

kidney living®

Winter 2015

Issue 13

SMILE!

TAKE CARE OF YOUR
TEETH AND GUMS

CLASSIC WINTER

RECIPES

DON'T LET DIALYSIS

KNOCK YOU
DOWN



National
Kidney
Foundation®

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DESIGNING KIDNEY LIVING

In my 13 years as a graphic designer at the National Kidney Foundation, it's been a pleasure to use my abilities to reach out to millions of patients. I've worked on interesting projects, from funny holiday cards to annual reports and marketing pieces. Three years ago, I was delighted have the opportunity to work on Kidney Living.

Kidney Living allows me to reach new creative heights while offering a valuable resource for kidney patients. Through my work, I feel like I am communicating directly with people coping with kidney failure.

Although I am not a kidney patient myself, I find myself relating to many of the articles and struggles faced by those who share their stories. While Kidney Living is fun for me to work on and create, what's been even better is getting to know our kidney community. I even enjoy the recipes and cook them for my coworkers to test out!



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dialysis getting you down?

take charge
of your life!

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don't let dialysis knock you down

By Terry Goodman

Terry received an All Star Award at the 2015 NKF Patient Education Conference in D.C.



"I may do dialysis, but dialysis don't do me!"

I was diagnosed with kidney disease in July of 2010, and found myself on dialysis two days after that. I had never been very proactive about my health and had always self-diagnosed instead of going to a doctor. Then, in August of 2010, I had emergency surgery because the kidney disease was causing my body to fill up with fluids—and it was up to my lungs and my heart. When I woke up from surgery, I had a stroke. It affected my right side, so that I had to re-learn how to write, talk, and walk. All I can say is, wow, you take those things for granted until they're gone.

I was lying on my back in the hospital and, even though I was told never to question God, I had to ask, "Why me, God? Why me?" I think it was because I had not been taking care of myself, not loving myself, and not making my wellbeing a priority. It was overwhelming for me to be on dialysis and recovering from a stroke. The only thing I could do was pray and finally start taking control of my health.

The first two years of dialysis were not good for me. After each treatment I felt as though I had been beaten up by Mike Tyson. I would go home and sleep all day, completely drained. But then I took control of my health and my life. With spiritual guidance and a positive attitude,

I began to watch my fluid levels, follow my kidney diet, and exercise. The support and love I received from family and friends helped me in this journey. Now my motto is, "no more drama and no more stress."

The one thing I have realized after four years on dialysis is that life isn't over. In fact, it can get better and better.

Since 2012, I've traveled to Chicago, St. Louis, the Outer Banks, Virginia, Jacksonville, and more. I am able to schedule my dialysis treatment everywhere I go (thank you, Medicare part B). I like seeing different dialysis centers and meeting new nurses, technicians, center managers, and fellow patients. I like being able to give them inspiration.

I've also pursued a long-held dream of becoming a stand-up comedian. I completed a "Five Minutes to Funny" class at the DC Improv Comedy Club. My goal is to make people laugh from the gut.

Laughter is the greatest medicine for everybody, but especially for those going through trying times. I have been performing since April 2014, and am still going strong. As I like to say, "I may do dialysis, but dialysis don't do me."

smile

dental care and dialysis



Good oral hygiene has been shown to have many benefits for those on dialysis.

You may be surprised to learn that good dental care involves more than just brushing, flossing, and a cleaning by a dentist. In fact, taking care of your teeth and gums should be a vital part of your overall health regimen, since it helps prevent heart attack, stroke, and other serious illnesses! For those with kidney disease or on dialysis, it is important to visit the dentist regularly, because complications like gum disease, tooth loss, and thinning enamel may arise.

When the kidneys are not functioning properly, urea can build up in the blood, which can then leave a bad taste and odor in the mouth. In addition, the body may

not be capable of using calcium in a helpful way, which means teeth may become loose and painful.

If you are on dialysis, you should aim to schedule dental appointments within 24 hours of your treatment. It is important that you tell your dentist which medications you are currently taking to ensure there are no complications. For example, patients who are on blood thinners may be at increased risk of bleeding. Your dentist will also need to know which medications you are taking before prescribing any additional medications.

Good oral hygiene has been shown to have many benefits for those on

dialysis. Daily brushing and flossing, changing your toothbrush regularly (every 3 months), and using mouthwash were all associated with improved health outcomes in a recent study. Maintain your smile and your health by talking to your doctor and visiting your dentist every six months.





climbing out of depression

By Leilah Sampson

with support & coping skills

Have you ever felt like you were drowning? Like you can't breathe but you're actually breathing just fine?

