

Headlines

A Special Publication
for people with kidney disease.



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- ...and more stories just for you!



Myth
Busters

For more information, to request a printed copy of this newsletter or to file a grievance, please contact:



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www.facebook.com/heartlandkidney

Your feedback is important to us!

Visit <http://bit.ly/2DjNTas> to tell us what you think of this newsletter.

Throughout this issue, you will see a magnifying glass symbol.



When you see that symbol, you can find more information in the MY KIDNEY KIT (at the dialysis clinic) or online at www.mykidneykit.org.

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A Message from the Patient Advisory Council (PAC) Chair

Hello everyone!

My name is Delmer Esters, and I am the new Patient Advisory Council (PAC) chair. The PAC advises Heartland Kidney Network on their activities to make sure the patient voice and perspective is always included.



Delmer Esters

My journey as a kidney dialysis patient started in Lincoln, Nebraska, 12 years ago when my kidneys failed. I was a hemodialysis patient for three years, then I was blessed to have a co-worker donate her kidney to me! That transplant lasted for six years and now I've been back on dialysis for the last three years. It's been a tough journey, but my family and friends have supported and encouraged me throughout it.

Being on dialysis has given me the opportunity to be a patient advocate at my dialysis center as well. This journey can be a scary one; I witness first hand what patients went through, as my father was on dialysis for six years before he sadly passed away. When the opportunity came to work with my center and the PAC, I jumped at the chance. It truly is an honor to work on behalf of patient care. We are fighting the same battle, and it's important to me that all patients understand what they are up against.

They deserve it; WE deserve it!

Being on dialysis isn't the end of your life, it is only the beginning! I hope to be a positive force in your journey. Keep fighting the good fight, and keep living! I hope you enjoy this issue of *Heartland Headlines*.

Patient to Patient:

“It’s not what you have, but who you have that counts.”

Avery Wills
PAC – Iowa Representative
NPR – North Liberty Dialysis Center (UIHC)



During an interview, you have someone asking questions and you find yourself answering those questions without any problem. When you are asked to write about yourself, I find that to be much harder. As the song says – “where do I begin?”, I guess we need to start at the beginning.

I started dialysis in 2014 and from the very beginning I let it control my life. I stopped doing the things that meant a great deal to me. I stopped singing, hanging out with my friends, and I lost interest in my cheesecake business.

However, I did find that I liked to do one thing and that was sleeping, sleeping and more sleeping. Every chance I got, I would crawl into bed and I could sleep for hours.

My dialysis center’s nephrologist recommended me for transplant. A very good friend of mine went with me to the transplant evaluation and informed me at that time she would be with me every step of the way. I was recommended twice and denied twice.

Something having to do with my heart not being able to handle the stress, so I asked if they had talked to my cardiologist and I was informed “she was not a part of my team”.

This is when I started advocating for myself when it came to health matters. I was no longer going to sit back and accept anyone’s word as final.

During this time, I also became aware of “Honoring Your Wishes”, a decision-making guide to help people write what they want for their health care if they are ever unable to make decisions for themselves.

As I was filing it out, it occurred to me, with my family being so far away I had taken the guess work out of what needs to be done. With two denials, I didn’t give up. I ended up at another hospital in Iowa and things went much better than before.

On November 6, 2015, I received a call saying, “I was listed”. On November 22, 2015, I received a call they had a kidney for me.

I give God the Praise. I thank God for putting wonderful people in my life. I’m singing again, I’m entertaining friends, and I’m back to creating new cheesecake flavors.

Thank you,
Avery Wills



My Network: PAC



Patient Rights and Responsibilities

As a dialysis patient, you have certain rights and responsibilities that are owed to all patients — the right to be respected, honor your dignity and recognized for your individuality and personal needs.

This includes being sensitive to your psychological needs and ability to cope with dialysis. Just as important is your responsibility to treat staff, patients, and visitors with mutual respect.

Unfortunately, in recent years, extreme acts of violence are becoming more frequent and have led us all to be more cautious and watchful in our daily lives.

The dialysis clinic is a very busy place with people of all walks of life coming together to give and get care, each person with their own history, own way of coping and own daily stressors.

Differences can often lead to conflict. Conflict is natural but when conflict leads to threatening behavior, action needs to be taken to keep everyone safe. Together, we can work to make sure everyone is safe and gets the care they need.

Here are a few things you can do to help keep the dialysis clinic safe:

- **Talk** to the staff and/or contact the Network if you have concerns about your care
- **Ask** for help by telling staff if you are having thoughts of hurting yourself or others
- **Never** bring a weapon to the dialysis clinic
- **Never** make threats (physical or verbal) to cause bodily harm or death to another person (even if you do not mean it- staff have to take all statements seriously)
- **Never** make statements that a reasonable person may think of as a threat of violence
- **Speak up**; tell staff if you have safety concerns about the statements or behavior of another patient, staff or visitor
- **Ask** your clinic for information about your rights and responsibilities
- **Ask** your clinic for information on the clinic rules and code of conduct

Medicare & YOU!

There are several programs available through Medicare to help dialysis patients know their options and find out how their clinic is doing compared to others.

