SIDE EFFECTS
COPING WITH THE EFFECTS OF DIALYSIS

HOW WELL DO YOU WANT TO FEEL?
QUALITY OF LIFE

DELICIOUS SUMMER RECIPES
THAT EVERYONE WILL LOVE
If you ask a person what they most want out of life, the response will almost always be something like “to live life to the fullest,” “to achieve my goals,” or “to enjoy my life.” It is no different for those with kidney disease. With a renewed emphasis on patient empowerment and partnering with your health team, living a normal life is more possible than ever before. As a member of the Kidney Living editorial board as well as being both a nurse and a former home dialysis care partner for my husband, I can attest to that fact firsthand.

This issue of Kidney Living emphasizes how to have the best quality of life. Turn the pages for articles about choosing the best dialysis modality, recipes even non-kidney patients will love, tips for organizing medical information, dealing with dialysis side effects, and more.

Quality of life is unique to each person. It may mean employment, community involvement, volunteerism, hobbies, travel, marriage and family, school, socializing with friends, or a host of other personal goals. My husband did all those things and more. Together, we lived the life we had envisioned. You can too!

Denise Eilers, BSN, RN
Professional Editor
What’s in this Issue?

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NEW RESEARCH CAN HELP PATIENTS DECIDE

When you first learned that you would have to begin dialysis, you may have thought about which type — hemodialysis or peritoneal dialysis — would work better for you. Or, your healthcare provider may have recommended a certain kind of dialysis, based on his or her opinion and experience. Depending on a person’s specific needs and lifestyle, one type of may be a better fit than the other.

The National Kidney Foundation is involved in a current 3-year research project to learn what is most important to kidney patients when choosing between different kinds of dialysis. The research is called Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT), led by the Arbor Research Collaborative for Health. The goal of the project is to empower patients to make fully-informed decisions about their treatment options.

Researchers interviewed more than 180 people with kidney disease to learn about their experiences before and after starting dialysis. Patients provided valuable insights, and one patient noted “Having kidney disease, actually, affects me emotionally more than it affects me physically... it’s always on my mind.”

Initial results show that some of the most important factors to patients include maintaining independence, quality of life, and flexibility in one’s daily schedule. The results also show differences among different groups of people. For instance, maintaining independence and quantity and quality of life were more important to kidney patients who had not yet started dialysis, compared with patients already on hemodialysis or peritoneal dialysis. Men who were interviewed for this study placed a greater value on quantity and quality of life, and the ability to go to work or school, while women valued spending time with other patients at a dialysis center more highly.

When this research is complete, at the end of 2015, a website will be developed by the research team to help patients and their families choose the treatment option that is right for them.

The Patient-Centered Outcomes Research Institute (PCORI) awarded funding to Arbor Research Collaborative for Health to conduct this research in partnership with the University of Michigan, Henry Ford Health System, the American Association of Kidney Patients (AAKP), and the National Kidney Foundation (NKF).

Learn more at http://choosingdialysis.org
Dialysis has saved countless lives around the world, but researchers believe we have yet to unlock its full potential.

Dr. Sahir Kalim, a nephrologist at Massachusetts General Hospital, has dedicated his career to discovering ways to improve the lives of individuals with kidney failure, and finding therapies that could work more like healthy kidneys.

“Typically, routine hemodialysis only replaces a small fraction of normal kidney function, leaving some patients with an overload of metabolites that can contribute to adverse health effects,” Dr. Kalim said. “Additionally, dialysis itself can deplete patients of essential nutrients such as amino acids (building blocks of protein), further exacerbating poor health.”

Supported by a Young Investigator Grant from the National Kidney Foundation, Dr. Kalim is investigating amino acid supplementation in patients on dialysis.

Currently, some patients who cannot take food by mouth receive amino acid solutions through an IV for nutrition. Dr. Kalim is studying whether similar amino acid solutions can benefit others on dialysis.

“By receiving an amino acid supplement on dialysis, people may experience improvements in their health,” Dr. Kalim said. “They may also feel better and could live longer lives.”

Dr. Kalim plans to publish initial results of his study later this year. He hopes these results will lead to larger studies that can have a direct impact on medical practice.