Like the weight of the world is on your shoulders and nobody around you understands? Have you felt the pressure to be normal and have it all together? Do you seem just fine on the outside, but feel like you're falling apart on the inside? I know these feelings well. The feeling of being overwhelmed affects us all, but many of us don't have the words to describe the feelings.

Some people believe the only way out is to end it all—to commit suicide. They may contemplate it, thinking about when and where, and the note they'll leave to loved ones saying goodbye. In 2011, I attempted to kill myself through an overdose. I was in stage 4 kidney disease due to FSGS, which means my creatinine was more than 11 and I was spilling 17g of protein into my urine. I hadn't started dialysis yet, and I felt like I was drowning in my own body. My face, legs, and stomach were swollen all the time. I was retaining over 40 pounds of fluid every day. By this time, I'd been hospitalized more times than I could count.

My family was pressuring me to continue to work and take college courses. I don't think they understood how much this pressure

was affecting me. They were used to my being the "old me." I wasn't speaking up about how much emotional and physical turmoil my body was in, because I didn't have the words, and I didn't want to let them or myself down. So, I let this pressure build up, until one day when I was short on paying my rent and scared of getting evicted, I decided the only way to relieve this pressure was suicide. This was my



Leilah Sampson

turning point. After being admitted to two psychiatric floors over the course of a month, I learned that everything I was feeling was normal. Those feelings of anger, depression, anxiety, and failure were to be expected when dealing with any chronic illness. I just hadn't found a way to cope with it yet.

In the psychiatric unit, we attended daily groups and one-on-one

sessions with therapists, nurses, and doctors who validated my feelings. Once I was given permission to feel my emotions, I never let depression take me to that dark place ever again. The groups we attended taught us how to use coping skills for times when we start to feel depressed or overwhelmed.

The coping skills that work for me are listening to my favorite music, spending time with friends, and playing games on my phone. I also learned that when you're dealing with a chronic illness, you will have peaks and valleys. You will have happy days and very low days. But it's what you do to cope during each bad day that will pull you through to the next good day. Because, one thing is for sure—the sun WILL rise again.

Now, it's been almost 4 years and I continue to see a therapist regularly. I can't stress enough how important it is to have a professional you can talk to and help you to sort through issues as they arise. It can be difficult to get the support you need from family, because they, too, will struggle to cope with your illness. Since I've been in therapy, I have endured numerous surgeries, bad days, breakdowns, and family turmoil, but with the help of my therapist, I am able to overcome them all. I am armed with coping skills and an emotional outlet to face anything that comes my way.

get help!

ASK

Ask your healthcare practitioner for a referral to a therapist in your area.

JOIN

Join a support group or contact NKF Peers
855.653.7337

TALK

Talk with your social worker or National Suicide Prevention Lifeline **800.273.8255**

kidney raising awareness

Many people on dialysis wish they had known sooner that diabetes or high blood pressure could one day lead to kidney failure. Many people also find that when they try to explain kidney failure and dialysis to family and friends, most people do not understand what it truly means. In an effort to raise awareness about kidney disease, risk factors, and kidney health in the general public, NKF continues to innovate and develop new programs and campaigns. These are just a few.



YOUR KIDNEYS AND YOU®

A program that trains volunteers to educate the community about the risk factors for kidney disease. This includes an animated video to teach the importance of kidney health in less than 3 minutes.



KIDNEY ACTION COMMITTEE

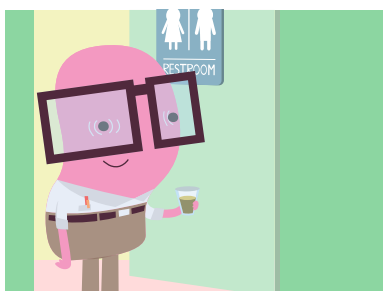
A group of over 70 patient liaisons from around the country. These individuals are engaged in their local communities and actively communicate with the lawmakers who make decisions on legislation and policy relating to kidney disease, making sure the patient voice is heard.



KEEP HEALTHY®

Our free, kidney health screening program that helps evaluate people across the country for risk factors.

Ultimately, our goal is to bring about a “culture change,” so that kidney disease will be as commonplace as recognition of diabetes and heart disease. The goal of these programs is to increase awareness that will then lead to early detection and treatment of kidney disease, improved patient outcomes and will save billions of healthcare dollars in the process.



EVERYBODY PEES

A fun video and website (everybodypees.org) that uses humor to educate about what kidneys do and the importance of urine screening to check for the early signs of kidney disease.



