WHAT GIVES YOU STRENGTH?
Inspiration from Real People

RECIPES
FOR HEALTHY HOLIDAYS

5 TIPS
FOR BEING YOUR OWN BEST ADVOCATE

Support provided by:
AFFYMAX, Takeda
The National Kidney Foundation is pleased to share the very first issue of **kidney living**, our brand-new lifestyle magazine for people on dialysis.

I've been a nephrologist for years, and during that time, I've cared for many patients on dialysis. My patients have told me, again and again, how very important it is to continue to live their lives to the fullest while on dialysis. Life is meant to be enjoyed, after all!

In each issue of **kidney living**, we'll share our tips for living well while on dialysis, and for becoming an active, empowered member of your healthcare team. Our editorial board is comprised of both dialysis patients and professionals who work hard to bring you the most useful information.

Each of us is responsible for living a healthy lifestyle, which includes watching our diets, exercising, taking medications, getting to dialysis and seeing health care providers on a regular basis. We hope that each issue of **kidney living** will inspire you and enrich your life for many years to come.

**Beth Piraino, MD**

Beth Piraino, MD
President, National Kidney Foundation
What’s in this Issue?

FEATURE ARTICLE
4 Be your own best advocate!
Our five top tips on how to manage your own healthcare so you can feel better and focus on living!

IN EVERY ISSUE....
5 Ask Your Healthcare Team
In this issue: what’s the deal with phosphorus? Is it really important to watch my levels?

8 Kidney Kitchen
In this issue: our best tips and tricks for healthy holiday dining, along with dialysis-friendly recipes for Apple Sage Dressing and Rum Pear Tarts.

14 kidney living Voices
We want to hear from you, our readers! In this issue, patients share what gives them strength and hope through tough times.
Having a chronic illness means that, like it or not, we have to manage our own care, at least in between doctor visits. Learning about our own health is critical so that we take our medications correctly, get refills when we need them and know the difference between an emergency and a routine problem. Here are five tips to help you get started:

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<thead>
<tr>
<th>Tip</th>
<th>#1</th>
<th>Tip</th>
<th>#2</th>
<th>Tip</th>
<th>#3</th>
</tr>
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<tbody>
<tr>
<td>#1:</td>
<td>Gather your medical records on an ongoing basis. You may need them for a variety of reasons, from an insurance appeal to getting a second opinion. When my doctors do labs or other diagnostics, I ask them to have the lab or diagnostician copy me on the report. Although I don’t have all of my doctors’ office notes, I do have test and study reports – what I consider “the essentials.”</td>
<td>Keep a list of your medications. Update the list when you make any changes. If you go to any doctor’s appointment or hospital emergency room, bring a copy and take it with you. Even better, keep a list in your wallet with your insurance cards at all times in case of an emergency.</td>
<td>Keep a list of your doctors and their contact information on you at all times. If you have a smartphone, list them clearly under “doctor” rather than by name. In an emergency, somebody can check your phone for your doctors. Make their contact information easy to find. In my phone, I also have a person listed under “emergency contact,” just in case.</td>
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<td>#3:</td>
<td>When you go to a doctor, take a list of questions, symptoms, and concerns with you. Take notes when speaking to your doctor, especially if you are going to the appointment alone.</td>
<td>Remember to take your medication and take it correctly. Errors are very common, but can be dangerous. It’s important to take your medication as prescribed. Get refills before you run out. Lay out medications once every week. Have a pill container that has three rows of seven boxes representing three doses for each day of the week. This helps to make sure you take the right medication at the right time.</td>
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The key members of your healthcare team include your doctor, advanced practitioner, nurse, social worker, dietitian, patient care technician and YOU! To be an active, informed member of your healthcare team, you need to ask lots of questions. In each issue of *kidney living*, we will respond to common questions from dialysis patients.

**Q** My phosphorus is high. I take my binders and try to follow a low phosphorus diet. But I don’t feel any different when my phosphorus is high, so what’s the big deal?

