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# kidney living

Spring 2013

Issue 2

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## kidney living

*Wants to hear from you!*

My name is Sheldon Francis and I live in the Bronx, New York. I was diagnosed with kidney disease in November 2011 and am currently on hemodialysis. My faith, the love and support of family and friends, along with my desire to be the best I can be, allow me to live the best life possible! It might sound strange, but I love dialysis. Why? It keeps me alive and has improved my quality of life.

As a member of the National Kidney Foundation (NKF) **kidney living** Editorial Board, I wanted to thank all of you, our readers, for picking up a copy of this magazine. In each issue, we offer stories, tips and advice for living well on dialysis. But this is *your* magazine, so we really need to hear from you about what you'd like to see in it! What's on your mind? What are your favorite articles? Are there issues that you struggle with that you'd like us to tackle in the future? Or do you have advice you can share with other readers?

Share your thoughts by either taking our quick survey online at [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving) or by simply mailing your comments to us at the NKF address below. If you do, you'll have a chance to win a \$40 American Express gift card.

So, talk to us! We'd love to hear from you.



*Sheldon Francis*  
Patient Editor, Kidney Living

*5 readers  
will win!*

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# Departures



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## What's in this Issue?

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#### 4 **Top 10 Things Every Dialysis Patient Needs to Know**

There's a lot to learn and think about if you are on dialysis. But you have lots of options! Here are some important things you need to know.



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In this issue: Why am I thirsty all the time? What tips can help me manage thirst?

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In this issue: Baked custard, pine-apple fruit whip, and almond cookies! These sweet treats are easy, delicious and great for dialysis patients and those with diabetes.

#### 14 **kidney living Voices**

We want to hear from you! In this issue, our readers share their best tips for traveling successfully on dialysis.



Talk Therapy 8

# top 10 tips for dialysis patients

Dialysis can help those with kidney failure live longer, healthier lives, but as a patient, you may feel overwhelmed making decisions surrounding your treatment. It's important to realize that when it comes to your care, you have many rights and options! Here are our Top 10 tips for those on dialysis!

## 1. You have treatment choices.

Options exist for *how*, *where* and *when* you dialyze. There are different types of dialysis – peritoneal and hemodialysis. Dialysis can be done in a hospital, in a dialysis unit, or at home. Work with your healthcare team to choose a treatment that makes you feel comfortable, and ask them if another type of treatment might be better for you.

## 2. Compare in-center dialysis facilities online.

Information on over 5,600 U.S. dialysis centers is available online through “Dialysis Facility Compare” at [www.medicare.gov](http://www.medicare.gov). You can compare different facilities based on geography, quality, hours available, and other features.

## 3. You can plan ahead for an emergency.

Ask your dialysis facility about the emergency plan

in case of a snowstorm, fire, power outage or other natural disaster. Make sure you have the names, locations and phone numbers of other dialysis units and hospitals in your area. If you dialyze at home, make sure you have at least two weeks’ worth of unexpired supplies on hand. If you have to miss a dialysis treatment, begin your emergency meal plan. NKF offers more information about preparing for emergencies, along with a grocery list and meal plan for a 3-day emergency diet, on our website: [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving)

## 4. There is an easy way to transfer medical records between clinics.

There is an easy, secure way for your healthcare team to transfer your treatment records through the CROWNWeb website. For example, if you’ve been

