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# kidney **living**<sup>®</sup>

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Summer 2016

Issue 15

## ***BE PREPARED***

PLANNING FOR  
EMERGENCIES

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## **GET TALKIN'**

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FRIENDS AND FAMILY WANT  
TO HEAR ABOUT YOUR  
HEALTH. TALK TO THEM.

OVERCOME YOUR FEARS

TRAVEL ON  
HOME HEMO



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# kidney living®

A MAGAZINE FOR PEOPLE ON DIALYSIS

## A MAGAZINE FOR US!

I am so excited about all of the amazing tips in this issue! I found myself gaining a lot of insight on topics I often have concerns about; such as traveling on dialysis, troubleshooting home dialysis, and those pesky Quality of Life surveys.

As someone who was on peritoneal dialysis and hemodialysis for 5 years before receiving a transplant last year, I learned a lot as I went along. I was able to travel often, taking my manual peritoneal dialysis supplies with me on a plane for a short trip. The airline was very helpful in making sure I wasn't charged for my medical supplies (even though the bag weighed over 50 lbs), and also tagging the bag with a special sticker to ensure it was handled carefully and received top priority to make it to my destination. When I was on hemodialysis, coordinating my treatments at a nearby facility with my social worker was a breeze and everything went smoothly. I know traveling on dialysis is a huge concern for many patients, but it is possible! You just have to put your fears aside, reach out for support and step out on faith!

Kidney Living has allowed me to feel more connected to my kidney community that is so diverse and spreads throughout the country. It allows us to bridge the distance gap and relate to one another. Many of us feel alone or that no one understands what we're going through. But Kidney Living changes all of that, so now we have a place to call our own.



I hope you enjoy this issue as much as I did.  
And most importantly: enjoy your summer—you deserve it!

*Leilah Sampson*

Leilah Sampson, Patient Editor

## National Kidney Foundation

30 East 33rd Street  
New York, NY 10016  
800.622.9010 | 212.889.2210  
Email: [kidneyliving@kidney.org](mailto:kidneyliving@kidney.org)  
[www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving)

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let the  
adventure  
begin!



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### take the survey

For **YOUR**  
well-being

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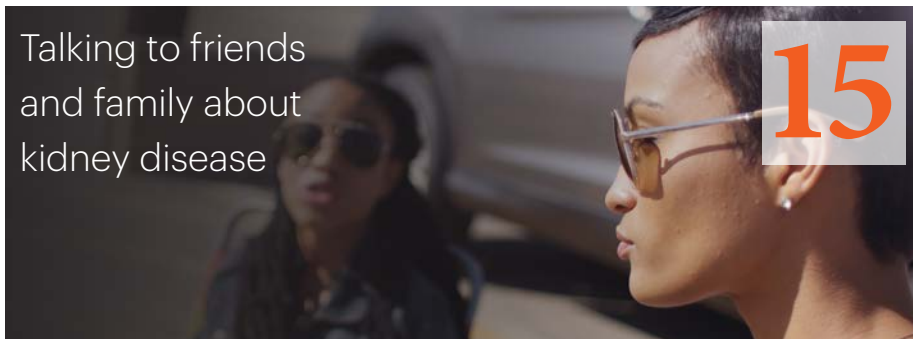
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Talking to friends  
and family about  
kidney disease

15





**PREPARING FOR AN  
EMERGENCY**

**IN THE DIALYSIS CLINIC OR AT HOME**

**—ARE YOU PREPARED?—**

While we hope that an emergency or disaster won't happen while we're on dialysis, it is very important that we're prepared for how to respond if one does occur.



## IN CLINIC

By Eileen Boyte, MSW, Patient Services Director, ESRD Network 18

All dialysis facilities are required by the Centers for Medicare and Medicaid Services (CMS) to have an Emergency Preparedness Plan in place. As a part of this requirement, they also need to educate all patients on what to do if there's an emergency. This includes training on safely disconnecting yourself from the dialysis machine, using what is often referred to as the "Clamp and Cap" procedure.