**A** Even though you might not feel the effects, high phosphorus levels can cause damage to your body. Some people may feel itchy when their phosphorus is high, while others feel nothing at all. It is extremely important to keep your phosphorus within normal range.

Phosphorus is a mineral that is needed for building healthy, strong bones. Too much phosphorus causes your body to pull calcium out of your bones, making them weak. High phosphorus and calcium levels may also lead to dangerous calcium deposits in your blood vessels, lungs, eyes, and heart.

Controlling phosphorus can be challenging because phosphorus is found in many foods and may not be labeled clearly. Talk with your dietitian about how to adjust your diet to avoid high phosphorus foods and to choose better options instead.

For a list of common foods that are high in phosphorus:

www.kidney.org
800.622.9010

**Phosphorus Binders**

- **Are medications** that help control the amount of phosphorus your body absorbs from food.

- **Work while food** is in your stomach to “bind” with the phosphorus and eliminate it from your body.

- **Must be taken** with each meal and even with snacks. If you take them too long before or after eating, they may not work properly.

Talk with your doctor or dietitian about how much you should take, because each patient has different needs.
Hitting All the Right Notes Even While on Dialysis

Mayra Martinez, of Chula Vista, California, is a 29-year-old dialysis patient and a Grammy award-winning musician. Mayra had hypertension that led to her kidney failure. After trying peritoneal dialysis for a short while, Mayra switched to in-center hemodialysis.

Mayra is a member of the Mariachi Divas. She plays the vihuela, a guitar-like stringed instrument that she learned in high school.

“Being a part of the Mariachi Divas gives me a reason to keep pushing forward and makes me really happy,” she said. When she’s not practicing music, Mayra likes to read and watch her favorite TV shows. She also takes her dog, Pumpkin, for regular walks down by the bay.

Watch Mayra’s story in the “Dialysis Saves Lives” video on NKF’s website!

Dialysis patients share their experiences online

It’s normal for people on dialysis to experience fear of the unknown and even depression.

To help patients understand what’s involved and show that dialysis can be both life-saving and life-enhancing, the National Kidney Foundation created “Dialysis Saves Lives,” a video that focuses on four patients, ages 9–70, who share their experiences on camera.

Viewers can follow the patients’ initial fear at being diagnosed, treatment routines and ultimate realization that they can still lead normal, productive lives.

The 6-minute video can be found on NKF’s YouTube channel at www.youtube.com/user/KidneyFoundation
Not just a care giver, becoming a care partner

By Denise Eilers, RN, BSN

My late husband Jerry was a home hemodialysis patient for nearly 25 years, but I was never his caregiver. Rather, I considered myself to be his care partner.

What’s the difference? The word “caregiver” seems to imply a one-sided situation with one person providing all the care while the other remains passive. The word partner, however, denotes teamwork, equality, trust and shared decision-making. I believe this distinction goes to the heart of the patient and care partner relationship.

Perhaps the best definition of care partner comes from the Eden Alternative, which defines it as “those who work together respectfully and effectively for the long run.” Note that this definition does not specify who that person might be or the division of the workload. In fact, both of these may change over time. For example: when I was a stay-at-home mom, I certainly did not expect my husband to come home from a grueling eight or nine hour work day only to deal with the dialysis machine set-up and clean-up in addition to his treatment. But, when I returned to work full time, we divided the chores more equitably. As our son grew older, he often spent dialysis evenings getting homework help from Dad or playing board games with him. Is that care partnering? I believe so! Not all care partners are spouses or family members, however. They can be friends or even professionals.

Was life always easy? Of course not! Chronic kidney failure impacts every aspect of life. It changes not only the patient’s life, but the lives of the family members as well. Just like any other family, we had our share of difficulties and struggles. Our most important coping strategy was working as a team to meet both the needs of Jerry’s dialysis and our needs as a family.

Tips to being a successful care partner:

• Remember to take care of yourself! Being a care partner can be tremendously gratifying but the responsibility can cause burnout and take a toll physically and emotionally, so care partners must also make taking care of themselves a priority.