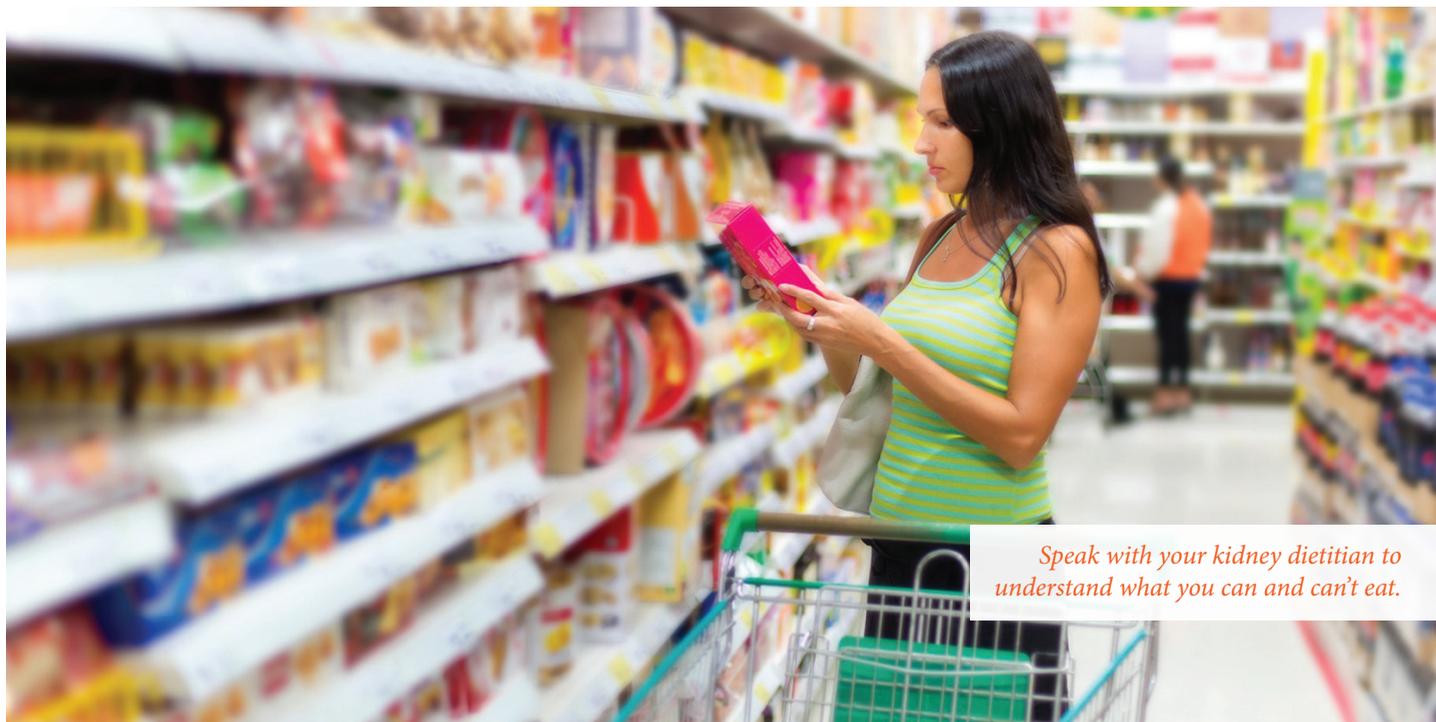
admitted to the hospital, or if you needed to relocate during an emergency evacuation, your doctors and healthcare team can access up-to-date information about your dialysis so that you continue to receive appropriate care no matter where you are.

## 5. You can travel.

Dialysis centers are located in many places around the U.S. and internationally, so there’s no reason to stay put. It’s important, however, to plan ahead by making an appointment at a dialysis center in your destination before you leave. The staff at your center may be able to help you make these arrangements.

## 6. Be your own best advocate.

Know what key questions to ask your doctor or other healthcare professionals. Take notes so that you can refer back to them later. Partner



*Speak with your kidney dietitian to understand what you can and can't eat.*

with your healthcare team and decide on a treatment plan together. Advocate for yourself and share how you're feeling.

### **7. You have rights and responsibilities.**

You have a great deal of control over your treatments. The NKF's "Dialysis Patients' Bill of Rights and Responsibilities" can help you learn more about receiving quality care, privacy and your rights and responsibilities. Visit [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving) to read it online or call 855.NKF.CARES (855.653.2273) for a copy.

### **8. You can receive insurance coverage.**

If you have end stage kidney failure, you are likely eligible for Medicare insurance coverage. Speak with your healthcare

team and social worker for help with insurance paperwork.

### **9. You will need to follow a special diet.**

When your kidneys are not working properly, you will need to change your diet and limit how much you drink. Although your diet may vary according to the type of dialysis you receive, dialysis patients typically need to limit sodium, phosphorus and potassium in their diet. It is important to speak with your kidney

dietitian so that you are able to understand what you can and can't eat.

