



A PROGRAM OF
RSN
Renal Support Network

Live & Give

Volume 7, Issue 2
Fall/Winter 2011

The bi-annual update helping to educate and motivate people living with chronic kidney disease.

Perspectives



Fall Seven Times, Stand Up Eight

by Julie Glennon

The rigors of treatment mean that it's hard for dialysis patients to sustain employment, although many continue to work. One such patient is 23-year-old Jessie Frysz. Her kidney failure resulted from a disease called Atypical Hemolytic Uremic Syndrome. She started dialysis at the tender age of 12 months. She did get a transplant once, but it lasted only 9 days. Despite all the challenges she has faced, she maintains a

"normal" life.

While dialyzing as an in-center patient three times a week, she continued to go to school. Lots of children on dialysis are home-schooled, but not Jessie! While in school, she participated in musicals and worked in the bookstore. Jessie is also an animal lover who has three pets.



Jessie Frysz at her college graduation with her former nurse; Mary O'Shea.

In college, along with her studies and her dialysis treatments, she had part-time jobs

.....
Fall Seven Times.. Continued on page 7

Look Inside!

- 2 **LORI'S LINES**
Building Your Confidence
- 3 **2ND PLACE WINNING ESSAY**
She's Gone to Pot
- 4 **IT'S YOUR TURN**
How to Engage the Dialysis Team
- 6 **PERSPECTIVES**
Employment Barriers and Solutions
- 8 **TIPS TO REMEMBER**
Am I a Germaphobe?
- 9 **1ST PLACE WINNING ESSAY**
A Breath of Fresh Air
- 12 **RENAL DIET**
To Eat, or Not to Eat

Professional Points



Understanding How Fluid Gains Affect Dialysis

by Raffi Minasian, MD



How much fluid a patient gains between dialysis treatments and how that fluid is removed are emerging as two of the most important issues in explaining why so many dialysis patients develop heart disease.

Patients on hemodialysis have two basic fluid-related problems. First, gaining too much fluid between treatments damages the heart muscles by overstretching them. Second, when fluid is removed too quickly, there's an undetected but harmful effect on the heart muscles.

This double-whammy is the norm for most patients who get conventional hemodialysis three times a week. Patients often exceed safe levels both in how much fluid they accumulate between treatments and in how fast that fluid is removed. Avoiding these problems can preserve heart health.

The first concern is the amount of fluid gain between treatments. The general rule is to gain no more than 3% of your dry weight. When that point is

exceeded, blood pressure rises, and the heart muscles thicken and stiffen, leading eventually to heart failure. This occurs even when patients don't notice any consequences from the excess fluid.

The second concern is how fast fluid can be safely removed during hemodialysis. The rule is not to exceed 10 mL per kg of body weight per hour of dialysis. For example, if you weigh 70 kg, your ultrafiltration rate should not exceed 700 mL per hour.

Although the excess fluid is distributed throughout many body compartments, hemodialysis removes fluid directly only from the blood

.....
Understanding Fluid Gains Continued on page 5



Building Your Confidence

by Lori Hartwell



When the ups and downs of kidney failure get to me, it shakes my confidence, and I wonder whether I can ever do what I used to do or whether

I have the courage to try something new. You see, I have this jury in my head: About half of the jurors think I should live freely and joyously, and the other half are ready to abandon me to my insecurities.

Going back to work after starting dialysis or receiving a kidney transplant can be daunting because you're afraid of losing benefits or just don't feel up to it. Working is part of life, and if we're able to work, we need to do everything we can to stay employable or employed.

When I was in my late teens, I took a job delivering flowers; in exchange, the owners of the shop promised to teach me how to create flower arrangements. I was on daily peritoneal dialysis and didn't know whether I could navigate Los Angeles streets and carry heavy flower arrangements to the door.

But I so wanted to learn how to arrange flowers that I said I'd do it. I took out the Thomas Guide and studied it. I learned that if I dumped most of the water out of the vases first, they were easier to carry. I even learned to parallel park. With each step, my confidence grew.

My goal was to learn how to work with flowers, but I was given so much more. Delivering flowers has to be the best job ever. Everyone—and I mean everyone—is happy to see you. Once, I delivered a black flower arrangement from one company to a competitor that had had better sales that year. The flowers were a promise that the sender was going to bury that competitor the next year. That one was really fun to deliver!

On Valentine's Day, I delivered 40 arrangements. Since I didn't have a boyfriend, I lived vicariously and

enjoyed seeing the reactions. Some women were pleased, while others were hoping that the flowers were from someone else; they wore a cheerful smirk anyway. One of the

“One of the steps in building confidence is being around positive people.”



steps in building confidence is being around positive people, and my customers were certainly that. In addition, I got some exercise, which boosts your confidence.

When I worked at the flower shop, I would walk next door to the deli for lunch, and the same three men ate there a couple of times a week. Over time, I got to know them, and when they had a job opening, they asked whether I'd like to apply. This was a different area altogether and involved displays and packaging for the entertainment industry. I applied and got the job. They not only taught me how to do the job, they taught me the business too. I was eager to

learn, and I had to dress for a corporate environment. I couldn't wear sneakers and jeans anymore. Dressing up every day and putting on some make-up boosted my confidence again. I helped the owner grow his business so that sales reached several million dollars a year. Another step in building your confidence is getting out of those jeans and sprucing up a bit.