Each dialysis station should have an Emergency Disconnect Kit. They are often hanging on the side of the machine in a clear bag. The contents may vary from unit to unit, but typically they will contain the materials required to clamp your lines so you can disconnect and then cap the ends of the lines, preventing any bleeding from your access site.

### HOW TO CLAMP AND DISCONNECT:

- Clamp both access needle lines.
- Clamp both thicker bloodlines. If the lines have pinch clamps, pinch all four clamps closed.
- Unscrew the lines between the closed clamps.
- Cap the ends of your needle lines with the caps provided in your emergency take-off packet.

Remember, these directions are for emergency evacuation situations only. Never proceed with this process unless told by the staff at the dialysis center. Your access needles should be left in place until you get to a safe place.

Keep in mind that blood may remain in the blood lines after you have disconnected. Clinical staff will provide you with proper medical help to address this blood loss once all patients are moved to a safe location.

It is very important that you are aware of this course of action and confident that you are able to carry out the tasks required. If for any reason you are unable to safely disconnect yourself from the machine, staff will help you. Being prepared for any type of emergency or disaster will increase your chances of getting through the situation without major harm. This is no different when it comes to dialysis.

If you have any questions about the Emergency Preparedness Plan in place at your dialysis facility, speak to the staff right away and ask for training, or a refresher, on what actions you need to take. Your local ESRD Network is also on hand to provide educational information that will help you get ready for an emergency both at the clinic and in your home. For the contact information for your network, please visit [esrdncc.org](http://esrdncc.org).

## IN HOME

By Cathy Cox, BSN, MS, Indiana University Health Home Dialysis, Indianapolis, IN

Being ready for a non-medical emergency requires careful planning ahead for dialysis patients. You should discuss a plan with your dialysis center in the event of long lasting power outages, contaminated water, or evacuation.

Let your local utility companies (electric, gas, water) and fire department know you are on dialysis, especially if you dialyze at home. In case of emergency they may be able to prioritize restoring service to your home.

### GENERAL PRECAUTIONS

It's helpful to put together an emergency kit that is easy to find. In a sealed plastic bag, you should have:

- Current medication list
- Your dialysis prescription
- Copies of insurance cards and picture ID
- Dialysis center name and number
- Your kidney doctor's name

*Your kit should also include:*

- Flashlights and radios (with extra batteries for each).

- Extra medications. Home hemodialysis patients need to remember to bring heparin. Patients with diabetes will need blood sugar (glucose) monitoring supplies, as well as insulin (if necessary).
- Hand sanitizer is helpful to have if there is a problem with your water supply.

*For peritoneal dialysis (PD) and home hemodialysis (HHD) patients:*

- A two to three day "backup" supply of bagged fluid.

*continued on p. 6*

- Extra caps, masks, needles, gauze, tape, and any other essential supplies for treatment.

If you are unable to do your regularly scheduled treatment in an emergency, your dietitian can give you sample emergency meal plans. They also recommend having some of the following items on hand:

- Canned or sealed plastic containers of foods that don't need refrigeration (for example, fruit, dry cereal and graham crackers).
- Peanut butter and canned meats are good sources of protein (don't forget a manual can opener!).
- Patients with diabetes should have hard candies on hand for low blood sugar.
- Bottled water (one gallon per person) is also needed. To avoid fluid overload during an emergency, limit your fluid intake to under 2 cups per day.

These measures are all safeguards, but planning ahead for emergencies can help you to worry less during a stressful time.



## SPECIFIC EMERGENCIES FOR HOME DIALYSIS PATIENTS

You needed to learn many new things to start home dialysis: new words, how to set up the machine, and emergency procedures, to name a few. You and your training nurse spent lots of time learning what to do and practicing for emergencies. It is helpful to review some of these situations to be prepared.

### For home hemodialysis patients

**Air embolism:** Air enters the return blood line or venous port of a tunneled catheter.

**What to do:** Turn on your left side and lie flat. Call 911.

**Chest pain during treatment:**

Tightness or crushing chest pain.