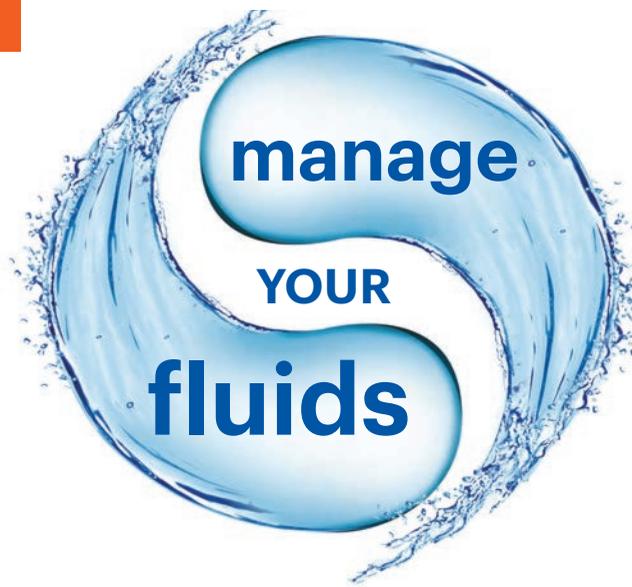
### **10. Dialysis patients can work.**

Many dialysis patients can go back to work or school after they get used to dialysis. After establishing a routine, many patients have more energy and find they can work around this new schedule. Some even find ways to work remotely using a laptop or cell phone, depending on their profession.

# NKF Cares

**Patient Information Help Line**

Call toll-free 855.NKF.Cares (855.653.2273)  
or email [nkfcare@kidney.org](mailto:nkfcare@kidney.org)



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 dialysis nurse keeps telling me my dialysis treatments will be easier if I don't drink as much fluid between treatments. But I'm thirsty all the time! Doesn't that mean that I need to drink more?**

**A** Fighting thirst and reducing fluid weight gain between treatments can be hard. Your dialysis team knows this and can help you find ways to manage your fluid intake.

If you gain a lot of fluid weight between hemodialysis treatments, your thirst will increase. When more fluid has to be removed per hour, you may have low blood pressure and/or cramping. Your dialysis team tries to use lower levels of sodium for your dialysis treatment, but higher levels may be needed to remove extra fluid and to keep you comfortable during your treatment. Higher sodium levels and low blood pressure can both lead to increased

thirst. A longer treatment may be required to avoid these complications.

A person on peritoneal dialysis will need to use exchanges with higher amounts of dextrose (sugar) to remove larger amounts of fluid, which may cause increased thirst.

Gaining less fluid weight between treatments causes less stress on your heart. It also helps to prevent buildup of fluid that can cause shortness of breath.

Discuss the amount of fluid you should have with your dietitian and other members of your healthcare team. Your kidneys used to work non-stop to keep your sodium and fluid in balance, but now this is

done less often with dialysis. Take control of your fluid intake between treatments and your treatments will be easier.



*Be sure to discuss the amount of fluid you should have with your dietitian and other members of your healthcare team.*

# A Patient Perspective thirst tips

By Dorothy Davis

I started dialysis in 1977. I've had two previous transplants and am waiting for a third. I can attest to the fact that dialysis treatment has come a long way! I also know that most dialysis patients need to limit their fluid intake in order to be as healthy as possible.

Too much fluid can raise blood pressure, damage the heart, cause swelling, and make dialysis very uncomfortable. It is very important to get a handle on thirst control as early as possible; this leads to healthier "kidney living"! So, what can you do when that "thirst bug" hits?

Here are some tips I've learned over the years:

- Freeze your allotted amount of water in a jar or pitcher overnight. Grab it the next day, and as the ice melts, sip the water. Once the water

is gone, you know that you have used up your daily allotment of fluid.