When we have an illness, we often compare ourselves to others.

I know I did. Since I grew up with the runner-up to Miss America, my jury was in constant session. Christa was tall, blonde, and beautiful. Whatever was I thinking? But over time I learned that she was very insecure and had her own jury in her head. I learned that I had more self-confidence than she did! So comparing yourself to others is silly and only makes you feel inadequate.

In my early twenties, I joined Toastmasters, which helped me learn to speak in front of a group or even with another person. At first, my voice was barely a whisper, and I wasn't sure people wanted to hear what I had to say. I learned quickly that the people in the group were inspired by my story and by the life lessons I had to share. I also met people from different backgrounds, and

I found my perspective shifting as I learned from them.

The jury in my head still mutters occasionally, but I now have strategies to hold on to my confidence and tell that jury to take a long recess so my confidence stays strong. ✎

Lori Hartwell, President & Founder of Renal Support Network was diagnosed with kidney disease at the age of two. In 1993 she founded RSN to instill “health, happiness, and hope” into the lives of those affected by chronic kidney disease. Lori is also the author of the book *Chronically Happy: Joyful Living in Spite of Chronic Illness* and is a four-time kidney transplant recipient.

Renal Support Network &
Love Across the Ocean
Invite you to go

All-in to Win
for HOPE

Texas Hold'em Celebrity Poker Tournament

Saturday, October 29, 2011 ♠ Los Angeles, CA

RSNhope.org/poker

KidneyTimes Essay Winner



She's Gone to Pot!

Second Place (Theme-What hobby helps improve your quality of life?)

by Ellen Sonenthal

She's gone to pot! What's your first thought when you read this? Someone is crazy, has let herself go, is smoking an illegal substance (in most states), or has a hobby that involves a pottery wheel, clay, and creativity. In my case, it's the latter.

When I was a child, we went to lots of Midwest art fairs. My parents always knew that I would gravitate to the pottery, especially if there was a demonstration. I was mesmerized by the motion of the wheel and the elegance of the forms that would be "thrown" on it. Wow! I could watch for hours and often did. Best of all, this was a free activity, an important aspect when you're poor.

After my college graduation, I vowed that I would learn to throw pots. And I did. It lived up to my expectations. Taking a ball of clay and turning it into a usable vessel was thrilling! My first pots were—well, first pots. But you have to start somewhere.

For years, I told everyone that pottery classes were for stress management and definitely cheaper than therapy! Also, I ended up with lots of bowls that I enjoy using daily. Then, late last year (2010), I found it increasingly

difficult to find the strength and stamina to make pottery. Much to my shock, I was diagnosed with end-stage renal failure. Depression set in, and my stress management tool wasn't available to me.

In late December, I was in the emergency room to start dialysis. At first, I really didn't feel much better, but as I inched toward my dry weight, I started to feel better and get my strength back. Every week, I went to the pottery studio—sometimes I just went to chat and see the demonstrations, sometimes I would find simple projects to complete, but always it was the one thing that I really looked forward to.

After the placement of my fistula, I had less strength in my arm. But I persevered. I asked others to get my clay down and replace it when I was finished since I couldn't lift the 25 pounds. Slowly but surely, I've gained more and more

abilities as my fistula has matured. My pottery isn't as elegant and accomplished as it was before, but I can do a lot and I can trim to get the right shapes. I could throw again, and all was right with the world. Once again, I was mesmerized by the movement of the wheel, as I was during my childhood.

Most of my bowls are donated to the "Empty Bowl Project"; this is a nationwide initiative of American potters to help feed the homeless. All bowls are donated and then sold to the public for \$16. The bowls are washed, and then you can choose a soup you would like to eat. In Las Vegas, there are silent and live auctions as well. Last year, we raised a little over \$42,000!

Now, my hobby of taking a lump of clay and throwing it into a functional bowl is not only a hobby, but also a stress management tool and my salvation once again. It helps me feel normal and alive, instead of just a dialysis patient! When I'm in class, I'm a potter and proud of it! ☺



Ellen Sonenthal works at her pottery wheel.



Ellen Sonenthal, worked for IBM 30 years in various technical sales, programming and management positions. Diagnosed with end stage renal disease in December 2010, currently a hemo dialysis patient. Ellen enjoys spending time with family (husband, son and step-daughter), volunteering, making pottery and developing new renal friendly recipes. She currently resides in Henderson, Nevada.



How to Engage the Dialysis Team

by Debra Hain, PhD, APRN, GNP-BC

The Centers for Medicare & Medicaid Services has recommended that health care professionals take a patient-centered approach to care. This means that patients have a right to know about their health care and to be involved in the decision-making process. As a person undergoing dialysis, what does this mean for you? It means that you should feel empowered to ask questions and to express your beliefs, values, desires, and preferences about your treatment. Empowerment means that you can exert some control over factors that affect your life. Hence, you should have a say in your care. You have the right to be educated so that you understand your treatment options and participate in shared decision making. Although this sounds like a good idea, not all dialysis teams practice patient-centered care or are aware of the role of the patient. By understanding your role, you might be able to help your dialysis team engage in patient-centered care.