**What to do:** Slow blood flow rate to 200-250. Take nitroglycerin if ordered. Call 911 and return blood if possible.

**Venous infiltration:** Blood is leaking out of the access into surrounding tissue.

**What to do:** If blood pump has not already stopped, stop the pump. You can return the blood through the arterial needle. Clamp both blood lines; connect the venous (blue) line to the arterial needle. Connect the arterial (red) blood line to the saline and return the blood. After bleeding has stopped, apply ice to the site.

**Power loss while in treatment:**

Loss of power for a short time.

**What to do:** Have a working flashlight in treatment area. Check power cords at outlet and at back of machine. If power is not back on right away, return the blood manually. Remember that air detectors may not be turned on and you should watch the venous line for air. If air is seen, clamp venous line and end blood return.

### For peritoneal dialysis patients

**Tubing comes apart:** Catheter becomes disconnected at the transfer set.

**What to do:** Put a clamp on the catheter. Do not do an exchange until your nurse changes your tubing. Call your dialysis nurse for instructions.

**Leak:** Swelling across abdomen ("spare tire") or swelling of genitalia.

**What to do:** Stop exchanges and call your nurse.

**Transfer set contamination:** Tip of transfer set is infected by touch or missing cap.

**What to do:** Call your PD nurse! Do NOT do an exchange until you have seen your nurse.

**Hernia:** "Knot" in abdomen or belly button.

**What to do:** If the knot is painless, call your nurse or show it to your doctor at a clinic visit. If it is painful and hard, go to the Emergency Room.

The goal for all patients is safety. When you go to a clinic visit, discuss some of these events with your nurse. Going over these "how to's" from time to time can ease stress for you and your care partner. Keep in mind, you have been trained for these emergencies! You should have the manuals and information your nurse gave you. Your center is just a phone call away.

# Q & A

## QUESTION:

I have so many doctors' appointments. Why do I have to go to the vascular surgeon to check my fistula regularly?

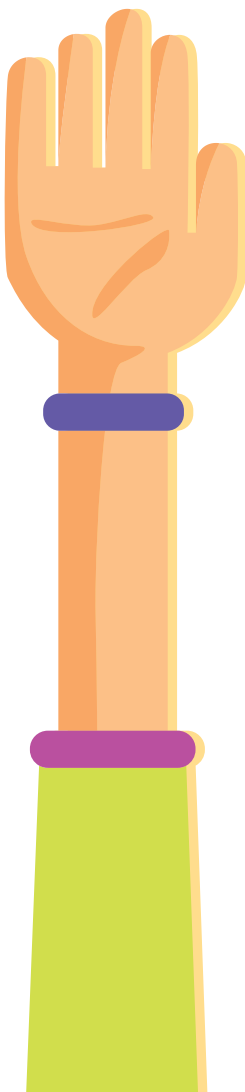
**ANSWER:** Your vascular surgeon is an important part of your dialysis team. Once your access is placed, you will be referred to the vascular surgeon as a regular part of taking care of your access.

Your dialysis team checks blood flow rates and venous pressures of your access during each treatment. Changes in flow rates and pressures may show a blockage or narrowing in your access, which would prompt your dialysis team to refer you to the vascular surgeon. A blockage or narrowing doesn't mean that you or your dialysis team has done anything wrong. It is important to see the vascular surgeon as soon as possible when anything abnormal is seen.

The vascular surgeon may order a fistulogram. This is an X-ray procedure, in which dye is injected into your blood to look at how your blood is flowing and to check for blood clots or blockages. This allows the vascular surgeon to find and fix the problem. The vascular surgeon will contact the dialysis team to give them an update on your access.

It is important to remember to follow the day-to-day access care your dialysis team has taught you and to report anything unusual. Your vascular access is an important part of getting adequate dialysis and requires routine monitoring by you and your dialysis team. Finding problems early—and going to the vascular surgeon as needed to fix them quickly—will help keep your access working well.