- Use small glasses, such as juice glasses, at meals. If you use larger glasses, don't fill them up completely.
- Limit the amount of salt in your diet. Salt makes your body hold on to water. Limiting it helps with feelings of thirst.
- Keep a supply of hard candy, like mints, lemon drops, or sour balls. They lubricate your mouth and help decrease thirst.
- Take sips, not gulps. Try to savor whatever liquid you're drinking and make it an experience, not just a thirst quencher.
- Divide your fluid allowance into manageable parts. For example, if you can have 32



*Hard candy is a great way to curb thirst!*

ounces per day, you could drink 8 ounces at 4 different times of the day, like at 10:00 am, 2:00 pm, 6:00 pm, and 10:00 pm.

- If you plan to attend a social event in the evening, you can decrease your intake earlier in the day so you can enjoy a beverage at the event.
- Use a refreshing mouthwash daily, and be sure to brush your tongue, since good oral hygiene habits also help get rid of that "dry mouth" feeling.

Check with the dietitian at your unit for additional tips and ideas.



## kidney living is online

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additional features and stories

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your thoughts on our latest "kidney living Voices" question



[kidney.org/kidneyliving](http://kidney.org/kidneyliving)

# talk

your way to better

# health

Got  
any new  
recipes?

Thinking of taking a good nap next time you're on dialysis? Think again. Ditch the ZZZZs, channel your inner social butterfly, and chit-chat your way to better health!

According to a recent study, socializing between dialysis patients and healthcare professionals actually led to improvements in patient lab values. Think outside the box (and your traditional treatment) all in the name of your own health.

Researchers found that "talking control" therapy helped stabilize and in many cases, improve, lab values in hemodialysis patients. This was the first study to evaluate the effect of "talking control" on patient health.

Researchers analyzed data from conversations held with 49 patients during hemodialysis sessions. A "getting better" cart, which included games, brochures, food, and small notebooks, was used as a conversation-starter. Discussions covered various aspects of patients' lives, including dialysis. Results showed 24% stabilization and 76% improvement in three lab values: albumin, phosphorus and parathyroid hormone levels.

"These findings show the importance of connecting with patients on a more global level, not just to 'talk shop' about their treatment. As more people use social media to connect with

What do  
you do for  
work?



others, it's important that professionals learn to share information, rather than deliver it. We all have a lot in common – being mothers, grandmothers, gardeners, scrabble-players. When we used this to our advantage by connecting with patients and sharing about ourselves as we shared health information, we found that their health actually improved," said Judith Beto, PhD, lead researcher of Loyola University Health Systems in Maywood, Illinois.

This study has implications for healthcare team members. "Professionals can create a more collaborative effort. Patients can be members of the healthcare team if we invite them to join us and learn their life stories, not just their medical history," said Lynda Szczech, MD, National Kidney Foundation Immediate Past President. "This innovative approach to education has tremendous potential for improvements in quality of life as well as health."

*Get talkin'!*  
*Patients do better*  
*when socializing*  
*during dialysis.*





# Balancing diabetes and the kidney diet

By Dawn Berry, Registered Dietitian

If you have diabetes and are on dialysis, you may feel lost when it comes to your diet. About half of people on dialysis have diabetes. In fact, diabetes is the leading cause of kidney disease, so you are definitely not alone!

The first step in managing diabetes is balancing your carbohydrates. Carbohydrates (or “carbs”) are foods that turn into sugar when you digest them. Any carbohydrate food will raise your blood sugar.

**Complex** carbohydrates raise sugar more slowly (it takes your body longer to digest and absorb these), while **simple** carbohydrates can raise your sugar level more quickly.

Along with more obvious sugars like candy and chocolate, many other foods contain carbs, like milk products, bread, cereal, fruit and some vegetables (corn and potatoes). Everyone needs some carbs, since the sugars they provide help power many body functions. If you have diabetes, your body can't process a large amount of carbs at once. When you have diabetes and eat too many carbs at one time, the

sugar that is not processed stays in your blood instead of being broken down. This can cause problems and damage organs throughout your body including your kidneys, eyes, feet and hands.

Portion control is the KEY! With proper portion control, you can enjoy a wide variety of foods, but still keep your dietitian happy, your body healthy, and your lab values under control.