Implementation of patient-centered care involves developing a partnership with your dialysis team. A partnership is formed when two parties (patient and dialysis team) come together as experts to establish an appropriate plan of care. You, the patient, know yourself and your wishes and preferences, and the dialysis team has expertise in end-stage-renal-disease and treatment. Together you mutually establish goals that are potentially achievable.

Any successful partnership requires respect and trust. This means that you and the dialysis team can participate in a discussion where each person can talk freely without feeling threatened. You can ask questions and tell the dialysis team how you feel about the recommended treatment. Effective communication is the key to a successful partnership.

In 2002, in an effort to promote patient safety, the Joint Commission along with CMS began a campaign called SPEAK UP. The aim is to encourage patients to become actively involved in their care by becoming informed consumers. I have adapted SPEAK UP for persons undergoing dialysis:

S: Speak up if you have questions or concerns. If you still don't understand, ask again. Discuss your wishes and preferences to be sure the dialysis team's recommendations will fit into your lifestyle; discuss alternative options if they don't.

P: Pay attention to your care. Don't assume anything. Always make sure that you're getting the right treatments and medications. Protect your dialysis access by understanding how to care for it.


E: Educate yourself about kidney disease and dialysis. Feel free to write down the information, or else ask a team member to help you. Share this information with your family and friends. Understand what your blood tests mean and why the dialysis team may make recommendations for changes in your diet or your treatment based on your laboratory results.

A: Ask a trusted family member or friend to be your advocate, to ask questions that you may not think of when you're stressed, and to speak for you if necessary. Let the dialysis team know whom you have chosen and how much involvement you want that person to have.

K: Know what medications you take and why you take them. Ask for written information, including brand and generic names. Also ask about possible side effects. Whenever you get a new medication, remind the dialysis team about any allergies. Understand your blood test results and why they may necessitate changes in your medications.

U: Use a dialysis center that you know provides quality care; talk with the dialysis team about patient-centered care and patient involvement.

P: Participate in all decisions about your treatment. You are the center of the dialysis team.

To get your dialysis team engaged, you must be actively involved in your care. Establishing a partnership can benefit both you and your dialysis team. Remember, speak up for your health. 



Full article including references available on KidneyTimes.com ELA# 556

Debra Hain, PhD, APRN, GNP-BC has over 25 years of nursing experience, working in various areas of nephrology. She is an Assistant Professor at Florida Atlantic University, Christine E Lynn College of Nursing and works part-time as a nurse practitioner at Cleveland Clinic Florida, Department of Nephrology in Southeast, Florida.

Communication Prescription

A video presentation for professionals on how to better communicate with patients.

Watch it for free or purchase a DVD to show others at
RSNhope.org/CommunicationPrescription



Understanding Fluid Gains

Continued from page 1

vessels. The body responds by shifting fluid from other tissues to refill those blood vessels. These fluid shifts can happen only at a certain rate. If the rate at which fluid is removed from the blood vessels exceeds the rate at which they're refilled, blood pressure drops, and over time damage to the heart results. This damage, unfortunately, is clinically undetectable to patients and their caregivers.

Let's look at some examples. The 3% safe weight gain between treatments can be found by multiplying body weight in kg x 0.03. For a patient who weighs 70 kg or 154 lbs, the safe weight gain is 2.1 kg. The safe rate of fluid removal can be found by multiplying body weight in kg x 10 mL/kg/hour. For that same patient weighing 70 kg, the safe removal rate is 700 mL or 0.7 kg per hour.


For a patient who follows these recommendations, the 2.1 kg of safe weight gained can be removed in only 3 hours at the safe rate of 0.7 kg per hour.

However, if instead the same 70-kg patient gains 3.5 kg over the weekend, things change drastically. First, 3.5 kg is 5% of dry weight, so the heart muscles have been stretched and damaged from the excess fluid volume. Now, in order to remove 3.5 kg at the safe rate of 0.7 kg per hour, dialysis would need to last for 5 hours. A weight gain of 4.2 kg would take 6 hours to remove safely.

What happens in reality is that treatment hours don't change, and the rate of fluid removal is instead cranked up beyond the safe rate so the excess fluid can be removed during the scheduled appointment. This may be good for operational efficiency, but it's not good for heart health.

Although limiting fluid gain between treatments isn't easy, it's extremely important. Weekends, in particular, are a major challenge. The serious consequences of an extra day without dialysis are revealed by the fact that sudden cardiac death in dialysis patients occurs twice as often on Mondays and Tuesdays as it does on other days of the week.

Two strategies can help avoid excess fluid gain. First, limiting fluid gain entails limiting salt intake and controlling diabetes. Second, shortening the time between treatments means less opportunity to retain fluid. More frequent dialysis generally means home therapy, either peritoneal dialysis or home hemodialysis.

