



# Network

## Consumer News

**LARGE PRINT VERSION**

### **Transplant Success Story**

*Editorial by Roger Gravgaard*

My journey to transplant started in March 2006 when I began dialysis. Soon after, I was asked to serve on Northwest Renal Network's Patient Advisory Committee (PAC). In June 2007, my family and I went to Seattle for the PAC's in person meeting. While there, we toured Virginia Mason Hospital, a transplant center my nephrologist in Montana works with. We left certain we would be back soon for my transplant.

Due to some issues that developed, I was on and off the "active" transplant list for over 3 years. It wasn't until my wife developed breast cancer that my transplant began to become a reality. One of my surgical nurses, Vickie, had watched a program on TV called "The Doctors" where the topic was living organ donation. She decided to look into this further. Summer 2010 she called me and asked my permission to get tested as a living kidney donor for me. How does one respond to that phone call? I was shocked and extremely humbled, but gratefully accepted her offer. Vickie stopped by the dialysis unit 2 weeks later to tell me we were a match.

Plans were made fast and furiously with Virginia Mason to schedule the procedure. I needed someone to stay with me in Seattle after my transplant, and my uncle volunteered. On August 23, 2010, I arrived at the transplant center for a full day of medical appointments. I thought I knew what to expect, but was amazed at what I didn't know or consider about the transplant process. Vickie and I both discussed our experiences when we met

in the surgical waiting room the morning of the transplant. Vickie went into surgery about 45 minutes before I did and the transplant was done with no complications.

I recall waking up in the Critical Care Unit (CCU). Once my head had cleared, I knew the best way for me to heal was to get active. The nurses in CCU weren't used to a patient like me. The first time I strolled out of the room with my IV pole, it looked like a fire drill. I assured them I wouldn't wander off and was just going to walk around the unit to get blood flow to my limbs. Due to a shortage of beds, I had to stay in CCU for longer than expected and I ended up wearing a path in the floor around the nurses' station.

I was released from the hospital 5 days after my transplant with my new kidney working great! I stayed in Seattle for 6 weeks due to a couple of "bumps" in the road that ended up being nothing serious. One involved a biopsy of my transplanted kidney due to possible rejection activity. After 3 days of steroid treatment, my symptoms were reversed. As a former high school coach, I appreciated the "team" approach the transplant center had with my care during my recovery.

While I waited to return to Montana, I visited NW Renal Network and participated in a conference call with my fellow PAC members. Also during my recovery period, my uncle and I marked the anniversary of my cousin's (his son's) passing. He was an organ donor whose selfless act gave a new lease on life to more than 10 people. It would have been more, but he passed away on 9/11/01, which was a "no fly" day, so his lungs and heart weren't able to be transported to a transplant center for someone to receive.

Since my transplant, I've continued to advocate for dialysis patients, and participate in pre-dialysis workshops for patients and their families. Now I also promote organ donation awareness, for both living donors and deceased organ donation, to increase the number of people who are listed in the organ

donor registry. I was blessed to receive an amazing gift. We all need to share this opportunity to give the gift of life.

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## Dialysis – You Have Options

There are different ways to do dialysis. One of them might be a good fit for your lifestyle and needs right now or in the future. Learn more about each type of dialysis.

- **In-center hemodialysis** – Removal of waste products, electrolytes, and fluid from the blood, at a dialysis center using an artificial kidney called a dialyzer. Usually done 3 times a week but some facilities are now offering nocturnal and daily schedules. This option allows you to interact with others on dialysis.
- **Conventional home hemodialysis** – Requires the patient and a helper to undergo training. Done 3 times a week at home. Benefits include a flexible schedule and fewer trips to the clinic.
- **Daily home hemodialysis** – You and a helper train to do your treatments at home, 3-6 nights a week. This frees your days, and allows fewer trips to the clinic.
- **Peritoneal dialysis (PD)** – Uses the inner lining of your abdomen (the peritoneum) as a dialysis filter. The peritoneum is lined with tiny blood vessels. Wastes and extra water in your blood can flow out of those blood vessels, through the peritoneum, and into special fluid that you can put in your abdomen. Then you drain the fluid, and the wastes, out of your body and put in clean fluid (this process is called an exchange). To do PD, you will have a soft plastic tube, called a catheter, placed in your abdomen or chest by a surgeon. PD requires no needles, and patients have less dietary restrictions.
  - **Continuous ambulatory peritoneal dialysis (CAPD)** – A manual form of PD, with no machine. This option is flexible and adapts to your schedule.
  - **Continuous cycling peritoneal dialysis (CCPD)** – A form of peritoneal dialysis using a machine called a cycler at night while you sleep. This option allows you to have your days free.

If your facility does not offer one of these options, they will tell you about facilities in the area that do. You may also call the Network to learn more, or locate facilities at Dialysis Facility Compare [www.medicare.gov](http://www.medicare.gov).

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## Fluid and Dialysis

### Why are my fluids limited?

One of the jobs of healthy kidneys is to remove extra fluid from the body. When the kidneys fail, dialysis can remove some of the fluid. But you also need to drink or eat less fluid.