When counting carbohydrates, remember that one slice of bread or ½ cup of pasta is counted as one serving of carbs. Generally, people need 3-4 servings of carbs at a meal and 1-2 servings for a snack (you will also want to add protein and a little fat to each meal and snack). To make up for the extra fiber you may be missing by avoiding whole grains, try eating low potassium fruits and vegetables with the skin on. Listed here are some examples of carbohydrate servings for meals and snacks. This list should only be used with the help of your dialysis dietitian to find an eating plan that meets your health needs and include foods you like.

## Example Carbohydrate Servings

1 serving = 15g carbs

Bread — 1 slice

Dry cereal — 3/4 cup  
(unsweetened)

Hot cereal — 1/2 cup cooked  
(oatmeal, grits, etc.)

Pasta — 1/2 cup cooked

Rice — 1/3 cup cooked

Corn — 1/2 cup

Apple, peach, pear — 1 small

Canned fruit — 1/2 cup  
(unsweetened)

Apple or — 1/2 cup  
Pineapple Juice





# sweet treats

It's often said the quickest way to someone's heart is through the stomach. If you want to surprise your sweetie, these dessert recipes are sure to please! They're healthy for people on dialysis and those with diabetes, too.

## Pine-Apple Fruit Whip

Serves 8 (*1/2 cup per serving*)

### INGREDIENTS:

- 1 envelope unflavored gelatin
- 1 cup canned unsweetened pineapple juice
- ¼ teaspoon grated lemon peel
- 3 tablespoons honey
- 2 cups unsweetened applesauce
- Cinnamon or nutmeg

### DIRECTIONS:

In a saucepan, sprinkle gelatin over pineapple juice to soften, and stir over low heat until gelatin is dissolved. Stir in lemon peel, honey and applesauce. Refrigerate, stirring occasionally. When mixture mounds slightly if dropped from spoon, beat until fluffy. Divide among 8 dessert dishes. Refrigerate until firm. Garnish each with a dash of cinnamon or nutmeg.

### ANALYSIS:

Calories 71  
 Carbohydrates 18g  
 Protein 1g  
 Fat 0g  
 Sodium 3mg  
 Potassium 114mg  
 Phosphorus 8mg  
**Kidney and Kidney  
 Diabetic Exchanges:**  
 1 Medium Potassium Fruit



## Chinese Almond Cookies

Serves 24 (3 cookies per serving)

### INGREDIENTS:

1 cup margarine, softened

1 cup sugar

1 egg

3 cups flour

1 teaspoon baking soda

1 teaspoon almond extract

#### ANALYSIS:

Calories 158

Carbohydrates 20g

Protein 2g

Fat 8g

Sodium 99mg

Potassium 18mg

Phosphorus 17mg

**Kidney Exchanges:**

1 Starch, 2 Fat

### DIRECTIONS:

In a medium mixing bowl, cream margarine and sugar. Add egg and beat well. Sift dry ingredients and add to creamed mixture. Add almond extract and mix well. Roll into balls about  $\frac{3}{4}$  inch in diameter. Press a small hole in the middle of each cookie. Bake at 400° F for 10 to 12 minutes, until cookies are golden brown around edges.



## Baked Custard

Serves 1

( $\frac{1}{2}$  cup per serving)

### INGREDIENTS:

$\frac{1}{2}$  cup lowfat (2%) milk

1 egg

$\frac{1}{8}$  teaspoon nutmeg

$\frac{1}{8}$  teaspoon vanilla

Artificial sweetener

### DIRECTIONS:

Scald milk, then cool slightly. Break egg into small bowl and beat slightly with nutmeg. Add scalded milk, vanilla and sweetener to taste. Mix well. Set bowl in a baking pan with water  $\frac{1}{2}$  inch deep. Bake at 325° F for 30 minutes.



#### ANALYSIS:

Calories 135

Carbohydrates 7g

Protein 10g

Fat 7g

Sodium 124mg

Potassium 249mg

Phosphorus 205mg

**Kidney and Kidney Diabetic**

**Exchanges:** 1 Milk, 1 Meat

# WANT MORE RECIPES

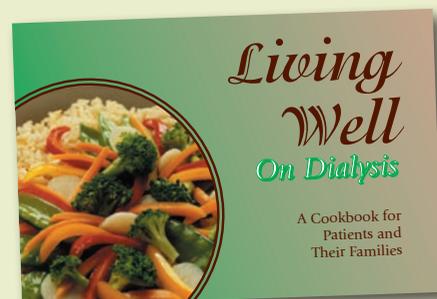


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# Employment and Dialysis yes you can!