CKD INTERCEPT

An initiative to help change the way primary healthcare providers (PCPs), labs, and institutions think about—and act on—kidney disease. Aimed to educate PCPs with tools to identify signs and symptoms earlier—allowing them to alert patients and slow disease progression.

YOU CAN HELP!

To learn more, visit kidney.org/kidneyliving



I suffer from
severe cramping
during my hemodialysis sessions.

WHAT CAN I DO TO HELP STOP THIS PAIN?

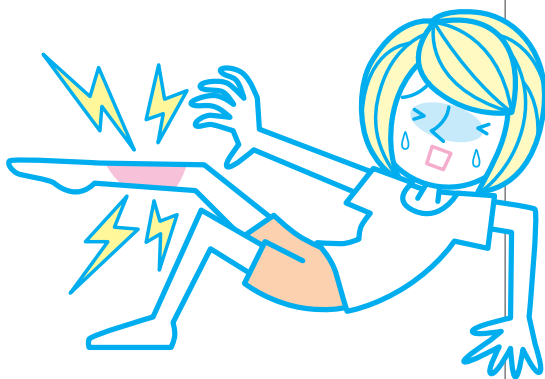
*It feels
like
torture.*

Cramping during dialysis is often related to the balance of water and sodium in your body. Your dialysis care team may tell you not to drink too much fluid between treatments, because people on hemodialysis are often limited to 32 ounces of fluid per day. Remember, fluid intake includes any liquid (soup, smoothies) and anything that melts (ice, sherbet).

You also have to be careful about the amount of sodium in your diet. The amounts of salt and water in your body are constantly changing to stay in balance. Eating too much salt can make your dialysis treatments more difficult. This is because salt retains fluid, and a high amount of salt in your body will resist the dialysis machine's efforts to remove extra fluid. This causes cramping in many patients.

If you experience cramping at any point during dialysis, it is important to let your dialysis care team know. While following your kidney diet and watching your fluid and salt intake are important, there may be other adjustments that need to be made to your dialysis treatment to reduce the risk of cramping or discomfort. Each person's dialysis machine is programmed to follow an individual treatment prescription. What works for one person's body may not work for another's. Sometimes longer treatment may be advised so that fluid can be removed more slowly to avoid cramping.

If you are on hemodialysis, you may also want to consider home hemodialysis or peritoneal dialysis. Both offer longer and slower treatments in the comfort of one's home. Patients who have more frequent treatments often report feeling better overall and experiencing fewer side effects like cramping.





winter classics



Chicken Noodle Soup

Makes 8 1-cup servings

INGREDIENTS

1½ lbs boneless skinless chicken breasts
 2 cups carrots, peeled and chopped
 1 medium yellow onion, diced
 3 stalks celery, chopped
 3-4 cloves garlic, minced
 3 tbsp extra virgin olive oil
 ½ tsp dried thyme
 1 bay leaf
 6 cups chicken broth (low-sodium)
 1 cup water
 ½ tsp salt & ¼ teaspoon pepper, or to taste
 2 cups uncooked wide egg noodles
 3 tbsp chopped fresh parsley

DIRECTIONS

1) In a 6 quart slow cooker add in whole chicken breasts, carrots, onion, celery, garlic, olive oil, thyme, and bay leaf. 2) Add chicken broth, water, and season with salt & pepper. 3) Cover and cook on low heat 3-4 hours. 4) Remove cooked chicken breasts and cut into bite sized pieces. Put chicken back into slow cooker. Add egg noodles and parsley. 5) Cover and cook until noodles are tender, 5-10 minutes.

ANALYSIS

Calories 292	Sodium 230mg
Protein 15g	Potassium 306mg
Total Fat 4.6g	Phosphorus 200mg
Carbohydrates 47g	

Submitted by Manju Khanna, RD



Roasted Harvest Salad

Makes 5 ½-cup servings

INGREDIENTS

2 cups brussel sprouts
 ½ cup cranberries
 1 tbsp olive oil
 ⅛ tsp salt

DIRECTIONS

1) Wash and dry brussel sprouts. 2) Trim off the bottom of sprouts, add salt, and toss in olive oil. 3) Place on a 9 x 13 pan, and roast for 15 minutes at 350° F. 4) Flip sprouts and add cranberries. 6) Roast for an additional 5-10 minutes until warmed through.