*By Annmarie Correia, RN*







# TRAVEL ADVENTURES

## ON HOME DIALYSIS

*By N. Gedney*



I started dialysis about two years ago and was pleasantly surprised to find that I actually got my old life back when I started hemodialysis at home. I do my treatment daily at home, but it takes less time than traditional in-center dialysis. However, my biggest challenge was still ahead. I have always enjoyed traveling, so I had to start planning another adventure.

This would be my first opportunity to travel with my home dialysis machine (or R2-D2 as I affectionately call him), and I'll admit—I was a bit anxious. The thought of being saddled with a 100 lb. machine while traveling was pretty scary, but I found it was doable with lots of planning ahead of time.

After successfully tackling a short plane trip to New Orleans with my machine, I decided to go on a cross country drive to Glenwood Springs, Colorado, where I would trade my house for a cute cottage in the foothills for three weeks. Hot springs, here I come. So with much pre-planning, I loaded up the car with my medical supplies, machine, and a small suitcase of clothes. The dialysate bags would be delivered to my temporary home in Glenwood. I took off on a sunny Thursday morning, heading west.

Traveling alone has its challenges, and being on dialysis adds a few more, so I won't lie and say that I had

no fears and concerns about taking a four week cross country trip! True to form, I mentally planned every part of packing, both clothing and treatment supplies. It paid off.

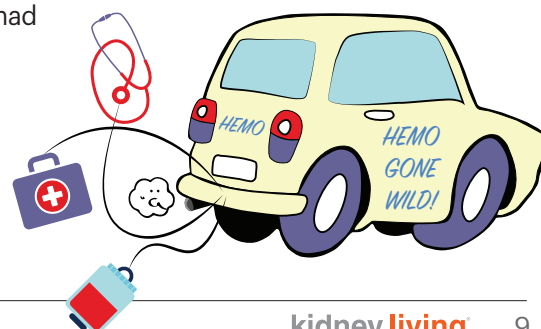
I arrived at my "home away from home" in Glenwood early in the afternoon. It had been an easy drive, with lots of memorable sights. I spent the afternoon settling in, and only after unloading all my clinic supplies was I brought back to reality. Time for a dialysis treatment. There was nothing missing from my normal treatment routine, but my view certainly improved!

We all deserve a little escape from reality once in a while, and this trip to Colorado did it for me! I feel lucky since I've started home hemo and have included the treatments into my daily life the way most people would brush their teeth. Going from the safety and security of my home routine was frightening, but I was more curious to know what traveling with my new buddy would be like. I am happy to report that life goes on, swimmingly!

Since then, I have taken several more trips by air to San Diego, Nashville and Indianapolis, and am planning an Alaskan cruise in 2017. The only trip left on my bucket list will be seeing the Canadian Rockies by train!

A ROOM WITH A VIEW:  
THIS IS THE VIEW  
FROM MY LIVING  
ROOM WHILE  
DIALYZING  
IN GLENWOOD  
SPRINGS.

N. Gedney



A person's hands are visible, holding a black clipboard with a silver clip at the top. The clipboard has a white sheet of paper with handwritten text. The background is a bright, sunny beach scene with a clear blue sky, turquoise ocean, and white sand. Two colorful Adirondack chairs, one pink and one green, are visible in the background. The person holding the clipboard is wearing a dark long-sleeved shirt.

Quality of Life  
is  
important!

By Dorothy S. Muench,  
MSW, LCSW, NSW-C

**W**hile many of you may be familiar with the Quality of Life (KDQOL-36) survey your social worker does with you each year, you may not know how completing the survey helps you—and why it's important to take the time to answer the questions honestly and thoughtfully.

The survey lets your healthcare team understand how YOU think you are doing physically and emotionally.

While regular blood tests and lab reports tell your healthcare team important information about your treatment, it's also important for you to share how you are feeling. It's a chance to ask yourself important questions and talk with your healthcare team about your concerns.

After completing the survey, your social worker will review your results. There are five different sections that will be reviewed. The first two are the physical component summary (PCS) and mental component summary (MCS), which report how you feel about your health right now. Your responses will be given a numerical value that translates to an overall "score" in each section. While the word "score" might make you think of a game with winners and losers, this is not the case in this instance! In reality, the scores from the survey help your healthcare team figure out how you are feeling, find any concerns or problems you may have, and make changes to your care plan to improve how you feel.

