

# kidney **living**<sup>®</sup>

Spring 2016

Issue 14



**SPRING!**

WHAT IS YOUR  
FAVORITE ACTIVITY?

**PROTEIN**

YOU NEED MORE  
THAN YOU THINK

SHARED DECISION MAKING

GET  
INVOLVED!



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## kidney living®

A MAGAZINE FOR PEOPLE ON DIALYSIS

### CHANGING OF THE GUARD!

Please join us in welcoming our New Editorial Board! First, we would like to thank our previous Editorial Board for their hard work over the last four years, making *Kidney Living* such a success. We look forward to this new team contributing their own points of view, experience, and knowledge as we continue to bring you inspiring stories and information you need to live well on dialysis.

We value the positive feedback and responses we receive from our readers. You continually inspire us! We invite you to share comments and suggestions for future topics.

Also, did you know that March was Social Work Month? We encourage you to join us in celebrating all nephrology social workers for the outstanding work they do every day to improve lives.

Thanks for reading!



Best,

*Kelli Collins*

Kelli Collins, MSW  
Senior Director of Patient Services

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weighing in on  
your favorite

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# sleep

## how it impacts **kidney health**

A good night's rest is extremely important to your overall wellbeing and, it turns out, your kidneys.

Researchers already know that there's a link between sleep deprivation/sleep disorders and higher rates of diabetes and cardiovascular disease. Now, the link between shut-eye and kidney function is becoming clearer, too.

With the support of a Young Investigators Grant from the National Kidney Foundation, Dr. Ciaran McMullan, MD, of Brigham and Women's Hospital is studying how sleep impacts the kidneys and whether more sleep and melatonin supplementation can improve kidney function.

"Kidney function is actually regulated by the sleep-wake cycle. That cycle helps coordinate the kidneys' workload over 24 hours," Dr. McMullan said. "We also know that nocturnal patterns can affect chronic kidney disease and that people who sleep less usually have faster kidney function decline. What we're doing now is looking at the specific hormones that may be behind these declines."

Dr. McMullan's research will take a closer look at melatonin secretion, which is the hormone our bodies produce naturally to sync our nocturnal functions. As part of the study, healthy participants will have their sleep restricted and their hormone levels and kidney function measured.



*Kidney function is actually regulated by the sleep-wake cycle.*

*Dr. Ciaran McMullan, MD*

The study will also include people who are habitually sleep restricted and will ask them to sleep longer hours to see if it affects their physiology, blood pressure, blood glucose levels and kidney function. Half of this group will also be given melatonin supplements to see if that impacts their kidney function over time.

"So not only are we looking at people's sleep patterns, we're trying to see if there may be some interventions that can be taken by people with sleep deprivation," Dr. McMullan said.

By better understanding how the kidneys work and interact with our hormones at night, this research might also help determine better nutrition guidelines and optimized times for medication delivery. This is because the kidneys' ability to process medications and nutrients like sodium and potassium changes between day and night.

The study could identify new groups of people who are at higher risk for developing chronic kidney disease due to their lifestyle or work schedule, for example, those who work in shifts and those with chronic sleep deprivation issues.

"It pays to recognize these issues as risk factors because it means these individuals may need more aggressive kidney disease screening and blood pressure management," McMullan said.

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# DIALYSIS DATA trends

The United States Renal Data System (USRDS) collects data on all patients on dialysis in the U.S. Each year USRDS releases an annual data report. This year's report reveals some interesting findings and new trends:



More people are being diagnosed with **kidney failure**.



The size of the dialysis population increased 4% in 2013, reaching 466,607, and is now **63.2% larger than in 2000**.



People on dialysis and with transplants are **living longer!**



**Fewer deaths** were reported among dialysis and kidney transplant patients in 2013, dropping by 28% and 40%, respectively, since 1996.



**More people** are on home dialysis – 52% more than a decade ago.



**A family history** of kidney disease is a risk factor. Tell your family to check their kidney health with two simple tests – urine and blood!

“Overall trends for end-stage kidney disease are promising for those affected,” says Rajiv Saran, MD, professor of internal medicine at the University of Michigan Health System and director of the USRDS coordinating center. “Patients on dialysis are living longer and equally positive, survival rates have steadily improved among recipients of both living and deceased donor kidney transplants.”

While the report highlights several positive trends, Saran mentions it's important to also consider areas where improvement is needed.