The bottom line for everyone on dialysis is that living a longer, healthier life requires controlling your fluid gain. Whether this means careful regulation of diet and fluid intake or increasing dialysis frequency and length, keeping your heart healthy requires being mindful of these concerns. 



Dr. Raffi Minasian has been in private practice of nephrology over 20 years. He has particular interest in home hemodialysis and predialysis CKD. He serves as medical director for several dialysis facilities including a Fresenius dialysis clinic. His "Home Dialysis Centers" clinics are located in Glendale, North Orange County and Rancho Cucamonga.



WHERE NEW LIFE
REQUIRES A CHOICE







RockScar Love sportswear is designed to honor the scars that life's battles represent and the lesson they teach.

A portion of all sales go back to charity.








Get 10% off your order of \$20 or more
by using the promo code "Kidney"

www.rockscarlove.com
for more information

What makes you thirsty?

-  Salty and spicy foods
-  Uncontrolled blood sugar
-  Becoming overheated
-  Boredom

Tips for Controlling Thirst?

-  Read labels to avoid hidden sodium
-  When eating out request that no extra salt be added (sauces and dressings on the side)
-  Sip beverages or suck on ice
-  Manage dry mouth by chewing gum, suck on candy or a lemon, or rinsing with mouthwash.
-  Put grapes in the freezer and they become mini popsicles
-  Stay cool
-  Occupy your mind with other activities



Employment: Barriers and Solutions

by Denise Eilers, BSN, RN

In an unfortunate commentary on the state of renal rehabilitation today, a report from the Government Accountability Office recently stated that “participation in the Social Security Administration’s ...return to work program, known as Ticket to Work, while improved, remains low. According to Sam Johnson (R-TX), the Chairman of the House Ways and Means Committee’s Subcommittee on Social Security, ‘The program is supposed to be providing services to help people get back to work, but increasingly Social Security is simply paying service providers to keep people on the disability rolls.’” Across all dialysis facilities, slightly less than 19% of prevalent patients aged 18 through 54 were gainfully employed in 2004.

Those are the facts, but they do not measure the catastrophic psychosocial impact of unemployment on individual patients and their families. The ability to work is intimately tied to a person’s sense of self-worth, and the original intent of the Medicare End-Stage Renal Disease (ESRD) Program was to keep patients employed and productive. However, renal rehabilitation has generally been a dismal failure. All too often, patients have been channeled into perceived disability and learned helplessness.

ESRD disrupts every single facet of life dramatically and often suddenly—personal relationships, community involvement, family life, leisure, diet, socialization and employment. Numerous interrelated barriers at both the provider and the patient levels prevent people from maintaining employment or using vocational rehabilitation:

- Late referrals to nephrologists, with the resulting increase in symptoms
- Anemia-related fatigue
- Undiagnosed and untreated depression
- Comorbidities (other conditions)
- Dialysis scheduling, especially the lack of after 5 PM or nocturnal treatment
- Total time needed for in-center dialysis
- Short, debilitating dialysis treatments together with a long recovery time
- Preventable dialysis complications, such as hypotension and infection
- Insufficient or biased education about treatment options, including home therapy
- Lack of convenient access to all modalities
- Knowledge gap on the part of professionals about rehabilitation and employment
- High percentage of minority, disadvantaged, and underemployed patients
- Employer misinformation
- Misperceptions on the part of patients, families, and providers

It could be argued that the media bear some responsibility for fostering these misperceptions. With few exceptions, the media portray dialysis patients as sickly, debilitated, and unproductive and perpetuate the myth that all patients soon die without a transplant. Is it any wonder, then, that new patients come to dialysis burdened with so many fears that employment takes a back seat?

Despite these obstacles, there are steps that healthcare providers can take to help patients stay employed:

- Make employment a priority
- Address symptoms as early as possible before maintain-

ing employment becomes problematic

- Correct patient misconceptions about dialysis
- Include employment discussions in predialysis education
- Encourage the treatment options that best align with a person’s work schedule
- Educate the patient’s employer about dialysis
- Expect patient self-management whenever possible
- Provide work-friendly dialysis scheduling
- Revisit employment status regularly and track it over time
- Foster a “can do” mindset for both staff and patients
- Make appropriate referrals to vocational rehabilitation
- Provide mentoring by working patients
- Incentivize providers to keep patients employed

Patients should be encouraged and expected to become equal partners in their care. Shared decision-making should be mandatory:

- Keep open lines of communication with employers
- Be informed of the right to “reasonable accommodation” under the Americans with Disabilities Act
- Get the best dialysis possible to feel as good as possible
- Help providers adopt dialyzer-friendly schedules
- Provide matter-of-fact education to bosses and coworkers about dialysis
- Explore career options through local colleges and community agencies

Given the common knowledge that Social Security Disability Insurance is almost universally available to them, dialysis patients may wonder why they should bother to work. Besides increased income and possible employer insurance, there are tremendous psychosocial benefits. Work not only confers a sense of accomplishment and creates a sense of identity but it also fosters greater independence, creates increased opportunities for socialization, and ameliorates depression.