*Denise Eilers, RN, BSN*

I find it interesting that when I meet someone new, especially in a social setting, one of their first questions is “...what do you do?” Right or wrong, we are closely identified with our employment status and the ability to work is intimately tied to our sense of self-worth. Gainful employment also provides income and, often, much needed group health insurance.

Chronic kidney failure can dramatically—and often suddenly—disrupt many aspects of a person’s life including employment. Minimizing the impact of kidney disease on normal life activities, including work, should be a priority for both patients and professionals. Despite dialysis, staying employed or returning to work is a realistic goal. In-center treatments can be a challenge if the center isn’t open after 5:00 pm, but many offer evening hours for this very reason. Home hemodialysis and peritoneal dialysis can offer greater flexibility, so it’s important to learn about

all your options in order to choose the modality that best fits your lifestyle.

Regardless of the type of work you do, consider the demands of your job. Do you need to make modifications, transfer to a different department, or receive any training in order to stay employed? For example, the physical demands on an accountant and a construction worker are vastly different. You have a right to “reasonable accommodation” under the Americans with Disabilities Act. Ask your social worker for a referral to Vocational Rehabilitation, if necessary.

As you continue to work, it’s important not to minimize your health needs and to make every effort to stay as healthy as possible. Immediately bring any symptoms and concerns, such as fatigue or depression, to the attention of your healthcare team. This way you can work together to resolve problems before they interfere with your job. Keep the lines of communication open with your employer and, if necessary, enlist the help of

the social worker to educate your employer about dialysis and your treatment plan.

Know your options for taking a short break from work. The Family Medical Leave Act (FMLA) may allow an employee to take up to 12 weeks unpaid time off in a 12-month period. This benefit may help if you are training for home dialysis. For patients already on disability who desire to return to work, the Social Security Administration’s “Ticket to Work” program provides disability beneficiaries the choices, opportunities, and support needed to become and stay employed.

## FOR MORE INFORMATION:

### FAMILY MEDICAL LEAVE ACT

Call U.S. Department of Labor at 866.487.9243 or visit [www.dol.gov/whd/fmla/](http://www.dol.gov/whd/fmla/)

### AMERICANS WITH DISABILITIES ACT

Call 800.514.0301 or visit [www.ada.gov](http://www.ada.gov)

### SOCIAL SECURITY ADMINISTRATION’S TICKET TO WORK PROGRAM

Call 866.968.7842 or visit [www.choosework.net](http://www.choosework.net)

# the Beat Goes On

for a dialysis patient



Like many patients suffering from kidney failure, Carmichael Griffin has overcome plenty of challenges during his life. For the last 13 years, he's been on dialysis, but his love of music and acting always keeps him motivated to chase his dreams.

Carmichael, a tax preparer, started producing music when he was 13, and has run his own music studio for seven years. He produces many different styles of music, including gospel, R&B and soul. He also sings, plays the keyboard, writes songs and composes music. Active in the theater since childhood, he has performed in six stage plays in North Carolina. The most recent, "They Said I Wouldn't Make It," has been the most successful.

Carmichael continues to follow his dreams and believes he can achieve his goals, while

living an active and productive life – despite needing dialysis.

When he reflects on his health history, Carmichael realizes he can help inform others about what he didn't know. He learned he had high blood pressure at age 19 and his kidneys failed two years later. "I didn't know I had high blood pressure, and by the time I found out, it had already begun to damage my kidneys. I know the kidney failure is a direct result of the high blood pressure," says Carmichael.

Carmichael works to help the National Kidney Foundation get the message out about risk factors and the importance of early detection. "Diabetes and high blood pressure are the leading causes of kidney disease," says Carmichael, "yet I know there are millions out there like me, who will pay no attention until it's too late."

## IS YOUR FAMILY AT INCREASED RISK OF KIDNEY DISEASE?



What can your **family members** do if they're at risk? At lot!