ANALYSIS

Calories 43.6	Sodium 67.2
Protein 1.23	Potassium 145.4
Total Fat 2.8	Phosphorus 25.4
Carbohydrates 4.3	





Spicy Meatloaf

Makes 6 servings

INGREDIENTS

- 1 large raw egg
- 6 tbsp barbecue sauce, divided
- 1 clove garlic, minced
- ¼ tsp ground black pepper
- 1 jalapeno pepper, seeded
- 1 lb ground beef-90% lean, uncooked
- ½ cup chopped onion
- ⅓ cup oatmeal

DIRECTIONS

1) Preheat oven to 350° F. 2) Mix egg, 4 tablespoons barbecue sauce, minced garlic, black pepper, and seeded jalapeno. 3) Add ground beef, onion, and 1/3 cup oatmeal and mix well. 4) Spray a 9x13" pan with non-stick cooking spray. 5) Put meat into pan and shape into a loaf. 6) Top loaf with remaining 2 tbsp of barbecue sauce. 7) Bake 30 minutes or until center is 160° F or higher.

ANALYSIS

Calories 199	Sodium 229 mg
Protein 17.3g	Potassium 344 mg
Total Fat 8.7g	Phosphorus 184 mg
Carbohydrates 12g	



Minestrone Soup

Makes 9 1-cup servings

INGREDIENTS

- 2 tbsp olive oil
- ½ large yellow onion, diced
- 2 cloves garlic, minced
- 2 stalks celery, diced
- 1 large carrot, shredded
- ½ cup zucchini, diced
- 1 can green beans, no added salt, rinsed and drained
- 1 tsp dried basil
- 1 tsp dried oregano
- 1 tsp black pepper
- 1 can diced tomatoes, no added salt (14 ounces)
- 4 cups low sodium chicken broth
- 1½ cups macaroni pasta

DIRECTIONS

1) Heat olive oil in a large pot or dutch oven on medium heat. 2) Add onion and cook 2-3 minutes until translucent. 3) Add garlic, celery, carrot, and zucchini. Cook about 5 minutes until the vegetables soften. 4) Add green beans, basil, oregano, black pepper, tomatoes, and chicken broth. 5) Bring to a boil then reduce heat and simmer for 10 minutes. 6) Add pasta and cook 8-10 minutes or according to package directions.

ANALYSIS

Calories 75	Sodium 77mg
Protein 4.9g	Potassium 287mg
Total Fat 4.5g	Phosphorus 79mg
Carbohydrates 5.5g	



YUM! Turkey Bacon & Cheese

Deviled Eggs

Makes 6 1-egg servings

INGREDIENTS

- 6 large raw eggs
- 3 tbsp mayonnaise (light)
- 1 tbsp mustard
- 1 tbsp 2% milk reduced fat shredded sharp cheddar cheese
- 2 slices fully cooked turkey bacon
- ⅓ tsp ground black pepper
- 2 tbsp chopped spring onions or scallions

DIRECTIONS

1) Place eggs in a saucepan in a single layer. 2) Add water to cover eggs. 3) Cover pot and bring water to a rolling boil. 4) Immediately turn off heat and let eggs sit for 15 minutes. 5) Drain, place eggs in ice water, set aside, and let cool. 7) Crack and peel eggs. 8) Halve eggs lengthwise, remove yolks, and put them in a bowl. 9) Combine cooked egg yolks, mayonnaise, mustard, cheese, one piece of turkey bacon, and pepper. 10) Scoop egg yolk mixture back into halved eggs. 11) Garnish with remainder of bacon, cheese, and green onion.

ANALYSIS

Calories 107	Sodium 191 mg
Protein 7.3 g	Potassium 82 mg
Total Fat 7.9 g	Phosphorus 105 mg
Carbohydrates 1g	

dialysis

By D. Simondet

I'm lying here with such a view
To see all within my purview
The techs are moving about
With hardly nary a shout.

They weigh you and measure
Your pressure and weight
You know it's the right estimate.

Needles are placed to ease the flow
To continue the life we once knew
And soon we will have life anew.
Free of liquid, germs and brew.

The techs know how to do it
Their talent shows every day
You might even say: "that's the way"

They are beautiful people if you must know
Capable, trained and experts in their field
Their goal is renewing life anew.
And I am very grateful I can take part
In this department where life is given
Just so I could keep on living.

of my peritoneal dialysis machine

By Daniel Marlin

When the clock of your kidneys
ran down, your appetite gone,
the dinner before
untouched, you noticed my
hesitation to begin the meal,
smiled across the table,
said,

"Eat darling, eat for both of us."

I think of you, mother,
as I listen
to this machine,
which could have
cleansed the darkness of
fatigue
beneath your eyes,
spared you violent
morning heaves
fifty years ago.