In 1980, as my late husband and I began training for home hemodialysis, I distinctly remember one of our first conversations with the social worker. She said, “I understand you’re a busy CPA. Great! We don’t want dialysis to interfere with your job. So, what can we do to help? We’ll do our best to work your training around your jobs. Do you want me to contact your employer too?”

That type of mindset should be universal. However, patients habitually begin treatment suboptimally and fall into a downward spiral that ends in disability and unemployment. Work is one of the basic building blocks of a quality life. And quality of life is everyone’s goal! ☺

Full article including references available on KidneyTimes.com ELA# 555



Denise Eilers, BSN, RN lives in Davenport, Iowa, teaches nursing at United Township Area Career Center in East Moline, IL. Her husband Jerry was on home hemo-dialysis from 1980 until his death in 2004. She is also a member of the Network 5 End of Life Coalition and volunteers for Genesis Hospice.



Reprinted with permission from Jazz Communications, LTD

Work from Home Opportunities

Below is a brief list of careers and companies that are great for working from home. To see a full list with links to more information visit RSNhope.org/JobResources.

Companies

- Avon
- Dove Chocolate Discoveries
- Herbal Life
- The Longaberger Co.
- Mary Kay
- The Pampered Chef
- PartyLite Gifts
- Tastefully Simple
- Tupperware

Careers

- Answering Service
- Copy Writer/Editor
- Consultant
- Data Entry Clerk
- Desktop Publisher
- Freelance Writer
- Graphic Designer
- Insurance Underwriter
- Market Research Analyst
- Medical Biller
- Online Teacher
- Online Retailer (Ebay)
- Proofreader
- Translator
- Travel Agent
- Tutor
- Virtual Assistant
- Web Designer

Fall Seven Times...

Continued from page 1

(always with animals). I asked her whether she told her employers about her health, and she said, "Honesty is the best policy." Her dialysis schedule means that there's no hiding the fact that she has kidney disease. In May, Jessie graduated from college with a degree in Veterinary Technology. She's also just finishing up the last few tests needed to get on the transplant list.

I asked her how the kids in school treated her and how she dealt with the dialysis diet all these years. She said, "Kids are cruel but were much better in college." She's made some great friends and has a really supportive family. When friends have parties, they ask Jessie what food they should get for her. She added, "If there's any advice I would share with children, teens, or other young adults, it's to adhere to your diet." She noted that there are always substitutes for forbidden foods. "You might not be able to have potato chips, but you can have Doritos instead," she noted.


I asked Jessie how she manages to balance her busy life, and she said, "You just do it." To me, she's like a

bulldozer—she just keeps forging ahead. Now she's saving her money for a car and interviewing for a full-time position as a Veterinary Technician, and she hopes to move into her own apartment one of these days.

Myra Schwartz has had chronic kidney disease for many years. She was diagnosed with Light Chain Disease in 1970, but her symptoms didn't appear until the 1990s. She then spent 10 years on in-center hemodialysis. For many of those years, she managed a cookware store—a job she greatly enjoyed. Unfortunately, the store eventually went out of business, and Myra was left without a job. In addition, her husband couldn't deal with her illness, and they eventually divorced.

Humor and creativity have always helped Myra cope. As time passed, she began to feel better. An improved sense of well-being led to renewed energy, and she decided to throw herself a 40th birthday party. To her surprise, she was given many pieces of beaded jewelry. She said to herself, "I can make this!" These beads seemed to ignite her inner artist. She had always been artistic and remembered that "creating things with my hands always brought me contentment as a child." She also remembered that she had a box of antique beads in her parents' attic. She could see that box in her mind's eye and found it exactly where she thought it would be.

Myra started making jewelry, including necklaces, earrings, and bracelets that were adorned with all sorts of natural materials in the shape of a kidney. Friends began asking her to make custom pieces, and a business was born. She called it (aptly) Phases. She designed a website, went to jewelry shows, and eventually opened a gallery in her home. All her dreams were coming true.

Myra got a second chance when her cousin's wife, Fran, offered to donate her kidney. They had the surgery in 2002, and it was successful! Myra was fortunate to be able to turn a creative hobby into a business. Today she feels incredibly grateful for the life she has. As she sees it, "It took a medical crisis to turn my life around and help me find the work I was meant to do." 



Myra Schwartz wearing one of her beautiful jewelry creations.



Julie Glennon received a successful kidney transplant in 1999 after being diagnosed with both lupus and chronic kidney disease in 1998. She keeps active by volunteering with The Kidney Association of South Florida where she lives with her husband. She is also a weKAN activist and HOPEline operator with Renal Support Network.

“The quote is ‘there is no place like home’ and you can’t sum it up any better than that. This is my life, this is how I’m going to keep living my life, and this is how I’ll see my kids grow.”

- Duane, 2 year NxStage Patient



Discover the Life-Changing Benefits of Daily Home Hemodialysis with NxStage[®]

Go to www.nxstage.com/beingmeagain to request your free information kit with the “Being Me Again” video featuring Duane and four other patient stories.

The NxStage System One™ is a prescription device. Daily home hemodialysis with the System One involves risks and responsibilities which are detailed in the free information kit. Talk to your doctor to see if daily home hemodialysis with NxStage is right for you.

