until top layer is crisp and golden.

## ANALYSIS

Calories: 162  
 Carbs: 26.4 g  
 Fat: 1.8 g  
 Protein: 10.5 g  
 Sodium: 78.3 mg  
 Potassium: 260 mg  
 Phosphorus: 100 mg

Knowing the sources of potassium, phosphorus, and sodium that are in the building blocks that make up a meal, and altering them even slightly, can make for healthy changes for people on dialysis. Consider making some changes, or at the least preparing a side dish that you and your loved ones can enjoy without worry.

## HOW TO LEACH VEGETABLES

1. Peel and place the vegetable in cold water so they won't darken.
2. Slice vegetable ⅛ inch thick.
3. Rinse in warm water for a few seconds.



4. Soak for a minimum of two hours in warm water. Use ten times the amount of water to the amount of vegetables. If soaking longer, change the water every four hours.
5. Rinse under warm water again for a few seconds.
6. Cook vegetable with five times the amount of water to the amount of vegetable.





## Chicken and Rice Pilaf

Makes 12-1 cup servings

### INGREDIENTS

#### Beef:

½ cup white onion, chopped  
1 pound ground beef  
1 tbsp. allspice  
1 tbsp. seven spices  
½ tsp. pepper

#### Chicken:

1 pound skinless chicken breast

#### Rice:

2 cups low-sodium chicken stock  
⅓ cup white rice (uncooked)

#### Garnish:

1 tsp. olive oil  
1 tbsp. slivered, roasted almonds  
2 tbsp. raisins

### ANALYSIS

Calories: 173	Sodium: 53 mg
Carbs: 15 g	Potassium: 187 mg
Fat: 4 g	Phosphorus: 101 mg
Protein: 18 g	

### DIRECTIONS

1. In a large skillet over medium heat, add onions. Cook for about five minutes. Add the beef, allspice, seven spices, and pepper. Cook until beef is brown.
2. Fill a large pot with water and bring to boil. Add chicken breast and cook until tender.
3. Transfer chicken to a large mixing bowl and run under cold water. Shred chicken into pieces.
4. In a large pot, bring chicken stock to boil, then add rice. Cook for 10 minutes, then add beef mixture and shredded chicken. Cover and cook over medium heat for 15 more minutes, or until rice is cooked.
5. In a small skillet over medium heat, add olive oil. Sauté almonds and raisins for 3 minutes.
6. Serve chicken and rice warm. Top with almonds and raisins as garnish.

## Black Bean Burger

Makes 6 servings

### INGREDIENTS

2 cups black beans, cooked  
½ cup diced yellow onion  
1 tbsp. chopped garlic  
2 tsps. fresh parsley, chopped  
1 large egg  
½ cup ground pita chips  
1 tsp. black pepper  
1 tsp. allspice  
⅓ cup canola oil  
6 hamburger rolls  
Lettuce

### DIRECTIONS

1. In a food processor, mix black beans, onion, garlic, parsley, egg, pita chips, black pepper, and allspice.
2. Divide the mixture into six pieces. Lightly wet your hands. Carefully roll the mixture into balls, each about the size of a tennis ball. Set the palm of your hand and gently squeeze down to flatten into patties.
3. In a medium nonstick skillet over medium heat, add canola oil.
4. Place the patties in the skillet. Cook for 5 minutes, then flip them and cook for 5-7 more minutes.
5. Enjoy on a burger bun with lettuce.

### ANALYSIS

Calories: 284	Sodium: 490 mg
Carbs: 48.3 g	Potassium: 410 mg
Fat: 6 g	Phosphorus: 124 mg
Protein: 11.8 g	





## QUESTION:

I am concerned about falling. Is there anything I can do to prevent this from happening?

*By Melinda Martin-Lester, RN, BA, CNN, CHC*



**ANSWER:** Each year, one in every three adults age 65 or older are treated in the emergency room for a fall related injury. Patients with any type of chronic illness, such as kidney failure, may have a higher risk of falls, due to the chronic condition or medicines they may be prescribed. The long term consequences of falls such as hip fractures or brain injury, can impact the health and independence of already chronically ill individuals.

Falls are not inevitable and can be prevented with appropriate actions. Many organizations have programs and tips to prevent falls. Here are some suggestions from the Centers for Disease Control and Prevention (CDC):

**EXERCISE** Lack of exercise can lead to weak legs, which can increase the chances of falling.

**KNOW YOUR MEDICINES** Some medicines (or combinations of medicines) can have side effects such as dizziness or drowsiness. This can make falling more likely. Review your medicines with your healthcare practitioner or pharmacist to reduce the risk of side effects and possible drug interactions.

**KEEP YOUR VISION SHARP** Poor vision makes it harder to get around safely. Have your eyes checked yearly and have your glasses evaluated to ensure you are seeing clearly.

**ELIMINATE HAZARDS AT HOME** About half of all falls happen at home. Try to remove obstacles such as loose rugs, clutter, and poor lighting. For home dialysis patients, be sure to clean up any fluid leaks promptly and keep tubing out of the way of common walkways.

**EVALUATE HOME SAFETY** Install lights and handrails on staircases; put grab bars inside and next to the tub or shower and next to the toilet. Use non-slip mats in the bathtub and on shower floors.

**WEAR APPROPRIATE FOOTWEAR** Avoid going barefoot or wearing loose slippers. Make sure your shoes have a non-slip, sturdy sole.