In answering the survey, be honest about how you are feeling – it's OK if the truth is that you aren't feeling well, physically, emotionally, or both. Sometimes, you may be feeling poorly or even be depressed. This is important for your healthcare team to know so they can help make changes to your

treatment, give support, or make a referral to help you cope. While depression is common among dialysis patients, it isn't something that you have to accept. Your healthcare team is there to help treat your depression. You are not alone. Seeking help for depression is important because people who are depressed tend to have more physical signs of disease, not take their medicines as recommended, sleep poorly, make poor food choices, or skip dialysis treatments.



The last three sections of the survey (burden of kidney disease, symptoms and problems, and effects of kidney disease) help find how kidney disease affects your daily life. Your healthcare team will work with you to address your concerns and create goals to help improve your quality of life.

Everyone is an individual with their own challenges, goals, and concerns in life.

This survey is a way to help personalize your care and help you and your healthcare team discuss what's important to you. Be sure to think about what matters most to you and what your goals are for the future. Also, it is especially important to note if you experience changes in how you feel. Taking the survey each year can be a way to check how you're feeling and think about the goals you set for yourself. While your social worker may be the one to give you the survey and review your results, your entire dialysis care team is involved in reviewing the survey results and working on a plan to address your concerns.

So the next time your social worker comes to you and says "It's that time of year again," rather than groaning about "another survey," consider it a great way to check-in on your physical and emotional health and create a plan together to ensure the best quality of life possible for you!





# Sizzlers

## SUMMER

### Citrus Seared Tofu Stir-Fry

#### INGREDIENTS:

5 oz. extra firm tofu  
2 tbsp. olive oil, divided  
1 cup cubed yellow squash  
2 cups cubed zucchini  
1 tbsp. all-purpose flour  
1 tbsp. balsamic vinegar  
½ tsp. black pepper  
1 tbsp. grated, fresh ginger  
1 tsp. minced garlic  
1 tbsp. granulated sugar  
1 lime, juiced  
¼ cup water  
4 oz. soba noodles, cooked  
1 cup snow peas

#### DIRECTIONS:

Preheat oven to 400°F.

Cut tofu into 1" cubes. Lay between two paper towels and cover with plate to dry for 10 minutes, replacing towels as needed.

Lay tofu on non-stick baking sheet and bake until golden brown, about 30-40 minutes.

In a large skillet over medium heat, add 1 tbsp olive oil. Stir in squash and zucchini, and cook for 15 minutes.

In a large bowl, stir flour, vinegar, pepper, ginger, garlic, sugar, remaining 1 tbsp of olive oil and lime juice to make sauce.

Add sauce and water to vegetables and mix well.

Transfer tofu to stir-fry and mix.

Follow package instructions to cook soba noodles.

Add cooked noodles when vegetables are soft and then add snow peas.

Continue to stir for 5 minutes.

#### ANALYSIS

Calories: 259  
Carbs: 32.5 g  
Fat: 9.8 g  
Protein: 8.4 g

Sodium: 220 mg  
Potassium: 208 mg  
Phosphorus: 80 mg



## Salmon with Pineapple and Pear Chutney

Makes 4 servings

### INGREDIENTS

#### Baked Salmon:

4 – 3 oz. salmon fillets  
 ½ tsp. pepper  
 1 tsp. garlic powder  
 1 tsp. olive oil

#### Pineapple and Pear Chutney:

1 cup diced pineapple  
 1 lime, juiced  
 1 tsp. juice of orange  
 1 tbsp. chopped fresh parsley  
 1 medium Bartlett or Asian pear, cored and diced  
 1 tbsp. brown sugar  
 1 tsp. honey

### DIRECTIONS

Marinate salmon fillets with pepper, garlic powder and olive oil. Refrigerate for 1 hour.

Preheat oven to 350°F.

Bake salmon on non-stick sheet for about 20-25 minutes.

In a large bowl, stir together pineapple, lime juice, orange juice, parsley, pear, and brown sugar.