©2011 NxStage Medical, Inc. NxStage is a registered trademark of NxStage Medical, Inc. System One is a trademark of NxStage Medical, Inc. CAUTION: Federal law restricts this device to sale by or on the order of a physician. APM523 Rev. A

Tips to Remember



Am I a Germaphobe?

by Marissa Carr

Ta Duh...Ta Duh....TA DUH TA DUH! Hearing the first few notes of the score from “Jaws” sends chills down my spine. To this day, I still look every which way when I go to the beach, even though only about 60 shark attacks are reported around the globe in a year. Since I never let the waves reach higher than my ankles, the chances of my being attacked by a shark are just about nil. Yet before I received my kidney transplant, I thought about shark attacks more often than I thought about the consequences of getting an infection from germs.

Germs are microscopic bacteria, viruses, fungi, and protozoa that can cause disease and infection. Ta Duh, Ta Duh. They’re everywhere. TA DUH TA DUH! For the most part, people whose immune system isn’t compromised can live their lives without thinking too much about germs. But now that I’ve received a transplant and have to take immunosuppressants, I must be extra careful not to get an infection and risk rejection of the kidney.

When I was on dialysis and after I had my transplant, my healthcare team made sure that I understood

that frequent hand washing is the best way to prevent infection and illness. I immediately adopted hand washing as my number one method of keeping myself healthy. I spoke with every member of my family about how proper hand-washing techniques could help me stay healthy and help keep everyone else healthy too.

According to the Mayo Clinic’s website (www.mayoclinic.com/health/hand-washing/HQ00407), there are a few simple steps to follow:

1. Wet your hands with running water.
2. Apply liquid, bar or powder soap.
3. Lather well.
4. Rub your hands vigorously for at least 20 seconds. Remember to scrub all surfaces, including the backs of your hands, wrists, between your fingers and under your fingernails.
5. Rinse well.
6. Dry your hands with a clean or disposable towel or an air dryer.
7. If possible, use your towel to turn off the faucet.

Unless my hands are soiled or dirty, I find that hand sanitizers or

alcohol-based hand wipes are good alternatives to hand washing. There are many brands and formulas of hand sanitizers on the market, and I learned that the alcohol content must be 60% or higher to be effective. Bath & Body Works carries moisturizing hand lotion with different scents, and it’s great if your skin becomes dry from using hand sanitizers.

I keep a small bottle of sanitizer with me at all times. In addition, I place bottles around the house in visible, handy locations so that everyone sees and uses it throughout the day.

Yes, I’m a germaphobe. I spent 6 long years on dialysis and don’t plan on having to go back to it because of an infection. If you’re on dialysis, an infection can bump you off the transplant list or require a course of antibiotics or a stay in the hospital. If something as simple as washing my hands frequently or using hand sanitizer will help keep my new kidney healthy and therefore keep me healthy, then I’ll cheerfully do it.

Germaphobes Unite, I say!!! ☺



Marissa Carr was diagnosed with PKD in 1986. She went through six years of dialysis followed by a successful transplant in 2007. Now very happy and healthy, she enjoys being a HOPEline operator and volunteering with Renal Support Network.





A Breath of Fresh Air

First Place (Theme-What hobby helps improve your quality of life?)

by Valen Cover

I'm thankful for the vast amount of hospital memories that have been tucked away in a box, in the bottom shelf of a dresser drawer, down a long hallway, in the back of my mind. However, if I close my eyes there are some memories I can retrieve instantly and re-live the moment.

In 2002 I was lying on a gurney, ready to be taken to another operation. I had been in the hospital for several months, and my tiny veins couldn't handle the daily blood draws. A port was put in my neck so blood could be drawn easier. I was accustomed to being pushed through cold, dark hallways of Johns Hopkins, from one building to another, hearing the wheels squeak in the quiet hallways and

feeling every bump along the way. The usual view was the plain ceiling and cement walls. However, one day my father asked the transport service: "Is there any way we can get her some fresh air?" They paused, and said: "Sure, we can go a different way today."

Off we went down the hall, turning left, then right, and straight ahead for a long time. All of a sudden I heard the noise of a door opening and my view of the plain ceiling was transformed into a gorgeous blue sky, with puffy clouds. A cool breeze blew across my face. I felt alive. This breath of fresh air was the medicine I needed. As fast as the freedom arrived, it vanished as we entered the next building. That day I experienced a feeling that I embraced, a sensation that gave me hope; let my imagination run wild. It was an emotion that led me to my love of the great outdoors.

Whether you have had a bad day at work, or like me, have been battling polycystic kidney disease from an early age, we all need a breath of fresh air, an escape from reality. Today, my escape is hiking in the great outdoors.

This year I hiked the tallest waterfall trail in the US, and the second tallest in the world: Yosemite Falls. I never underestimate what our bodies can endure. I spent 11 months in the hospital when I was 19 and 20, when both my kidneys were removed. I was on dialysis, and thankfully received a kidney transplant. I believe there is nothing I can't overcome.

As I hiked 2,425 feet up Yosemite Falls, I did not think of the challenges I face on a daily basis due to kidney disease. Instead, I felt empowered. Hiking has improved the quality of my life, not only physically but mentally.