• “Time does not equal energy.” In other words, a task that only takes minutes or an hour may actually consume more energy and emotional strength than it may seem. Both patients and their care partners need to remember this.

• Honest, open, and non-judgmental communication is vital to successful care partnering. Nothing is too trivial to discuss if it is of concern to either party.

• Accept others’ offers to help and ask for help when you need it. Remember you don’t have to do it all, all of the time. Speak up when you’re in need and give people specific tasks to assist you, even if this just means letting someone else drive your loved one to a doctor’s appointment or make a meal.
Healthful Holiday dining

By Janelle Gonyea RD, LD

The holiday season is almost upon us, bringing along a host of temptations. From family dinners to holiday parties, treats are everywhere, and it’s hard not to indulge. Start your menu planning now to ensure that you have healthy options available.

SHOPPING TIPS:

• Read labels – Aim to purchase foods lower in sodium and phosphorus. Look for ingredients that include “phos” in the word, indicating added phosphorus.

• Choose cooked seafood, unsalted crackers, allowed fruits and raw vegetables. These items make quick appetizers that are colorful and much more healthful than the typical meat and cheese platter.

• Skip the packaged pies, cakes and cookies. Make baking part of the festivities by having friends and family join in. By doing it yourself, you can eliminate added salt and higher potassium and phosphorus ingredients.

If you can keep the above tips in mind, you can stay healthy through the holidays. Don’t forget to ask your registered dietitian for additional tips on holiday dining.

FOOD PREPARATION TIPS:

• Stuffing is a holiday classic, but can be high in sodium. Make your own version by using low sodium broth and mixing in dried cranberries, celery or chopped onions.

• Instead of bottled and prepackaged gravy mixes, make your own with low sodium broth.

• Roasting or grilling meat, seafood and allowed vegetables is easy and brings out the natural flavors in the foods. Consider grilled pork chops topped with cooked apples rather than baked pork chops smothered in mushroom soup.

For more recipes visit NKF’s Kidney Kitchen at www.kidney.org/patients/kidneykitchen/
Apple Sage Dressing

By Chef Duane Sunwold

Serves 8

INGREDIENTS:
1 teaspoon canola oil
1 large yellow onion, diced
4 stalks of celery, diced
2 Granny Smith apples, peeled, cored and diced
2 tablespoons ground sage
1 tablespoon poultry spice
1 ½ cups apple cider
1 cup low–sodium chicken stock
12 cups of cubed low–sodium bread (¾ to 1 whole loaf)

DIRECTIONS:
In a large fry pan, add oil, onions, celery and apples and sauté until onions are translucent. Add sage, poultry spice, apple cider and chicken stock; simmer for 10 minutes. Place cubed bread on a cooking sheet and bake in a pre-heated 400°F oven until the bread is brown, turning the cubes occasionally to brown all sides. When bread cubes are brown add to the fry pan and mix together. Bake the dressing in a covered 9” x 13” pan in a 350° F oven for 20 to 30 minutes.

ANALYSIS:
Calories 190
Total fat 3 g
Saturated fat 0.5 g
Monounsaturated fat 1.5 g
Polyunsaturated fat 0.8 g
Cholesterol 0.5 mg
Calcium 84 mg
Sodium 79 mg
Phosphorus 68 mg
Potassium 226 mg
Total carbohydrates 36.5 g
Dietary fiber 2.8 g
Sugar 11.2 g
Protein 4.8 g

Rum Pear Tarts

By Chef Duane Sunwold

Serves 4

INGREDIENTS:
½ of a 3 oz. package vanilla pudding, cook and serve
1 cup rice milk, unfortified
1 ½ teaspoons rum extract
1 Bartlett pear
1 package mini phyllo cups (12 count)

DIRECTIONS:
Follow microwave directions on how to make the pudding using ½ a package. Add rum extract and chill. After chilling thoroughly, spoon 1 heaping teaspoon of pudding into each phyllo cup. Peel and slice pear, place ½ slice on each cup and serve immediately.