### What happens if I have too much fluid?

If you come to dialysis with too much fluid:

- Your treatment could make you feel bad
- Your blood pressure may drop, so you feel dizzy or faint
- Your muscles may cramp
- You may have headaches, nausea, or pass out

Over time, too much fluid can harm your body. Too much fluid can cause:

- Heart problems
- Swelling in your feet or legs (called *edema*)
- Shortness of breath

### What counts as fluid?

- Anything you drink is a fluid. This includes water, coffee, tea, soda pop, milk, beer, wine, and so forth.
- Some foods count as fluids too. Any food that is liquid at room temperature, like ice cream or Popsicles, is a fluid. Soups, thin stews, and watery foods like watermelon count as fluids too.

## **How much fluid can I have?**

How much fluid you can have depends on how much urine you make. If you make a lot of urine, you can have more fluid. If you make no urine, you can have less fluid. Your urine will be measured to see how much fluid you should have. Measuring your fluids for a while will help you get used to your limit.

## **What does salt have to do with fluid?**

Salt makes you thirsty. It also makes your body keep more water. Healthy kidneys remove extra salt. When the kidneys fail, most people must limit salt and fluid. Ask your dietitian how to make foods taste good without adding salt.

## **What is dry weight?**

Dry weight is your weight without extra fluid. It is used as a target for each treatment. At your dry weight, you should feel good after dialysis. This is often measured in kg (kilograms). Each kg equals 2.2 pounds.

For more information about fluid and dialysis, visit Kidney School at [www.kidneyschool.org](http://www.kidneyschool.org).

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## **Medicare Part D**

The Medicare Part D benefit is drug coverage available for anyone who has Medicare Part A and/or Part B. You buy Medicare Part D coverage from insurance companies. It may help you pay for the drugs you need. If you have other drug coverage, you may not need Medicare Part D. You do not have to have limited income or assets to join a Medicare Part D plan. However, if you have limited income and assets you may get extra help to pay for a plan and for the drugs. In most cases, you can only switch plans once a year from November 15 – December 31, with your plan starting the first of the next month. There are a few exceptions to this rule so do ask questions.

Before choosing a plan, make a list of the drugs you take now or may need for the rest of the next year. Include on the list the dosage and amount you take. What drugs are covered, the copays required, and the prices of covered drugs are subject to changes, so the estimate of the amount you will pay over the next year is only an estimate.

To find the best plan for you, use the Prescription Drug Plan Finder on [www.medicare.gov](http://www.medicare.gov) (look for Resource Locator / Drug and Health Plans) or call 1-800-MEDICARE. You can also find helpful information specific to kidney patients at [www.kidneydrugcoverage.org](http://www.kidneydrugcoverage.org).

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## **Using the Buttonhole Technique for Your AV Fistula**

The buttonhole technique is another way of cannulating (putting needles in) your fistula. It requires putting the needles in the exact same spot at the same angle and depth every time your needles are inserted.

Research has shown that, with the buttonhole technique, there are:

- Fewer infiltrations (swelling from the needle going through the fistula wall);
- Fewer missed attempts to place needles; and
- Less pain when inserting needles.

There are dialysis patients who have been using this technique for over 20 years with the same AV fistula! Check with your nephrologist or dialysis nurse to see if this technique would work for your access.

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## **What is Self-Care Dialysis?**

You may have heard the term self-care dialysis and wondered what that involved and if that was something you could do. Self-care dialysis originally involved the patient doing dialysis at home and with the assistance of a

trained helper. Now patients who dialyze in a facility (in-center) can have the opportunity to participate in self-care. For instance, you may set up your dialysis machine, insert needles into your access, and put yourself on the machine. There are other things you may do such as check your own blood pressure and weight during your dialysis treatment. Many patients enjoy self-care, and feel more in control of their disease. Patients who stick themselves find it easier than having a nurse stick them, when he or she may be unfamiliar with the access. If you are interested in self-care, talk with the staff at your facility.

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## **RELATED WEB RESOURCES**

United Network for Organ Sharing (UNOS)  
[www.transplantliving.org](http://www.transplantliving.org)

Kidney School  
[www.kidneyschool.org](http://www.kidneyschool.org)

- Treatment Options for Kidney Failure

National Kidney Foundation  
[www.kidney.org](http://www.kidney.org)

American Association of Kidney Patients (AAKP)  
[www.aakp.org](http://www.aakp.org)

**Northwest Renal Network**  
4702 42<sup>nd</sup> Ave SW  
Seattle, WA 98116  
206.923.0714  
Fax 206.923.0716

**Patient**  
**Toll-Free Number**  
1.800.262.1514  
[www.nwrenalnetwork.org](http://www.nwrenalnetwork.org)

## PATIENT EVENTS

- The National Kidney Foundation presents the 2011 Kidney Walk on June 11, 2011 in Portland, Oregon. For details, visit [www.kidneywalk.org](http://www.kidneywalk.org) or call Shelly Jones at 503-936-7435.
- Join the American Association of Kidney Patients (AAKP) for its 38<sup>th</sup> Annual National Convention, taking place in Little Rock, Arkansas on August 26-28, 2011 at the Little Rock Peabody Hotel. To receive your copy of the AAKP Convention Registration Brochure, visit [www.aakp.org/events/Convention](http://www.aakp.org/events/Convention), or call 800-749-2257.

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