“Several lifestyle-related chronic health conditions, such as diabetes, high blood pressure and other cardiovascular diseases can contribute to kidney disease,” Saran says. “Monitoring and early treatment of those conditions are key to prevention, and can help patients keep their kidney disease under control.”

Saran mentions that the data report continues to emphasize the low awareness of kidney disease in the general population, as well as the fact that rates of screening for the condition by simple urine testing remain low, even among those with risk factors for the disease.

“Awareness of this silent, but deadly killer may help prevent those with early-stage kidney disease from progressing,” Saran says. “Learning more about risk factors for the disease and early diagnosis are of vital importance as symptoms of kidney disease develop much later.”

*Adapted from the University of Michigan Health System.*

# shared decision making



it matters for dialysis patients

By Caroline Wilkie

**I**f you are on dialysis, you have benefited from the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines. These are a series of best practices for health care professionals who diagnose and manage care for those with kidney disease.

NKF recently released an update to KDOQI's guidelines for hemodialysis. This update is important because it increases emphasis on having patients share decisions about our own dialysis care with our physician. This is called "shared decision making" and it allows us to work with our healthcare providers to make dialysis care decisions together. It takes into account not only the best scientific evidence available, but also our values and preferences as well.

I'm 30 years old, and I've been on dialysis since March 2010. From an early age, I have been an active participant in my dialysis treatment and made decisions with my healthcare team. Here, I have outlined some of the tips that I think are important for people on dialysis to know when it comes to shared decision making.

## SHARED DECISION MAKING: IMPORTANT TIPS

### RESEARCH YOUR OPTIONS.

Doctors and nurses only have so much time, so you have to accept some responsibility for your care. You need to be proactive to seek out the best treatments. Learn as much as you can about your condition and how it is managed. Some patients don't want to be involved, while other patients simply assume their healthcare team is giving them the best options. You won't know for sure unless you research your options.

### SQUEAKY WHEEL GETS THE GREASE.

Establish a working relationship with your healthcare team and don't be afraid to push back if you don't understand a decision or are not totally on board with how your treatment is progressing. Speaking up is the only way to make the changes needed to live the best life possible on dialysis.

### ASK QUESTIONS.

Ask questions from day one. Give yourself a goal to ask a new question every day. Personally, I would take a notebook to write things down so I would remember the questions I had and the answers I received. You'd be surprised how knowledgeable you become in a short period of time.

### YOU CONTROL YOUR CARE TEAM.

If you don't feel like you're getting the care you need, find someone new and get a second opinion or even a third opinion. Sometimes personalities don't mesh well together, so it's important that you work with someone you can trust and work with in an honest and open way.



*Doctors and nurses only have so much time, so you have to accept some responsibility for your care.*





## My dietitian says: eat more *protein, protein, protein!*

I try to be healthy and to eat fresh fruits and vegetables every day.

### WHY IS PROTEIN SO IMPORTANT?

**3oz =**

the size of a deck of cards,  
a medium pork chop,  
a ¼ pound hamburger patty,  
½ chicken breast, or  
a medium fish fillet.

**1oz =**

1 egg or  
¼ cup egg substitute,  
¼ cup tuna,  
¼ cup ricotta cheese, or  
1 slice low sodium lunch meat.

A low-protein diet has been shown to be healthy for much of the general population. You may even have been on a low-protein diet to limit the amount of waste products in your blood before you started dialysis. But when you are on dialysis, you actually need MORE protein in your diet.

So why do you need more protein when you're on dialysis? When the dialysis machine filters your blood and removes toxins and fluids, it also removes some good nutrients too, including protein. Imagine a strainer. When you pour pasta and water through the strainer, the pasta stays and the water passes through. But think about how big the holes are. If you included chopped onion with the pasta, some may be small enough to pass through too, even if this is not what you intended. This is what happens when the dialysis machine filters your blood. Molecules like protein that are small enough to pass

through the filter are removed from your blood.

Your healthcare team will look at your serum albumin in your monthly lab report to see if you are getting enough protein. A low level of albumin in your blood may be caused by not getting enough protein and calories from your diet. A low level of albumin may lead to health problems, such as difficulty fighting off infections.

Eating the right amount of protein is important. Generally it's recommended that people on dialysis eat a high protein food (meat, fish, poultry, fresh pork, or eggs) at every meal, or about 8-10 ounces of high protein foods every day.

Protein affects your overall health and how well you feel. Your body needs the right amount of protein for building muscles, repairing tissue and fighting infections.