Serve baked salmon topped with ½ cup chutney. Drizzle with honey as desired.

### ANALYSIS

Calories: 153	Sodium: 193 mg
Carbs: 8.5 g	Potassium: 437 mg
Fat: 1.8 g	Phosphorus: 182 mg
Protein: 15.8 g	

## Apple Cider Bean Salsa

Makes 6 servings

#### Apple Cider:

¾ cup apple cider vinegar  
 ¼ cup sugar  
 2 tbsp. olive oil  
 1 tbsp. low-sodium soy sauce

#### Bean Salsa:

¾ cup canned black beans  
 ¾ cup canned kidney beans  
 ½ cup low sodium canned corn  
 ½ cup pimentos  
 ½ cup chopped green peppers  
 ½ cup chopped white onion

### DIRECTIONS

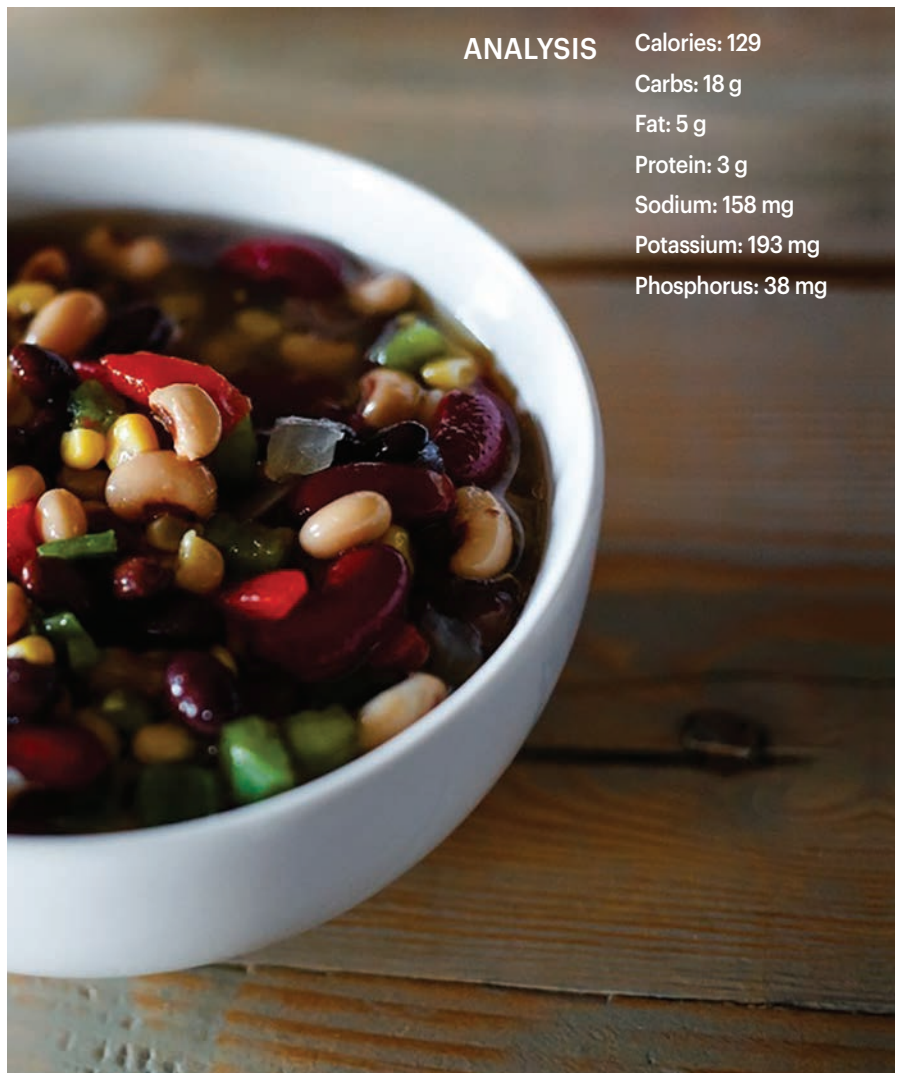
In a sauce pan, stir apple cider vinegar and sugar and bring to a boil, until sugar dissolves. Set aside to cool.