Its' tiny motherboard brain
has no code for fear or dignity,
gratitude or pity.
It does not know my name
as it fills me from five liter bags,
then drains through winding
tubes,
bearing away
the toxins in my blood.

Sometimes its' noise,
leading into sleep,
reminds of voyages,
the earnest rumble of
sturdy vessels
which delivered my limbs
through wind and time.
Its low *ratatat*,
like ropes whipped into the
ferry's mast
on Japan's Inland Sea,
headed to Oshima island,
to the farmhouse
where my wife was born.

Each night, the strange music;
a gentle crinkling,
the great sighs, like a
bus braking,
the hum, steady and dogged,
vibrating like the engine
beneath my bunk
on the black diamond freighter,
plowing swells of the
North Atlantic
as I escaped America at war,
1966.

Listen to the bag sucked dry –
hiss of an enraged raccoon;
and to the motor grown
suddenly still –
silence of a hummingbird
paused from its labor
at the tip of a branch.

I, who carry
your broken gene, mother,
that falling star
in the firmament of cells,
savor, for both of us, the gift
of resurrection by machine.



taking medication as prescribed

When Jenny Shen, MD, started her training to become a doctor, she was surprised by the poor outcomes, such as heart and bone disease, that many dialysis patients face. She realized that many of those poor outcomes happened because people weren't taking their medications the way they were supposed to.

"Dialysis patients take an average of more than 15 pills a day, and only about half of patients take these medications as prescribed," she said. "That could potentially cause harm, either by not taking medications, or by taking them in such a way that could be detrimental to a patient's health."

"For example, some people are very strict about taking their medications in the beginning, but become less so over time, while others are the opposite, developing a consistent regimen over time," she said. "It's important to identify the factors that might be related to these different patterns. This helps us build tools to help people follow their medication plan as their doctor prescribed."

Results of the study will be used to create tools that can be customized to a patient's needs. These tools would help patients develop a plan for taking their medications and set them on a path toward the best health possible.



Jenny
Shen, MD

Dr. Shen is an Assistant Professor of Medicine in the Department of Medicine, Division of Nephrology and Hypertension at Harbor-UCLA Medical Center. In a new research study, supported by the NKF's Satellite Dialysis Clinical Investigator Grant, she will explore these issues with medications, and how they affect the heart health of people with kidney failure.

"Dialysis patients take an average of more than 15 pills a day, and only about half of patients take these medications as prescribed."

How do you stay on top of your **medication routine?**

Every morning it's a routine: I brush my teeth and go straight to the medicine cabinet. Having a journal or a note to yourself on the mirror, refrigerator or in your phone is also a good way to be reminded to take your medicine! *Kenyatta D.*

I simply use a weekly pill organizer and I keep a filled spare one in my car. This simple system has worked for me for 20 years! *Thomas P.*

I find that using a chart is the easiest way to stay on top of your medication schedule. Put the times of day across the top (for example, morning, afternoon, evening, before bed, or specific times if necessary) and the names of the medications along the side. For each medication, enter dosage at the time required. Then, make it a habit to check the chart every day! *Rose B.*

Set up a routine & use a pill box. I found taking the binder the hardest to remember. So when I get my meal ready I put them on my plate. This way they are part of the meal. If I'm eating out I tell whoever is eating with me, please remind to take my medication. *Olga P.*

For years I have been managing all of my meds with a weekly pill organizer, refreshing it once a week, according to my doctors' orders on the pill bottles. *Carol P.*

I take them same time every morning and every night I have my phone ring to remind me. *Ralph C.*

My husband used these little packets that have all of your pills for a specific time of the day together in a little easy to use packet. The packet has the name and info of each pill it contains. *Amy M.*

We have individual day medication holders that I fill once a week. Reds are for dialysis day medication regimen; other colors are non-dialysis days. The reason for the difference is dialysis is early morning and if he takes the other medicine besides his binders, it will wash them out of his system and he won't get full benefit. *Teresa H.*

I take my meds when I wake up, go to bed and at meal times. That helps me not to have to depend on a clock. I depend more on my own body time and moods. *Carlos W.*

The smartest thing is to put an alarm on your smartphone to remind you to take the pills on time. Remember to have your pills with you to take on time. *Brad P.*

As all kidney patients know, binders must be taken with all meals and snacks. I keep a bottle in my purse, several pills in my pocket, a bottle for the table, and a bottle for each vehicle. *Carol*

It's important to know each pill by appearance and also what it is for. It's best to separate the pills by day and time of day. I take 14 pills in the a.m. and 7 in the p.m. These habits work for me and I feel good.
Shirley S.





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and help fight kidney disease.



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