**GET UP SLOWLY** Some people have a drop in blood pressure when they stand up too quickly after laying down. When getting up at night or after a nap, sit up on the side of the bed for a bit before standing. If you feel dizzy or light-headed, don't stand up.

# ARE YOU A TEAM PLAYER?



My healthcare team is like a NFL team. I am the general manager who is, ultimately, responsible for results. The nephrologist is the quarterback, the dialysis nurse is the running back, the dietitian and the social worker are on the offensive line. We have regular meetings to evaluate results and fine tune the game plan for the next game. Our goal is to stay healthy enough to win the Super Bowl with a successful kidney transplant. *Jim E.*

I felt like I was a part of my nephrology office's family. They all knew me by face - did not even have to tell them my name when checking in. I was with the office since I was first diagnosed with IgA back in 2007. We just recently moved out of state, not only did I have to say goodbye to my family and friends but also my kidney family as well. Being in a new state, I feel very disconnected from my new kidney office. I hope over time this will change; but for now I am missing my old team. *Brianne*

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My healthcare team is like an NFL team. I am the general manager... the nephrologist is the quarterback...the dialysis nurse is the running back...and the dietitian and the social worker are on the offensive line.

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I have been on dialysis for 2½ years and I must say that my healthcare team is not only knowledgeable but very caring. I would advise everyone to make an effort to get to know your team on a personal level the best you can. Get to know the machine settings for your particular prescription. Know why they are this way for you – and when anything changes – ask why. Understanding this and why and how your team is doing it will give you a much better feeling of security. My team goes out of their way to educate me. This not only strengthens the bond between myself and my team, but also gives me the confidence to travel, knowing I understand my prescription, the settings, and why they are where they are. In addition, I know I can pick up the phone at any time and communicate with my team from the road if needed. I believe an honest relationship between you and your team is vital to live a fruitful lifestyle on dialysis. I am a part of my healthcare team and thankful for it. *Carl M.*

I learned quickly with kidney disease that you need to be your own advocate. You know yourself better than anyone - so don't be afraid to speak up. I am always reading up on the latest news and asking a bunch of questions, whether it be to the dialysis staff or the transplant team. Even in today's very tech savvy world, I still think the best way to communicate with my healthcare team is face to face. *Anjelica L.*



The way to be an active member of your health care team is to TALK TALK TALK!!! Ask questions; tell your team your concerns. Ask about what you don't understand. NOTHING is unimportant if you don't know the answer. Communication is the best way to be involved in your care. *Mary C.*



DO YOU  
LIKE YOU  
PART OF  
HEALTH  
TEAM

One must be proactive to be involved especially when interacting with members of the team. Ask questions: What are you doing? Why? Is that essential? Is there an alternative? How do my numbers look for the past week? Be curious. Get involved. *Mary B.*





My healthcare team became my reason to get up in the morning and go for treatment.

I would say that I am the conductor of my orchestra healthcare team. I ensure that everyone is kept in the loop with results from doctor appointments, bloodwork, scans, and more by emailing and faxing multiple doctors and their nurses/administrative assistants at once.

Typically I feel disconnected from my “team”. I have found that you really need to spend a lot of time making sure information is shared among various doctors. In short, I do not feel as connected as I could be. Medical professionals always seem rushed for time. They are so busy they typically spend about 10-15 minutes on an office visit, but the patient typically spends about 1-2 hours of travel & wait times to get to them. *Steve*

I feel like I am part of the healthcare team. I always ask questions, and I make sure I understand in my own way of thinking what is going to happen to me or how my kidneys are working. I believe the key to becoming a real part of the healthcare team is taking charge in your own healthcare. If you’re unsure of something, ask questions. If you feel uncomfortable asking too many questions or feel that your healthcare provider doesn’t have the time for you, standup for yourself and take charge. Become a self-advocate! *Bryant*

DO YOU FEEL  
YOU’RE A  
PART OF YOUR  
HEALTHCARE  
TEAM?



Yes, I am part of the team. The more I communicate concerning my illness, the team communicates with me. I keep myself informed by reading, asking questions, and talking to other patients about their treatments, and how dialysis has affected their lifestyle or work habits. *Thelma T.*

If I have any questions I make sure and write them down. If I need to have any of my prescriptions renewed I let the staff at the center know. The best and easiest thing to do to make dialysis easier for you is to be COMPLIANT with the doctor’s orders. *Caspar R.*

Yes, I feel a part of my dialysis treatment. Peritoneal dialysis is the dialysis treatment best for me. I meet monthly at the dialysis clinic with my health care team to discuss topics like: labs, medications, diet, life issues, mental health, etc. I feel strong, empowered, and a part of the decision making process. *Andrea S.*

I feel part of my healthcare team most of the time. When I first went on dialysis, I had no one to talk with who was going through the same thing. My healthcare team became my reason to get up in the morning and go for treatment. The team is always upbeat. If one person is having difficulty with the needle, another member of the team will jump in to help out. Without the positive attitudes of my team, my dialysis would be a difficult chore. *Barbara A.*

I honestly find that the best way to communicate with the majority of my doctors is through the healthcare portals and work email addresses that were given to me from specific doctors. The best way to communicate is to make sure everyone is on the same page! *Mary*

You must look out for yourself in conjunction with working with your health care team. If you feel that there is something missing or something that is not right you need to speak up and let your healthcare team or their supervisors know. Remember that your care is a team effort and you are part of that team. *Keith C.*

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