In another sauce pan, whisk together olive oil and soy sauce. Set aside to cool.

Using the process of leaching, rinse black beans, kidney beans and corn well and let sit in water for 5 minutes.

In a large bowl, add black beans, kidney beans, corn, pimentos, green peppers and onion.

Transfer apple cider and soy sauce to the large bowl and mix well together.



### ANALYSIS

Calories: 129  
 Carbs: 18 g  
 Fat: 5 g  
 Protein: 3 g  
 Sodium: 158 mg  
 Potassium: 193 mg  
 Phosphorus: 38 mg





## Orange Blossom Rice Pudding

Makes 6 servings

### INGREDIENTS

1 cup rice  
2 cups rice milk  
½ tsp. salt  
⅓ cup sugar  
1 tsp. cinnamon  
½ cup dried cranberries  
1 tsp. orange blossom water  
Cinnamon sticks, garnish  
Sprinkle of nutmeg, optional

If you have diabetes, please note this recipe is too high in carbohydrates

### DIRECTIONS

In a large saucepan over medium-low heat, combine rice, rice milk, and salt. Simmer, covered, for about 20 minutes (or until rice is cooked to al dente), stirring frequently with a whisk to prevent rice from sticking and milk from boiling over.

Stir in sugar and cinnamon and cook for another 10 minutes.

Add dried cranberries and orange blossom water, stirring for another 5 minutes.

Transfer the rice pudding to serving glasses, top with cinnamon sticks and/or sprinkle nutmeg on top.

### ANALYSIS

Calories: 252  
Carbs: 57 g  
Fat: 1 g  
Protein: 3 g

Sodium: 100 mg  
Potassium: 44 mg  
Phosphorus: 36 mg

MORE RECIPES



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# TALK

## TO YOUR FRIENDS, FAMILY & COWORKERS

about kidney disease and dialysis. What feedback do you receive? Are they supportive, turned off, interested?



It's easy to be guarded and protective of what you've been through or perhaps what lies ahead, but without being completely open and honest about kidney disease it will never get the recognition it needs. We are not alone! *Jason O.*

I'm not one to talk about my issues, but when someone asks about it because they see my fistula on my left arm, I gladly explain and fill them in on what kidney disease is, how I deal with it and how I take care of myself. My family is my BIGGEST supporter. Dating is a problem—it's hard at times. *Gregory M.*

I try to talk to my family about dialysis in particular and they're supportive but they don't take the time to educate themselves about it. I wish they would research my medical issues so we could be on the same page. It's hard not having someone to relate to. *Crystal*

I wear my peritoneal catheter like a badge of honor. I tell everyone I can to have their kidney function checked - it is painless and might save your life. I explain that I had no symptoms when my kidneys failed. *Douglas Wayne T.*

I was blessed with a caring family. They educated themselves on everything dialysis. What I find today, as a kidney and pancreas recipient, is an opinion that I am cured. People don't really understand the long-term ramifications of the medications and that there is always a chance of rejection. They don't understand that a transplanted organ may not last forever and it requires constant diligence to maintain. *Bill H.*

I am very open with friends, family and strangers about my kidney disease and my daily peritoneal dialysis. I tell people that, while this disease is very serious, my condition is managed in a way that I can live

a relatively normal life. I just had to get "OK" with the "new normal" for me. That involves keeping myself as healthy and fit as possible while I wait for a live donor kidney or a deceased donor kidney. *Jim E.*

The majority of people in my life have very little knowledge of kidney disease and the effects it has on my life. If asked I explain how my treatments work. My friends are supportive of helping me but really don't have a true understanding of what a person with the disease goes through. *Robin B.*

The first thing my mom said when I went into sudden kidney failure was that "No one in her family had it." There was a time I stayed away from some of my family because they acted like my arm was a pure anomaly. Or they cried every time we talked on the phone. I know they love me. All I can do is keep them informed. *Jacqueline R.*



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