After publishing his work, Dr. Kalim will continue to investigate therapies that could improve the lives of those on dialysis, focusing on metabolic imbalances that contribute to complications in kidney patients.

“I hope to continue determining which nutrient losses or toxin builds up are most important in patients on dialysis, and how we can fix these imbalances to improve health,” he said. “I also hope in the future we get better at slowing the progression of kidney diseases and improving dialysis to better simulate native kidney function.”

Dr. Kalim is supported by a Young Investigator Grant from the NKF.
DO YOU WANT TO
FEEL BETTER?

By Evelyn M. Watts, MSW, BSW

Medical advice and information flashes across television screens, fills newspaper columns and personal blogs, and dominates many social media newsfeeds on Facebook and Twitter. We put our trust in medical gurus like Dr. Oz, and follow their ideas and suggestions for health and wellness.

Yet, when we have face-to-face office visits with our primary healthcare provider and other medical specialists, such as the kidney healthcare team, who provide us with actual physical evaluations and tests for diseases, we don’t always follow through with their recommended courses of treatment. When we find ourselves at this crossroad, we need to ask ourselves—do we really want to feel better or not?

Why is it so difficult for some of us to carry out a medical plan of care? Are there changes we can make to feel better now and over the course of our lifetime? To answer these questions, I interviewed a dialysis patient who took an introspective look at what was keeping him from reaching his lifelong personal and health goals.
J.R. has been on dialysis since 1991 and has never missed a day of dialysis treatment. But he didn’t always follow his healthcare team’s recommended course of treatment. J.R. agreed to be interviewed so I could learn more about his choices and what he has learned over the years.

**EVELYN WATTS:** You have not missed a dialysis treatment since 1991. How come?

**J.R.:** I want to live a long life. If I am sick and cannot go to my dialysis unit, I call them to let them know and reschedule my treatment. If it’s after hours or the weekend, I go to the hospital’s emergency department.

**You stay for your full treatment. Why do you not cut your time short?** When I first started on dialysis, I used to cut my time short, but it caught up to me. I started to feel bad physically. What I didn’t realize was that I was hurting myself all along by cutting my treatment short. Damage was being done even though I couldn’t always feel it. I stopped cutting my time short. I wanted to feel better and take care of myself more than I wanted to save time.

**Taking medication regularly is important for all patients. Do you take your medication as prescribed and why?** Yes. I don’t like taking pills, but I know if I don’t, I will not be able to control my blood pressure or phosphorus. I ask questions about why I need a medication, but once I am satisfied with the answers, I will take my prescriptions correctly.

**Do you follow your kidney diet and fluid intake and if so, for what reasons?** Yes. I track my fluid and food intake using a food guide. This helps reinforce making healthy food choices within my dietary parameters because I don’t like it when I cannot breathe because I decided to drink too much fluid or when I itch due to phosphorus overload. My food guide helps hold me accountable for what happens to me as a result of what I eat or drink.

**Being on dialysis for a lifetime can cause people to be depressed. What strategies do you use to help you cope with kidney disease?** I never gave up my hobbies. I stay connected to my loved ones by joining in with their activities when I can. I do not isolate myself from my family. It brings me a lot of joy and pleasure to be with them.

**Your treatment time is 4 hours. On days that you have trouble sitting in the chair, but stay for the whole treatment anyway, what do you do to help pass the time?** Sometimes I read. Sometimes I watch TV. I realized a long time ago that sitting in a dialysis chair for 4 hours enables me to live well.

**Responsibility is a choice. What is the “payoff” for following the treatment plan you created with your healthcare team for dialysis, your diet, and medication regime?** Better quality of life! Who wants to feel sick all the time?

Going forward, the single most important question to ask oneself is — *Do I want to feel better or not?* Let’s tell ourselves every day — with help and our will to live — I can feel better!
I’ve been told by several doctors that life expectancy on dialysis is on average 5-10 years. But I have been on dialysis for 31 years nonstop and without a transplant. I’ve had one fistula and 5 grafts in my arms. A graft in my thigh is what I use now. I’ve had it for 15 years. I walk with a cane, but I still get around pretty well.