ANALYSIS:
Calories 150
Total fat 3.6 g
Saturated fat 0.3 g
Monounsaturated fat 1.2 g
Polyunsaturated fat 0.3 g
Cholesterol 0.0 mg
Calcium 10.2 mg
Sodium 125.8 mg
Phosphorus 51.2 mg
Potassium 62.7 mg
Total carbohydrates 28.3 g
Dietary fiber 1.5 g
Sugar 13.4 g
Protein 1 g
Most dialysis patients receive treatment in a clinic, but did you know that hemodialysis and peritoneal dialysis can both be done at home? Many people who chose home dialysis feel that they have more control over their treatment, greater independence, and a better quality of life. However, less than 10 percent of dialysis patients receive home therapy.

So why isn’t home dialysis used more often? In an effort to address this issue, more than 50 patients, health care providers, and policymakers met at the National Summit on Home Dialysis Policy last spring. Summit participants discussed the need to educate patients about home therapies, remove barriers to make it available to more people, and train professionals. Dr. Beth Piraino, NKF’s current President, was among the panelists.

After the Summit, participants created recommendations about how to increase use of home therapies. The National Alliance for Home Dialysis Policy was also created to help advance these recommendations. NKF serves on two of the Alliance work groups.

To learn more about home dialysis, visit NKF online at www.kidney.org/kidneyliving or call toll-free 800.622.9010 to request our brochures on home dialysis. You can also ask your health care team for more information.
What ERSD Networks can do for you

By Eileen Boyte, MSW

Have you heard of the ESRD Networks (End Stage Renal Disease Networks)? Do you know which one serves your area? As the Patient Services Manager for Network 18, I find that many kidney patients don’t know what the ESRD Networks do, but we can help you in many different ways!

• **File a Complaint:** If you have a complaint about a dialysis facility, your ESRD Network can investigate and help find a solution. We make sure that dialysis facilities are providing safe, effective and patient-centered care.

• **Ask for Free Educational Resources:** There’s a wide range of educational materials available to kidney patients and their families through your Network. We collect materials from other kidney-related organizations in an effort to be a “one-stop shop” for you.

• **Get Involved:** Each Network has a Patient Advisory Committee (PAC) that has different activities and events in your area. For more information about local activities, or to apply to be a member, contact us.

An involved and engaged patient is a happier, healthier patient. Contact your ESRD Network today to learn more about the services and resources available in your area. You can find contact information at [www.esrdncc.org](http://www.esrdncc.org) or by calling us at 516.209.5365.

The Medicare End Stage Renal Disease (ESRD) Program was established in 1972 and in 1978, the formation of the ESRD Network Organizations was authorized. Today there are 18 Networks in existence and each is responsible for providing oversight services for a specific geographical region.

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**kidney living**

is online

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Share your thoughts on our latest “kidney living Voices” question
I have been a nephrologist for 18 years. Early in my career, while telling one of my patients that she was nearing kidney failure, I immediately began detailing all the treatment options, reassuring her that everything would be alright. She took a deep sigh and said to me, “Doc, can you just give me a minute to be sad?”

Her reaction made me pause. I realized I was too eager to give her the information, and emphasize that she would be able to continue to live a productive life. But unfortunately, the reality of being diagnosed with kidney failure is that life is going to change and some of those changes may be difficult.

Everyone goes through different stages and emotions when confronting a life-changing illness. I realized I needed to let her just “feel” before she had to think or take action and that I needed to be sensitive to this in order to be effective and helpful.

If she hadn’t spoken up, my patient would have sat through an hour of meaningless words (remember Charlie Brown’s mother?). Because she took control of the situation and taught her doctor a thing or two, her quality of life improved at that moment. Although I still aim to educate my patients about their options in detail, I am much more aware of where they might be in accepting their diagnosis of kidney failure.

When patients are not afraid to communicate with doctors and let them know what they are ready to hear and when, it can decrease their stress and anxiety.

Everyone goes through different stages and emotions when confronting a life-changing illness.