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*Even though peanut butter, nuts, seeds, dried beans, peas, and lentils have protein, they are generally not recommended because they are high in both potassium and phosphorus. Ask your dietitian how to get the right amount of protein and calories in your diet.*

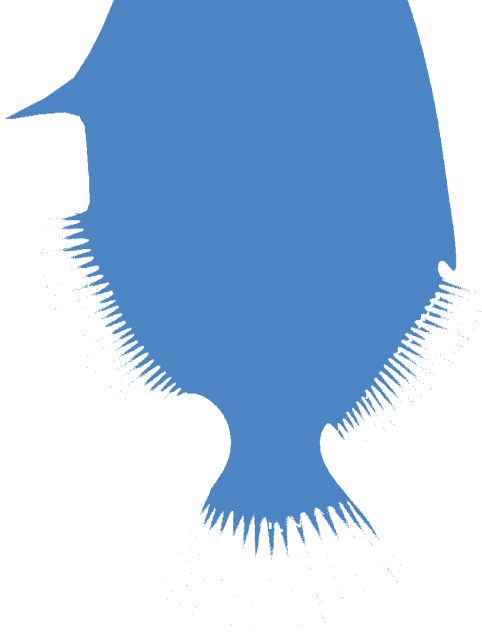
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# Spring Fling

Recipes for warmer weather



## Fillet of Sole with Lemon and Chive Sauce

Makes 8 servings

### INGREDIENTS

2 tbsp chopped chives  
2 lemons  
6 tbsp fat free margarine  
2 lbs sole fillet

### DIRECTIONS

Preheat oven 350°F. Grease baking dish. Check fish for any bones.

Melt margarine in a saucepan; then lightly brush fish with it. Squeeze lemon juice from half a lemon over fish. Cover with foil and bake for 30 minutes.

#### While fish is baking:

Combine remaining lemon juice, margarine and chives in a sauce. Stir and keep warm until fish is cooked. Pour sauce over fish and garnish with lemon slices. Divide into 8 equal servings.

### ANALYSIS

Calories 112	Carbohydrate 3 g
Total fat 1.9 g	Protein 21.6 g
Cholesterol 56 mg	Calcium 1 mg
Potassium 45 mg	Phosphorus 0 mg
Sodium 156 mg	