If you have kidney disease, your family members may be at increased risk of developing it, too. That's why it's important for them be aware and talk with their doctor. Other risk factors include diabetes, high blood pressure and heart or blood vessel problems. People over 65 are also more likely to have kidney disease, and it's more common in African Americans, Hispanic Americans, Asian or Pacific Islanders and Native Americans.

### Anyone at risk should:

- Visit their doctor for regular checkups and tests for CKD, including blood pressure, urinalysis, and a simple blood test to measure creatinine.
- Keep diabetes and blood pressure under control.
- Lose excess weight by following a healthy diet and exercise program.
- Reduce salt and protein intake.
- Quit smoking and limit alcohol.
- Avoid large amounts of over-the-counter pain relievers.

# What tips do you have for traveling on dialysis?



What's been hardest about traveling and how have you solved the difficulty? What advice do you have for others to ensure a great trip?

We asked our readers these questions through our website and email list. If you want to join our email list, please visit [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving) and under "Sign Up Today", be sure to provide your email address. You can also read more reader responses on our website.

Traveling on peritoneal dialysis just involves a little extra equipment. Contact your medical supplier so they can calculate what you will need and ship the supplies to your hotel. Notify the hotel in advance so they can hold the supplies until you arrive. Some airlines suggest you get a note from your doctor justifying your traveling with such a machine. – *Meg Banks*

I was on CAPD (Continuous Ambulatory Peritoneal Dialysis) for 18 years. Traveling wasn't difficult; the biggest challenge was finding a way to hang the bags in hotel rooms. About 4 years ago I found hooks that stick to the wall but could be removed without damaging it. They were a lifesaver. – *Melanie*

My husband was on dialysis for 7 years. The best advice I can give is to PLAN! Work with your doctor and clinic. Allow plenty of time to rest between treatment and activities. Go to a grocery store when you arrive and buy kidney friendly snacks. Most of all, have fun and remember that you can do anything you put your mind to! – *Leslie Guerrero*

I am a home hemodialysis patient. Before traveling, I compile a list of everything I need and line up backup facilities just in case. You have a lot of flexibility about when you can dialyze. I saved my days off for the nice sunny days and dialyzed on days with inclement/marginal weather. The worst thing is all the stuff you need to bring. Have a bellhop help you carry everything. – *Ken Balla*

You can travel just like everyone else with a little extra planning in advance. Involve your dialysis unit social worker, but be active in locating a unit and information on your own. It is important to personally confirm with your insurance which units will be covered. – *Akilah B*

Know how far the treatment center is from the hotel. Set up transportation. Travel with a flow sheet and inform the new center of any information that is not on the sheet. – *Lisa Baxter*

Make sure you have enough phosphorus binders and that you have the address, phone number, and travel directions to the clinic. – *Arthur Lueders*

## Let's Go! Traveling on Dialysis

Most dialysis patients can travel safely and continue their treatment away from home. You should always consult your healthcare team before you travel and **be sure to:**

- Plan your trip at least six to eight weeks in advance. More time should be allowed for popular vacation spots or travel during holidays.
- If you would have your treatments on specific days and at specific times, let the center know in advance. However, the unit may not always be able to honor your request, because space is limited.
- Carry a copy of your recent flow sheets, medication list, and medical history with you.
- Check with your insurance provider to see if they cover the cost of treatment when you travel.

### Special Considerations for Home Hemodialysis and Peritoneal Dialysis Patients:

- If you use a portable machine to perform your dialysis treatments, check with the airline before traveling to see if a doctor's note is required to carry the machine on the plane.
- Talk with your healthcare team, who can help to arrange for delivery of supplies to your destination.
- Arrange for a back-up dialysis clinic that would be available should a problem arise while traveling.
- Remember to carry the toll-free numbers of the dialysis and equipment companies for assistance 24 hours a day.

- Plan for adequate clean space where you can do your dialysis treatments or exchanges while traveling.

**For more information about traveling on dialysis, visit [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving)**



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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](http://www.affymax.com) and [www.takeda.us.com](http://www.takeda.us.com).