I’ve always been a positive person. I smile all the time. I greet and speak to people I come across. Most of the time when you walk around a dialysis unit, you notice that everybody sleeps and it’s very quiet. You can change the whole atmosphere of a dialysis unit by smiling and starting conversations with everyone. You’ll probably be surprised at how many people love the interaction and actually want to talk. I honestly think my positive attitude is the reason I have lived this long on dialysis. I always ask my doctor: “Will I live 10 more years?” and she always replies “Why not 20?”

So, I’m looking forward to living a long and happy life. When I first started on dialysis I thought it was the end of my life and I actually wanted to die. When I didn’t die and realized I didn’t have to, I started listening and paying attention to my doctors. I just wish I would have exercised more when I was told to earlier on, but for now I do what I can — walking as much as possible and always with a smile!

Attitude is everything!

By Walter L. Apperson
I’ve been on dialysis for 5 years. I go to dialysis on Mondays, Wednesdays and Fridays. Sometimes I skip treatments on Wednesdays because I know my body can handle it. My healthcare team keeps talking to me about the treatments I’ve missed. What’s the big deal? I feel fine.

Skipping dialysis treatments can be very dangerous. The amount of time you are on the machine and how often you go for treatment is actually a prescription determined by your healthcare provider to meet your individual needs. Getting the right amount of dialysis ensures that your blood is cleaned well enough for you to stay healthy.

Being on dialysis means that your kidneys are no longer able to remove waste products and extra water from your body. The dialysis machine takes over this function for your kidneys. Remember your kidneys used to clean your blood 24 hours a day, 7 days a week! When you skip treatment, extra fluid will need to be removed when you go back to dialysis and this may make your next treatment harder for you. It may cause cramping, headaches, or nausea as the healthcare teams tries to get you back to your dry weight.

Your kidneys are also responsible for helping to regulate your blood pressure and for keeping a safe balance of key minerals, such as potassium and phosphorus, in your body. Missing dialysis treatments places you at risk for these minerals building up dangerous levels in your body. High potassium can cause a heart attack. High phosphorus can weaken your bones over time and increase your risk for heart disease.

Although you may miss a treatment and not feel any immediate symptoms, do not be fooled – missing treatments is extremely dangerous! If you must miss a treatment, talk to your healthcare team about rescheduling that treatment for a different time slot that week.
1. **LOW BLOOD PRESSURE**

   is the most common side effect of dialysis, affecting one out of four patients at some point over the course of dialysis treatments. The two main causes are gaining excess fluid weight between sessions and having a weak heart. In order to avoid excess fluid weight gain, you should maintain a healthy fluid level by drinking no more than a quart (32 ounces) daily and avoiding salty foods that increase thirst. If you do gain excess fluid weight, discuss the issue with your dialysis team. They can adjust your dialyzing time accordingly.

2. **NAUSEA AND VOMITING**

   are associated with kidney disease in general, but low blood pressure and excess fluid weight gain are also common causes. If you have nausea and vomiting during a dialysis treatment, tell the nurse, so that she can adjust the machine accordingly. If you’re suffering from nausea at home, speak to your healthcare provider about a prescription for anti-nausea medicine.

3. **DRY OR ITCHY SKIN**

   is experienced by many patients undergoing dialysis, especially in the winter. The most common reason for itchy skin is high phosphorus, so it’s important to follow your diet plan and take your phosphate binders as prescribed. To help ease the symptoms, use soaps that don’t dry out skin as much, such as Ivory soap, and plain moisturizing lotions, such as Vaseline or Eucerine. Avoid lotions with fragrances because these may irritate sensitive skin.

4. **RESTLESS LEG SYNDROME**

   is another common side effect that causes patients to keep moving their legs as a result of the leg nerves and muscles creating a crawly or prickly sensation. Restless leg syndrome can be tied to some forms of kidney disease, diabetes, hardening of the arteries, or a vitamin B deficiency, so it’s important to speak to your healthcare provider for a diagnosis and a prescription which will address the specific cause.