## Ginger Roasted Chicken with an Asian Slaw

Makes 6 servings

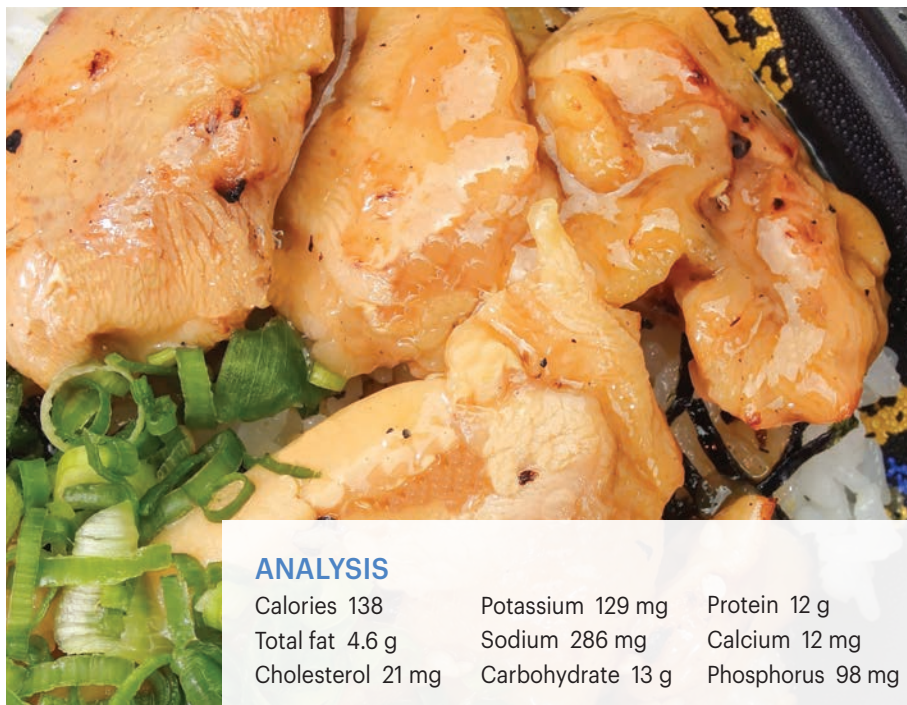
### INGREDIENTS

1 tsp honey  
1 tsp lemon juice—fresh  
 $\frac{3}{4}$  tsp garlic  
1 tsp dijon mustard  
1 large red delicious apple  
 $\frac{1}{4}$  tsp dry mustard  
 $\frac{1}{8}$  tsp five-spice powder  
1 green onion or scallion  
3 tbsp ginger paste  
2 tbsp vegetable oil  
 $\frac{1}{2}$  tsp salt-free lemon pepper seasoning blend  
 $\frac{1}{2}$  tsp salt free thai or oriental seasoning  
 $1\frac{1}{2}$  pound boneless, skinless chicken breasts  
2 cups shredded cabbage – red  
2 cups shredded cabbage – green  
 $\frac{3}{4}$  tsp sesame oil  
2 tbsp unseasoned rice wine vinegar

### DIRECTIONS

**For chicken:** Mix five spice powder,  $\frac{1}{2}$  tsp Thai or oriental seasoning, lemon pepper seasoning, pre-packaged ginger paste, garlic, and 1 tbsp rice vinegar into a paste. Place chicken breasts (3 breasts and cut in half) in an oiled baking dish. Spread the seasoning over the top of the chicken breasts and bake in a preheated 350°F oven for 45 to 55 minutes or until the chicken is cooked completely without becoming dry. Drizzle  $\frac{1}{2}$  tsp sesame oil over top of chicken before serving.

**For Slaw and Dressing:** Mix dry mustard, 1 tsp oriental seasoning, lemon juice, 1 tbsp rice vinegar, honey, vegetable oil,  $\frac{1}{4}$  tsp sesame oil and dijon mustard together and microwave for 20 to 30 seconds to warm dressing. Mix cabbage, apple (cored and diced) and green onions (sliced) in a bowl. Pour warm dressing over the cabbage mixture, toss to coat with dressing, cover and refrigerate for several hours. To serve chicken, place on top of salad.



### ANALYSIS

Calories 138	Potassium 129 mg	Protein 12 g
Total fat 4.6 g	Sodium 286 mg	Calcium 12 mg
Cholesterol 21 mg	Carbohydrate 13 g	Phosphorus 98 mg



## Beef Burritos

Makes 6 servings

### INGREDIENTS

1 lb ground beef  
(95% Lean Meat / 5% Fat)  
½ cup tomato sauce  
(no salt added)  
½ cup chopped onion  
¼ teaspoon cumin  
¼ tsp ground black pepper  
6 flour tortillas

### DIRECTIONS

Lightly brown the beef in a skillet and drain if necessary. Add tomato sauce, onion, pepper, and cumin. Fill each tortilla with approximately 2½ ounces of filling and roll up. Turn bottom edge under before rolling so the meat mixture doesn't fall out.

### ANALYSIS

Calories 242	Carbohydrate 26 g
Total fat 6.3 g	Protein 20.5 g
Cholesterol 47 mg	Calcium 9 mg
Potassium 304 mg	Phosphorus 152 mg
Sodium 388 mg	



## Tuna Croquettes

Makes 4 servings

### INGREDIENTS

2 tsp graham cracker crumbs  
1 pinch black pepper  
4 tbsp light mayonnaise  
2 slices white bread, broken into pieces  
1 small onion, chopped  
1 can white tuna – canned in water

### DIRECTIONS

Drain and flake tuna. Mix in onion, bread, mayonnaise and pepper. Divide into four portions. Roll in cracker crumbs. Bake at 450°F for 20 Minutes.

### ANALYSIS

Calories 224	Carbohydrate 10 g
Total fat 8.4 g	Protein 26.4 g
Cholesterol 83 mg	Calcium 80 mg
Potassium 542 mg	Phosphorus 258 mg
Sodium 94 mg	

## MORE RECIPES

ON YOUR PHONE,  
TABLET, OR COMPUTER!

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# LIFE + DEATH

## Committee

By Nancy Hewitt Spaeth

My kidneys were failing. It was 1966 and I was 18 years old. Only a few beds were available at Eklind Hall in Seattle, the first outpatient dialysis center in the world. There was a committee that chose the patients for dialysis, called the Admissions and Policy Committee or, as named by Life magazine, the “Life and Death Committee”. Would I be one of the chosen ones?



**B**ack in 1958, I was stung by a swarm of bees while at summer camp in the Cascade Foothills. I was 10. It turned out to be a life-changing day. The next year, after starting the seventh grade, my urine was brown and I was taken to the doctor. Mom was told that I had kidney disease most probably caused by an immune response to the toxins from the bee venom.

