

December 2016

QUALITY INSIGHTS RENAL NETWORK 3



# KIDNEYS R US

## NEWSLETTER

### Enjoy Your Holiday Eating While Watching Your Fluid Gain

Jean E. Burns, RD, LDN

Holidays are a time to enjoy family and friends. It is important to join in the activities. Being on a hemodialysis diet should not prevent you from enjoying family gatherings!

Try to plan ahead on the foods that may be prepared. Avoid foods that are high in sodium, such as ham and processed foods, as these will cause you to drink more. Concentrate on eating the protein in the meal first, turkey would be a good choice. Plan on drinking a few sips of fluid at the end of the meal. Try to drink only when thirsty.

**Limit your fluids to 32 ounces.** Using small cups (4 ounces) can help you portion out your fluid throughout the day. Try gum, hard candy, even frozen grapes that can stimulate your salivary glands to moisten your mouth. Sour candy like lemon drops will help quench your thirst. Take your medications with applesauce. Keep in mind foods that melt count toward your fluid allowance such as soup, gelatin, ice cream and ice. One medium ice cube has approximately one ounce of water.

Some fluids are allowed in small amounts, such as eggnog as this is high in phosphorus. Mulled apple cider, juices such as cranberry, grape and pineapple; nectars such as peach, pear and apricot are good options in small amounts. Sodas are allowed if they do not contain phosphate additives (avoid any drink that has "phos" in the ingredient list).

As far as alcoholic drinks, it is best to check with your doctor or dietitian. Beer is high in phosphorus (remember to take your binders) and wine is high in potassium. A small mixed drink may be your best choice but **avoid** high potassium and high phosphorus mixers such as orange juice, tomato juice and colas.

Don't forget to carry your binders when going to parties. Carry lip balm to moisten your lips. Many patients are now using mouthwashes and mouth sprays such as Biotene products to help control their thirst. There are small containers that you can easily carry in your pocket.

**Why is it important to limit your fluids?** Too much fluid can cause swollen feet and ankles, difficulty breathing due to fluid in the lungs, and increased blood pressure due to extra fluid in the blood stream. Most importantly, you want to protect your heart as excessive fluids stretch and weaken your heart and vessels.

For every kilogram (2.2 pounds) above your target dry weight, you have about 4 cups of extra fluid in your body. Having excessive fluid on when getting your dialysis treatment can cause cramping and make you feel washed out and weak the rest of the day. Having a good plan in place for the Holidays and keeping a positive outlook about your nutritional intake, will allow you the freedom to enjoy any kind of social gathering.

Happy Holidays!





## Patient Voices: One Patient's Journey to Dialysis

I was 21 years old when I experienced a persistent headache that prompted a visit to my primary care physician (PCP). During this visit, it was noted that my blood pressure was high, my urine had a significant amount of protein and the blood vessels in my eyes suggested signs of hypertension. These findings required a battery of tests, referral to an eye specialist and kidney specialist (nephrologist), and daily monitoring of my blood pressure. The tests confirmed that I had hypertension and signs of Stage 2 kidney failure. I was placed on medication and a special diet for my hypertension.

As a registered nurse (RN) I religiously followed my physicians' advice and observed healthy lifestyle habits; e.g. good nutrition, adequate sleep, sufficient exercise, avoiding stress, preventing infection, maintaining social support and so on. My blood pressure was well controlled, but as the years progressed, my kidney function showed gradual and persistent deterioration. Peritoneal dialysis, hemodialysis and A-V fistula placement were discussed during each part of each visit with my nephrologist, but I never arrived at a decision. It has been nearly 30 years since I had the signs of what is now known as End Stage Renal Disease ( ESRD).

In February 2016, my nephrologist informed me that it was time for me to begin dialysis. Upon hearing the word "dialysis" I cried uncontrollably. I kept asking myself "How will I tell my family?" and "What about my job?" The following days involved the placement of a catheter and tests to begin the process of having a fistula placed. I began out-patient dialysis within a week. I decreased my work hours and feared the worst of effects of dialysis ahead. But then I met other patients at my clinic who were working full-time and others who had just returned from vacations. I listened to their stories and realized I can still live life to its fullest with dialysis as a part of my life. In August I transferred to a clinic closer to my home. The staff encouraged me to consider home hemodialysis and I am happy to report I began training this November.

Reflecting on my journey to dialysis, I want to thank everyone who directly or indirectly cared/advocated for my well-being. Nurses, techs, nurse managers, nurse practitioners, social workers, dietitians, administrative assistants and most especially my nephrologists. As a patient receiving dialysis, I believe patient engagement is paramount. I want to encourage dialysis patients to:

- Actively participate with your own care: ask questions, share your thoughts, feelings, and concerns. As patients, each of us may have the same diagnosis of ESRD, but none of us are the same – we require individualized and culturally sensitive care.
- Follow the advice of your dialysis team members. These medical personnel have chosen this specialty to advocate for us.
- When you feel down, talk to someone. You will soon realize that you are not alone.
- Share your unique experience as a patient by serving as a patient representative at your facility or as a Network 3 Patient Advisory Committee Subject Matter Expert (PAC SME). The PAC SME description and contact information can be found at <http://www.qirn3.org>

Submitted by "J" with thanks for your time taken to read her ESRD journey.

### JOIN THE PAC

The Patient Advisory Committee (PAC) for QIRN3 consists of dialysis patients, transplant patients and family members of those patients. The committee meets once every two months to discuss issues relevant to ESRD patients. The PAC members have a genuine concern for quality of care issues and encourage patients to be involved in their healthcare. They are willing to share skills and experience with others. Each facility is encouraged to have a PAC representative. Talk to your social worker to volunteer!

Call toll free 1-888-877-8400 to join the PAC.

*To File a Grievance Regarding your Dialysis Care please contact:*

**QIRN3**  
**Cranbury Gates Office Park**  
**109 South Main Street, Suite 21**  
**Cranbury, NJ 08512**  
**Phone: 888-877-8400 (toll-free)**  
**Fax: 609-490-0835**  
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**[www.qirn3.org](http://www.qirn3.org)**

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*Best Wishes for Peace and Happiness in 2017*