So how can you take control of your own care? Here are some tips to become more active in your health care:

Let your medical team know what’s important to you, such as your work hours, weekly card game, bowling, traveling, school, sports, family. This way, they can help try to arrange your treatment schedule to be sure you don’t miss out on those activities.

Understand your lab results. Talk with your dietitian about why certain lab values are important and how can you work to improve your results.

Learn your new diet and make it work for you. Your dietitian can help you make a diet plan that is right for you. Visit www.kidney.org/patients/kidneykitchen for recipes.

Participate in your treatments. Ask the technicians and nurses what they are doing. Learn how the machine works and what alarms mean.

Know your options. Ask questions and do your own research. Visit www.kidney.org to learn more.
Looking for Support?

NKF’s Peer Mentor Program Can Help!

Dialysis might be the last place you want to be, but you also know that you need it to live. While your medical team can educate you about aspects of your health and treatment, only another patient can truly share what being on dialysis is really like and how he or she overcame the challenges in order to live well on dialysis. NKF’s Peers Lending Support program connects patients looking for support with other patients who have been trained to be mentors. Peer mentors can help share with you how they dealt with kidney failure and being on dialysis. They can also help you learn how to empower yourself and live better on dialysis. Here is some feedback from people who have been involved in the NKF’s Peers program:

“*It was just wonderful to talk to [my mentor]…he was so reassuring and answered my questions in a way that a medical person could not. Thank you so much for this amazing program!*”

“My mentor has helped keep my spirits up and keep me motivated.”

“There is so much information out there that at times I felt like, this isn’t so bad; I can deal with this and other times, I felt like this was my death sentence. I was so happy when I finally found the information for Peers. I cannot tell you what it has meant to have a mentor, she went above and beyond anything I could have ever expected. She always listened to my concerns and questions and was a huge encouragement for me. I can honestly say that the times we spent talking were invaluable.”

855.653.7337
Peer Mentoring takes place confidentially, free-of-charge, through our toll-free system. If you’d like to learn more about how to be connected with a trained peer mentor, call or email nkfpeers@kidney.org.
My daughter, family and faith give me strength. I keep my spirits up by knowing that my life is God’s plan and my faith will carry me through it. I know that having a positive attitude and staying involved in my medical treatment is a MUST. Educating myself and keeping myself informed about treatment options is important. This empowers me to continue.
— Monica Santalla

When faced with life challenges, I recall all the good I have in my life. I am not my disease. I am mindful of experiencing a healthy lifestyle and have already been healed where it counts the most, my heart. We can all find many things for which to be grateful.
— Rev. Francine Hillpot

I am a proud father of two wonderful kids, and they keep my spirits up daily. They give me the strength on the days after dialysis that I feel that I just cannot go on. I have a 14 year old son who is a honor student and is attending early college this year and he empowers me to “keep on keeping on.” I look forward to the day that he becomes the very successful young man that I know that he will be.
— Dexter Davis

So far I’ve spent 27 years on hemodialysis; the past 8 years have been nocturnal. I work hard to take good care of myself. What makes my day is positive feedback from the staff at my center, good nurses and doctors who I feel confident about, adequate dialysis, information to make informed decisions to be empowered.
— Rosalind Bowman

I have learned in my 3 years of dialysis that I am very fortunate to have dialysis available. It is not fun, but it is a life saver. I am on two transplant lists and one of my sons is in the process of trying to become my donor. That gives me the strength I need.
— Carol Joiner
I work very hard at maintaining a positive attitude. I spend as much time as I can getting out and LIVING. I have found that exercise helps. I also spend time volunteering at the local hospital’s ICU and listen to what other families are going through. It’s hard to feel sorry for myself when I do this! — Jane Carter
We are honored to support the National Kidney Foundation

About the Affymax/Takeda Partnership
In 2006, Affymax, Inc. and Takeda Pharmaceuticals U.S.A., Inc. established a partnership aimed at fostering innovation and teaming with the renal community to understand its needs and support the work it does for patients.

To learn more about each company, visit www.affymax.com and www.takeda.us.