5. **MUSCLE CRAMPING**

   causes extreme discomfort in many patients. The cause of this side effect is unknown, so the issue can only be addressed by trying to relieve the symptoms. Healthcare providers advise stretching the cramped muscles to release the pain or applying hot packs to the affected area to help increase circulation. Some medications may provide relief but these should be discussed with your healthcare provider. Some patients find that drinking small amounts of tonic water or apple vinegar can help. Although there is no research to support these remedies, there is little risk to trying them to see if they will work for you.
My Food Coach by NKF offers personalized nutrition information for you and your family. You can access My Food Coach by NKF online or via the mobile app. Search for recipes, ingredients and meals that fit your personal nutrition needs. This is especially helpful if you are on dialysis or have a family member on dialysis! You can also add your own recipes, check the nutritional content of your favorite dishes, build shopping lists, and create a personalized recipe box.

To sign up online visit [https://myfoodcoach.kidney.org](https://myfoodcoach.kidney.org) or download the app in your iTunes or Google Play store on your mobile device. It’s easy to take My Food Coach by NKF with you when you work, shop or dine out!

**Lime Float***
1 serving

**INGREDIENTS:**
½ cup lime sherbet
1 teaspoon lime juice
6 ounces diet lemon-lime soda

**DIRECTIONS:**
Add lime sherbet, lime juice, and top with lemon lime soda. Add a straw. Enjoy!

*Not suitable for diabetics

**ANALYSIS:**
calories 180
protein 0.5 g
total fat 0 g
carbohydrates 33 g
sodium 39 mg
potassium 11 mg
phosphorus 2 mg
Summer Recipes

Zucchini Bread
Serves 16 (1 Slice Per Serving)

INGREDIENTS:
3 eggs
1½ cups sugar
1 cup applesauce
2 cups unpeeled zucchini, shredded
1 teaspoon vanilla
2 cups flour
½ teaspoon baking powder
1 teaspoon baking soda
1 teaspoon cinnamon
½ teaspoon ginger
1 cup unsalted chopped nuts

DIRECTIONS:
Beat eggs. Mix sugar, applesauce, zucchini, and vanilla into eggs. Sift dry ingredients together and add to mixture. Pour into a loaf pan and bake at 375°F for 1 hour. Cut into 16 slices.

ANALYSIS:
calories 202
protein 3.7 g
total fat 6 g
carbohydrates 34 g
sodium 69 mg
potassium 110 mg
phosphorus 62 mg

Submitted by Denon Stacy, MS, RD, LD.

Summer Fruit Slaw
Serves 8 (a little more than ½ cup per person)

INGREDIENTS:
1 apple, washed with stems and bottom removed
1 crisp pear, washed with stems and bottom removed
1 large stalk rhubarb, washed with top and bottom removed
½ red onion, thinly sliced
½ cup orange juice
1 tablespoon apple cider vinegar
½ teaspoon honey

DIRECTIONS:
Slice the apples into quarters, cutting around the core and seeds. Slice pieces until you have a bunch of thin apple matchsticks. Repeat with the pears. And finally, cut the rhubarb into quarters, so that each piece is approximately the same length as your apple and pear matchsticks, and slice those pieces into thin matchsticks as well.

Place apples and rhubarb into a large bowl. Place pears aside in a smaller bowl. Add red onion, orange juice, apple cider vinegar, and honey to the apple/rhubarb bowl and mix well (with a wooden spoon or your hands). Cover both bowls with foil and place them into the refrigerator to cool and marinate, 30 minutes to 1 hour.

Before serving, add pears to the apple/rhubarb bowl and give it a good swirl.

ANALYSIS:
calories 38
protein 0.5 g
total fat 0 g
carbohydrates 9 g
sodium 0 mg
potassium 133 mg
phosphorus 12 mg

Submitted by Jess Goldman Foung, aka Sodium Girl.
Sunshine French Toast

Serves approximately 10

INGREDIENTS:
1 loaf french bread
1½ cups Egg Beaters
½ cup pineapple juice
1 tablespoon vanilla extract
Strawberries
Powdered sugar
Butter-flavored cooking spray

DIRECTIONS:
Cut french bread into 1 inch slices. Leave them out overnight to dry out. In a mixing bowl, mix Egg Beaters with pineapple juice and vanilla extract. Dip dry bread into mixture, coating both sides, and allowing excess to drain off. Spray baking sheet with cooking spray. Place dipped bread slices on baking sheet. Cover the bread and refrigerate overnight. Pre-heat oven to 350 degrees, uncover the bread and bake for 20 minutes or until the bread is golden brown. Serve with fresh strawberries and powdered sugar. For those with diabetes, use powdered sugar sparingly. For variation, try different juices, extracts and/or toppings.