Valen Cover takes in the stunning view at the top of Yosemite Falls.

It is vital to always have something to look forward to and set goals and achieve them. As my fiancé and I climbed up the granite cliff, I stood at the bottom and giggled and thought: "I'm going to hike to the top of that!" The journey to the top was difficult, with constant uphill grades and switchbacks, however the perfect blue sky and sunshine kept me focused and determined to reach my goal. Adventures like this contain mysterious, hidden treasures along the

way, and breathtaking views become snapshots in your mind.

My favorite moment occurred when I reached the top of the mountain and looked down to see how small everything was, and how far I had traveled. I looked at the mountains in the distance and my mind was clear, my imagination soared, and I was hopeful for my future. I took my 2:00 p.m. transplant meds at the top of Yosemite Falls, filled with sheer joy, proud of my accomplishment, and overwhelmed with the beauty of transplantation and what I am able to do today thanks to the gift I have been given.

When I am enjoying nature, life seems clearer to me. I consume the simple beauties of the world, re-energized. I reflect on what really matters and dream about the great future ahead of me. I felt like I was on top of the world, standing at the summit of Yosemite Falls. Birds soared at eye level and I was engulfed by a calm, peaceful feeling that told me: "Everything is going to be ok." I reflected on my life and how far I have come and how far I plan on going. Living with kidney disease is not easy, but I am proud to say I am not only surviving but I am thriving! 



Valen Cover was diagnosed with polycystic kidney disease (PKD) at age 10. At 19, both kidneys were removed; she was on dialysis and received a kidney transplant in 2002. Her passion is to educate, inspire and foster hope. To learn more about her triumph over adversity visit: www.dennismccloskey.com & UKROCharity.org/our-stories.

Renal Support Network

Who are we and what do we do?

Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run organization that provides non-medical services to those affected by chronic kidney disease (CKD). Through a variety of programs RSN strives to help patients develop their personal coping skills, special talents, and employability by educating and empowering them (and their family members) to take control of the course and management of the disease.

Chronically Happy: Joyful Living in Spite of Chronic Illness

Written by Lori Hartwell, this is an upbeat, motivational book that helps people living with chronic illness create joyful, fulfilling lives. **Available on Amazon.com for Kindle or in paperback. Audiobook available on CD from RSN and for download from ChronicallyHappy.com.**

HOPEline

A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease.

English **1-800-579-1970** Spanish **1-800-780-4238**

Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).

KidneySpace

An online discussion forum to air your questions, thoughts, and opinions on lifestyle issues related to transplant and kidney disease. Go to **KidneySpace.com** to join the conversation!

KidneySpeak

This program provides tools, resources and presentations to inform people on chronic kidney disease and organ donation. Developed patient speakers through the PEPP (Patient Educating Patients and Professionals) program can also be requested for healthcare and patient meetings.

KidneyTalk

An online radio talk show hosted by Lori Hartwell & Stephen Furst, covering a wide variety of kidney-related topics. Listen at **RSNhope.org** or download podcasts from **iTunes**.

KidneyTimes

An online resource with articles written by kidney patients and professionals on medical, social, nutritional, and lifestyle issues. Home of the annual "KidneyTimes Essay Contest." **KidneyTimes.com**

Patient Lifestyle Meetings

Based on the theme of "Health, Happiness, & Hope," meetings held nationwide offer a setting where people with kidney disease and their families can learn about issues related to their illness in a relaxed, friendly atmosphere.

RSN Renal Teen Prom

Annual prom held in the Southern California area each January for teenage kidney patients. Young people with CKD ages 14 to 24 come from across the United States to enjoy a night of glamour.

weKAN: Wellness & Education Kidney Advocacy Network

A national group of people with kidney disease who advocate on behalf of fellow patients. *Live & Give*—weKAN's biannual newsletter for patients—inform, inspires, and educates patients, family members, and healthcare professionals.

All of this information and much more can be found on our website

RSNhope.org

Like us on Facebook



facebook.com/RenalSupportNetwork

Follow us on Twitter



@RSNhope

Live & Give is a publication of the Renal Support Network's weKAN program. **weKAN** Patient Activists serve to educate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another.

Newsletter Staff

Editor-in-Chief

Lori Hartwell

Graphics, Layout & Design Manager

Jodie Younse

Editorial Advisor

Denise Eilers

© 2011 by Renal Support Network

All Rights Reserved EIN#95-4672679

Contact Information

Renal Support Network

866-903-1728 Toll Free

9 AM-6 PM Pacific Time, Mon-Fri.

Article Submissions

Renal Support Network

1131 N. Maryland Ave.

Glendale, CA 91207

info@RSNhope.org

Web Version (PDF files & archives)

www.RSNhope.org

If you have a change of address, phone number, or email address, please contact us to update it.

Thank You.

Sign up to receive Live & Give

- Yes!** I would like to receive a free subscription to the weKAN Live & Give newsletter.
- Yes!** E-mail me renALERT, RSN's electronic update! (Please provide your e-mail address.)
- Yes!** Please send me _____ additional copies of weKAN Live & Give to distribute.