Life became difficult and confusing. I was taken to the Children's Hospital in Seattle, about 40 miles south of our home, staying several weeks in the hospital for treatment. It was thought at the time that jiggling or jostling the kidneys would cause further harm. One of the treatments was large doses of cortisone to suppress my immune response and inflammation. This led to weight gain and facial swelling. My clothes didn't fit. Loneliness consumed me as I sat in the bed playing with puzzles or waiting for my brothers to come visit.

However, being chronically ill didn't stop me from loving high school and making good friends.

I graduated from high school and left in the fall for the University of Arizona, lived in the dorms and joined a sorority. Life was going well even as I faced some health challenges. On campus, finding low sodium food was difficult and walking to classes took all my energy, so my brother bought me a small motorcycle that I could ride around campus to my classes. Wow, this renewed my spirit, blowing through campus and giving rides to my friends.

And then I got worse. My feet began to swell and a few weeks into the second semester, I grew weary of vomiting in the planter boxes outside my physics class. My doctor said I needed to go home, that I was too sick to stay at school. So, with tears flowing down my face, I packed up my things, said goodbye to my roommates, sorority sisters, and boyfriend, and carried my giant panda bear up the stairs and onto the airplane. Mom picked me up at the airport and took me straight to the hospital.

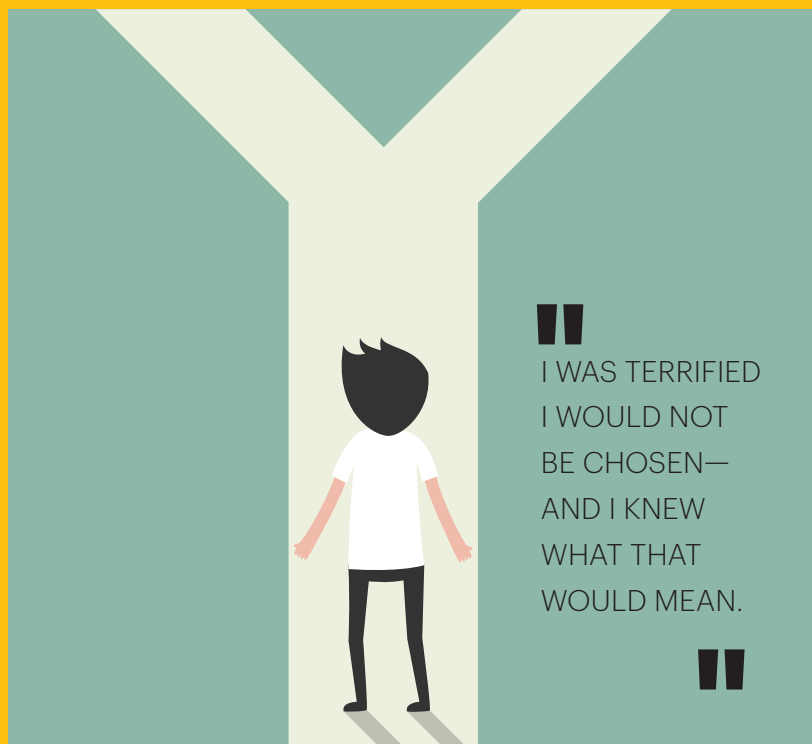
#### **Back at home, boredom and loneliness surrounded me.**

Missing school spurred me to apply to the local university. School made me feel happy and productive. Buzzing around on my Honda 50 motorcycle through the trees and beautiful spring blossoms lifted my spirit. I felt thankful to be active

and functioning. **My kidneys continued to fail but I was told little because I was not yet 21 and my family kept much from me.** Kidney failure is insidious, progressing slowly and not showing major symptoms until late in the disease.

Meanwhile, dialysis was starting in Seattle. Dr. Scribner, my doctor, had invented a device, later called the Scribner Shunt. It was placed in the inner lower arm. A tube was put into the artery and another into a vein. The tubes both came out near the wrist and connected together, forming a U shape that was covered with gauze wrapped around the arm to protect it. This invention made dialysis possible by creating a permanent access to the blood. It allowed blood to flow through the artificial kidney and be cleaned of the toxins, which healthy kidneys did constantly.

*continued.*





I AM GRATEFUL  
THAT I'M DOING  
WELL ON THE  
16<sup>TH</sup> YEAR OF MY  
FOURTH TRANSPLANT.