ANALYSIS:
calories 110
protein 5.9 g
total fat 0.8 g
carbohydrates 18.6 g
sodium 221.6 mg
potassium 119.9 mg
phosphorus 54.7 mg

Scrambled Egg Muffins

Makes 12 muffins

INGREDIENTS:
8 eggs
½ cup rice milk
1 tablespoon chopped chives
½ cup chopped green peppers
¼ teaspoon dijon mustard
¼ teaspoon ground sage
4 vegetarian sausage patties, browned, cooled and diced
Vegetable oil spray

DIRECTIONS:
Pre-heat oven to 350 degrees. Whip together eggs, rice milk, chives, green peppers, dijon mustard, ground sage, and diced sausage patties. Spray non-stick muffin cups with vegetable oil; pour egg mixture into each muffin cup (less than ⅓ cup). Place in the middle of pre-heated oven and bake 15–20 minutes, or until firm. Remove from oven, let cool for a few minutes before serving. Heat resistant spatulas work very well to help remove egg muffins from the tin.

ANALYSIS:
calories 84
protein 7 g
total fat 4 g
carbohydrates 5 g
sodium 150 mg
potassium 52 mg
phosphorus 69 mg

Recipes on this page submitted by CKD patient Chef Duane Sunwold.
I stay organized by computer spreadsheet. My history goes back 74 years. I carry a copy with me at all times (in the car). I update it every two weeks and give a copy to my dialysis facility.  

Fred G.

Keeping track of my medical information requires being a “proactive patient.” I have a big black binder with tabs that contain all my necessary medical information: doctor documents/notes, insurance, lab results, etc. It is my “Health Bible.” I make sure to never leave the office without the office note and my lab results. These documents are gold. They tell me how I am doing and how to take care of my precious and pre-owned kidney beans!  

Mary W.

I keep a list of all my medications and surgeries on my computer. Any time I go to the hospital or a new doctor, I just print out my lists and take them with me. This saves time when filling out admitting and new patient information.  

Dell W.

I have a notebook that I bring to all doctor and hospital appointments and a running list of all surgeries, procedures, etc. It tells me at a glance when, where, who did what for each of us. I record this on the computer and print a copy as needed. This list was invaluable, since my husband had several health issues with different doctors and in different health facilities.  

Carolyn K.

I have a list typed out and when I get a new medication, I add it to the list. This way it’s always up to date. I put small stickies on the lids saying what it is and what time I take them. I also keep a list in my wallet just in case I go to the hospital.  

Tom O.

I created a document. Part I contains my insurance information. Part II contains my medication list including those that I no longer take and the date they were discontinued. Part III contains all of my immunizations, surgeries, and diagnostic tests I’ve had in the last couple of years. I travel at least three times a year, and I’ve learned that keeping up with things like my latest PPD helps a lot.  

Jacqueline M.
VELPHORO®
(sucroferric oxyhydroxide)
chewable tablets

INDICATIONS AND USAGE
Velphoro (sucroferric oxyhydroxide) is a phosphate binder indicated for the control of serum phosphorus levels in patients with chronic kidney disease on dialysis.

DOSAGE AND ADMINISTRATION
Velphoro tablets must be chewed and not swallowed whole. To aid with chewing and swallowing, tablets may be crushed.

The recommended starting dose of Velphoro is 3 tablets (1,500 mg) per day, administered as 1 tablet (500 mg) 3 times daily with meals. Adjust by 1 tablet per day as needed until an acceptable serum phosphorus level (less than or equal to 5.5 mg/dL) is reached, with regular monitoring afterwards. Titrate as often as weekly.

DOSAGE FORMS AND STRENGTHS
Velphoro (sucroferric oxyhydroxide) chewable tablet 500 mg.

CONTRAINDICATIONS
None.