Name _____

Address _____

City _____ State _____ Zip _____

E-mail _____

Phone _____ home work cell

Please check all that apply:

- Patient:** transplant PD hemo
- Family Member** **Administrator**
- Physician** **Nurse**
- Dietitian** **Social Worker**
- Technician** **Company Rep**
- Other** _____

Credit Card: Visa Mastercard Amex

Donation charge to card \$ _____ Billing Zip _____

Card#: _____

Exp. Date: ____ / ____

Cardholder Name: _____

Signature: _____

Cut form on dotted line and mail or fax to Renal Support Network. Thank You! All Donations are tax-deductible.

Renal Support Network 1311 N. Maryland Ave. • Glendale, CA 91207 toll free 866-903-1728 ♦ 818-244-9540 fax

Give back to Renal Support Network

- YES!** I would like to help RSN continue the programs that help educate and motivate those affected by chronic kidney disease.

Enclosed is my gift of:

\$ _____

Method of Payment for contributions:

- Check or Money Order (payable to Renal Support Network)

To Eat, or Not to Eat

Continued from page 12

because there are risks involved:

- Your blood pressure could drop during the last half of treatment, and choking can occur when blood pressure is low. Some patients have died.
- You could drink too much fluid. Removing large amounts of fluid during dialysis can cause drops in blood pressure.
- You could have problems with your bowels after you eat, and you might need to interrupt your treatment or end the session early to go to the restroom.
- You could be tempted to accept food from another patient, but this could expose you to germs. Another patient could even spread a microscopic bit of blood to you.

Further, each person must evaluate several individual factors before deciding whether to eat during dialysis:

- Can you chew and swallow normally, or do you have problems with food or liquid "going down the wrong pipe" and causing you to cough or choke?
- Can you feed yourself?
- Can you provide your own food and drink?
- Do you have severe or frequent drops in blood pressure, especially during the first part of your treatment?
- Do you vomit or feel nauseated during dialysis?
- Are you mentally alert during dialysis, or do you sometimes experience changes in consciousness?
- Have you maintained your target weight within 5% since your last session? (You can ask the nurse or technician about this.)

Also, you should ask your doctor whether eating during dialysis is the best choice for you. Ideally, you should eat a balanced meal before you start. However, you might not feel like eating at 5:30 am when you have the 6 am shift! You might need to drive an hour to reach the unit and might not be hungry before you leave. Or you could have a tight schedule with no time to pack a meal.

Life happens, and we understand that it might not be easy for you to eat before you start treatment. So, if you and your doctor think that eating during dialysis is a good choice for you, here are some guidelines:

- Eat during the first half of the session since your blood pressure is usually more stable then.
- Sit upright (at least a 45-degree angle) while eating or drinking.
- Don't drink more than 1 or 2 cups of fluid.
- Don't chew gum or eat hard candy in case your blood pressure drops during treatment and you feel faint. Choking could result.
- Bring your own food and drink, don't share it, and remember to clean up after yourself.

Remember that it's up to you whether you eat during dialysis or not, and now that you know the benefits and possible risks, you can make a more informed decision.

iBuen Provecho! 



Karen Olsen Hall, RD, works as a renal dietitian for Fresenius Medical Care and has been a private consultant for dialysis patients. She provides motivational coaching for people and enjoys giving presentations on nutrition.

*In this issue of Live & Give...
Getting Back to Work*

Thanks to our sponsors!



Renal Diet

To Eat, or Not to Eat
By Karen O. Hall

Eating during hemodialysis could be a good idea for you. Dietitians are always reminding you to include enough calories and protein and not to skip meals. Since most hemodialysis shifts encompass a normal mealtime, you probably feel hungry when you're at the unit. Eating during dialysis would seem to make sense.

Moreover, if you have diabetes, you shouldn't go for long periods without food, especially if you're taking diabetes medications. Low blood glucose could result.

Dialysis increases your nutritional needs because of losses that occur during treatment and because your diet can be restrictive. You could also experience changes in your appetite or taste buds, and foods that you once liked may no longer appeal to you. Consequently, you could be eating less, and eating during dialysis could help boost your intake.

Some units ask their patients to not eat or drink anything during dialysis

To Eat, or Not to Eat Continued on page 11

Foods to Take with You to Dialysis

High-protein foods

- Sandwich (such as turkey, egg salad, or roast beef)
- Hard-boiled eggs with crackers
- Meat or turkey rolled up with a few low sodium crackers
- Cottage cheese and canned fruit



Turkey, Cranberry, Cream Cheese prepared by Ed Robinson, photo by Jodie Younse

Other snack foods

- Bagel with cream cheese
- Fruit, such as canned peaches, pears, or fruit cocktail; fresh apples, grapes, or strawberries
- Unsalted snack foods, such as pretzels or crackers
- Cereal bars, such as Nutri-Grain®
- Cookies, such as vanilla wafers, graham crackers, or animal crackers

Nutritional supplement

- Nepro®, Ensure®, Boost®, or Glucerna®

Protein bars

- Balance, Zone, Pria, or Vital Remedy