*Left: Nancy Hewitt Spaeth is an inspiration to our community.  
Above: Nancy on dialysis, 1967.*

A dialysis center was opened at Eklind Hall. There were only so many beds and a limited amount of funding. An anonymous committee was formed to select patients. Applicants had to have deteriorating, chronic renal failure, be stable, emotionally mature, and without other medical complications. They had to live in Washington and have money or insurance to help with costs.

Although my medical records showed that I had no medical issues except for kidney failure and my mom had good insurance with the state, I was terrified I would not be chosen - and I knew what that would mean. I'm not sure I can put into words how many emotions ran through my head. My family worried for me too. It was a very difficult time for all of us as we waited for a decision that would change my life.

In the fall of 1966, I moved in with my brother Jim and sister-in-law Wendy. My family was there for me and remained supportive. Just before Christmas, my Scribner shunt was placed in my left arm. My dialysis began at Eklind Hall on December 26. I had been chosen.

By January 1967, 34 patients were being dialyzed, 29 in the center and five at home. I was one of the 34, and within 18 months, I was doing dialysis at home, three nights a week for eight hour runs, on a Kiil kidney which had to be disassembled and rebuilt each week. I finished college and started my first job during these years.

Now, nearly 50 years since I first started dialysis, I realize how lucky I was to have lived in Seattle and to have had Dr. Scribner guiding me. I am so grateful that I am still doing well today, on the 16th year of my fourth transplant.

**In 1972, a law was passed that provided insurance coverage for nearly all Americans with kidney failure. This marked the end of "life and death committees". NKF was instrumental in the passage of the legislation - an End Stage Renal Disease (ESRD) benefit within Medicare. While Medicare covers medical care for the elderly and disabled, the ESRD benefit was, and continues to be, the only categorical coverage for any disease in the U.S. This federal program marked the beginning of an ongoing government relations component to the NKF's service and research mission.**



# DO YOU HAVE A FAVORITE SPRING SPORT OR ACTIVITY?



Have you had to modify your exercise routine due to dialysis?

I love bowling, dancing and learning something new. I am nervous about going back to bowling because of the weight of the ball but I am slowly going back to dancing. After 1½ years of eating right and helpful medication, I am working on getting better balance by attending some swing classes and also working on strengthening my leg muscles and mind by going back to school and taking a class. —*Ernestina P.*

Since starting dialysis it is hard for me to do much. But in the spring once the weather warms up and the paths are clear, I walk. I have other health problems too like a bad back but walking is the one hobby/exercise I love to do and I try to at least join a few 5k's each year for special causes. —*Stephanie G.*

I stay an active member in the game of baseball. I help coach high school baseball and it helps me feel good to be on the diamond. I'm still going strong after 72 years. —*Buck*

I enjoy riding my road bicycle. I can ride up to 20 miles on fairly flat routes without challenging my health the next day. If I exercise each day, I sleep better during my nightly peritoneal dialysis treatments. —*Jim E.*

My favorite activity in the spring is walking and riding my bicycle. Dialysis only interferes in that I often don't have the energy on treatment days to bike and hike but that comes and goes. —*Devon O.*

While on dialysis, I felt sick all the time, so my activity was more limited than before, but I forced myself to keep walking, especially in the woods. Now that I have had a transplant, I am hiking mountainous terrain for half days with my friends and loving it! —*Terry M.*

In the spring, my wife and I kept busy traveling to our grandchildren's softball, baseball, and karate. We also have a farm four hours away and spend a lot of time there in our pecan orchard grafting, removing trees, trimming trees, and stacking and burning brush. —*Derryll W.*

In 2009, I got peritonitis which turned into septic shock – I probably should have died, but I didn't! I had to go on hemodialysis and it was then I decided to start swimming. It made everything easier! I went slow but within a year I was swimming a mile a day before dialysis 3x a week! I worked up to doing 9,000 crunches and walking 7 miles a week. —*Ron K.*

I was told not to push myself too hard and to limit my lifting to ten pounds when using the arm with the access in it. —*Hughes*

My favorite spring time activity is watching my hometown baseball team the Detroit Tigers! I enjoy weekend games on a Saturday. To attend the game I rearrange my dialysis day and/or time. Luckily my dialysis center is very accommodating! —*Kristen*

I've always had a passion for playing sports. Basketball and baseball were always my favorite sports to play growing up. Luckily for me I was offered a head coaching job coaching junior high basketball and baseball at the high school I graduated from. It was a blessing in disguise and 6 years later I'm still coaching and loving every minute of it. —*Jason O.*

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