WARNINGS AND PRECAUTIONS
Patients with peritonitis during peritoneal dialysis, significant gastric or hepatic disorders, following major gastrointestinal surgery, or with a history of hemochromatosis or other diseases with iron accumulation have not been included in clinical studies with Velphoro. Monitor effect and iron homeostasis in such patients.

ADVERSE REACTIONS
In a parallel design, fixed-dose study of 6 weeks duration, the most common adverse drug reactions to Velphoro chewable tablets in hemodialysis patients included discolored feces (12%) and diarrhea (6%).

To report SUSPECTED ADVERSE REACTIONS, contact Fresenius Medical Care North America at 1-800-323-5188 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS
Velphoro can be administered concomitantly with ciprofloxacin, digoxin, enalapril, furosemide, HMG-CoA reductase inhibitors, hydrochlorothiazide, losartan, metformin, metoprolol, nifedipine, omeprazole, quinidine and warfarin.

Take alendronate and doxycycline at least 1 hour before Velphoro.

Inform patients that Velphoro tablets must be chewed and not swallowed whole. To aid with chewing and swallowing, the tablets may be crushed [see Dosage and Administration]. Velphoro should be taken with meals. Some drugs need to be given at least one hour before Velphoro [see Drug Interactions].

Adverse Reactions
Velphoro can cause discolored (black) stool. Discolored (black) stool may mask GI bleeding. Velphoro does not affect guaiac based (Hämocult) or immunological based (iColo Rectal, and Hexagon Opti) fecal occult blood tests.

HOW SUPPLIED/STORAGE AND HANDLING
Velphoro are chewable tablets supplied as brown, circular, bi-planar tablets, embossed with “PA 500” on 1 side. Each tablet of Velphoro contains 500 mg iron as sucroferric oxyhydroxide. Velphoro tablets are packaged as follows:

NDC 49230-645-51 Bottle of 90 chewable tablets

Storage
Store in the original package and keep the bottle tightly closed in order to protect from moisture.

Store at 25°C (77°F) with excursions permitted to 15 to 30°C (59 to 86°F).

PATIENT COUNSELING INFORMATION
Dosing Recommendations
Inform patients that Velphoro tablets must be chewed and not swallowed whole. To aid with chewing and swallowing, the tablets may be crushed [see Dosage and Administration]. Velphoro should be taken with meals.

Adverse Reactions
Velphoro can cause discolored (black) stool. Discolored (black) stool may mask GI bleeding. Velphoro does not affect guaiac based (Hämocult) or immunological based (iColo Rectal, and Hexagon Opti) fecal occult blood tests.

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Waltham, MA 02451

US Patent Nos. 6174442 and pending, comparable and/or related patents.

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Introducing Velphoro® (sucroferric oxyhydroxide)
Sustained phosphorus control and significantly lower pill burden over 52 weeks*1,2
– Efficacy comparable to sevelamer carbonate1
– 5.4 fewer tablets per day than sevelamer carbonate2
Starting dose of 1 chewable tablet per meal1
Non-calcium, iron-based formulation1
– Minimal systemic iron absorption
Well tolerated*1

*   A 2-part, 52-week, open-label, active-controlled, parallel-group phase 3 clinical study evaluated the safety and efficacy of Velphoro in lowering serum phosphorus. Patients (N=1054) had chronic kidney disease, were on hemodialysis or peritoneal dialysis, and had serum phosphorus levels ≥ 6 mg/dL. In part 1 (Study 05A), patients were randomized to treatment with either Velphoro (starting dose: 2 tablets/day) or sevelamer carbonate (starting dose: 6 tablets/day) for 24 weeks. After 24 weeks, 93 hemodialysis patients on Velphoro were re-randomized to either a maintenance dose of Velphoro or low-dose control (Velphoro 250 mg/day) for 3 more weeks. Following completion of Study 05A, part 2 (Study 05B), a 28-week extension study, began. Patients continued treatment with either Velphoro (n=391) or sevelamer carbonate (n=267) according to their original randomization.1,2

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Please see Brief Summary on the following page or visit www.Velphoro.com for full Prescribing Information

Now 1 Chewable Tablet Per Meal Can Provide...¹