Dialysis Facility Compare

By visiting Medicare's Dialysis Facility Compare (www.medicare.gov/dialysisfacilitycompare) you can look for dialysis clinics by zip code, city or state where you can:

- Find information about dialysis clinics.
- Compare the services and the quality of care that clinics provide.
- Get information on patient satisfaction survey results.
- Get other resources to learn more about chronic kidney disease and dialysis.
- Get links to learn more about how Medicare covers people with kidney failure.



My Network

Quality Incentive Program

The Quality Incentive Program (QIP) was developed by Medicare to improve dialysis patient care by setting performance standards for quality of care. Clinics that do not meet the standards may get a payment reduction of up to 2%.

Each year each dialysis clinic should post a new Performance Score Card for you to see how they are doing. Ask your clinic staff where the most recent certificate is posted in your clinic.

Improving care is a team effort. You can make a big difference for you and your clinic by being involved in your plan of care and coming to all your treatments.



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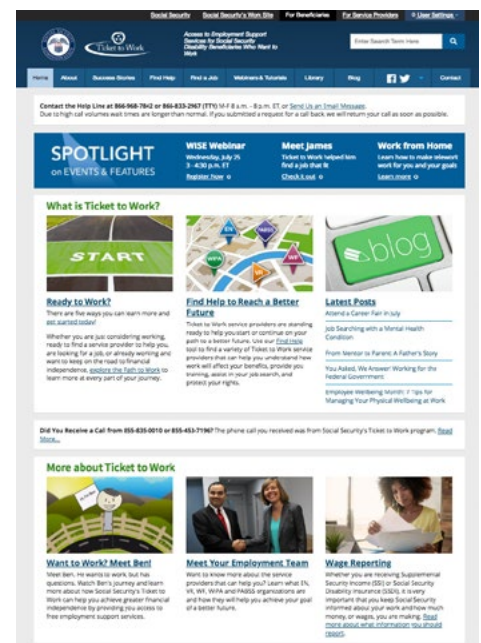
Ticket to Work

Are you between the ages of 18 and 64 years old and interested in working?

Social Security's Ticket to Work program supports career development for people who get Social Security disability benefits. The Ticket to Work program is free and voluntary and can help YOU progress toward financial independence.

Ticket to Work connects you with free employment services, from Employment Networks or Vocational Rehabilitation, to help you decide if working is right for you, prepare for work, find a job or maintain success while you are working.

For more info, call the Ticket to Work Help Line at 1-866-968-7842 or visit www.chooseworkttw.net



My Life: Occupation

Myth Busters: Transplant

Myth: Kidney transplant is a cure for kidney failure.

Fact: Transplant is another treatment for kidney failure. After getting a transplant you will still need to take care of yourself and take medicine in order to keep your new kidney. It is not a cure.

Myth: You can't get a transplant if you're over the age of 60.

Fact: Your overall health is more important than your age. People age 75+ have gotten transplants. The transplant team will let you know if you are suitable for transplant.

Myth: Since I am on dialysis, I am automatically on the transplant waitlist.

Fact: You must get evaluated and accepted by a transplant center to be on the waitlist. The transplant center will let you know if you are on the list by a phone call and/or mailing a letter to your home. If you are unsure, contact the transplant center.



**My Choices:
Kidney Transplant**

Myth Busters: Depression

Myth: Depression doesn't affect me.

Fact: About 16.2 million adults in the United States had at least one major depressive event in 2016.* This means that you or someone you care about could deal with depression at some point in life.

Depression happens a lot in patients with kidney disease. Some studies say it affects 20 to 25 percent of people on dialysis.

If at any point you feel so overwhelmed by feelings of sadness and hopelessness, you should talk with someone you trust such as a social worker or your doctor.

**To find help in your area contact
The HopeLine at 1-800-273-8255.**

Myth: Feeling depressed is a normal part of having kidney disease.

Fact: Depression can be helped even when the person has another illness. It is common to feel sad when you are trying to cope with health problems in your life. You may be dealing with new limits on what you can do and feel worried about your health and the future.

It may be hard to get used to a new way of life and to cope with the changes and ongoing care that comes with kidney disease. Brief feelings of sadness are normal, but if it lasts longer than a couple of weeks, you may have depression. Depression affects how you usually carry on with daily activities.



**My Life:
Coping with Dialysis**

Myth Busters: Home Dialysis

Myth: If I decide to do home dialysis, it will cost me more money than if I stayed at the dialysis clinic.

Fact: Not at all! Both Medicare and private insurance cover the cost of home dialysis.

Myth: My house has to be perfectly clean.

Fact: Your home does not have to be spotless, but you will need a clean space to do your dialysis. Your care team will teach you the steps.

Myth: I will get an infection if I go on Peritoneal Dialysis (PD)!

Fact: Peritonitis can be prevented and is rare with good infection control. Your PD team will teach you how to keep infection away.

Myth: You have to get rid of your pets to do at home.

Fact: Lots of people who do home dialysis have pets. Just make sure to clean well and keep them out of the area when you connect and disconnect.

Myth: I would need a lot of space to do dialysis at home.

Fact: There are patients who live in smaller homes or apartments. Supplies can be sent in smaller amounts, so less storage is needed.

Myth: Home hemodialysis (HD) is a huge burden for a care partner.

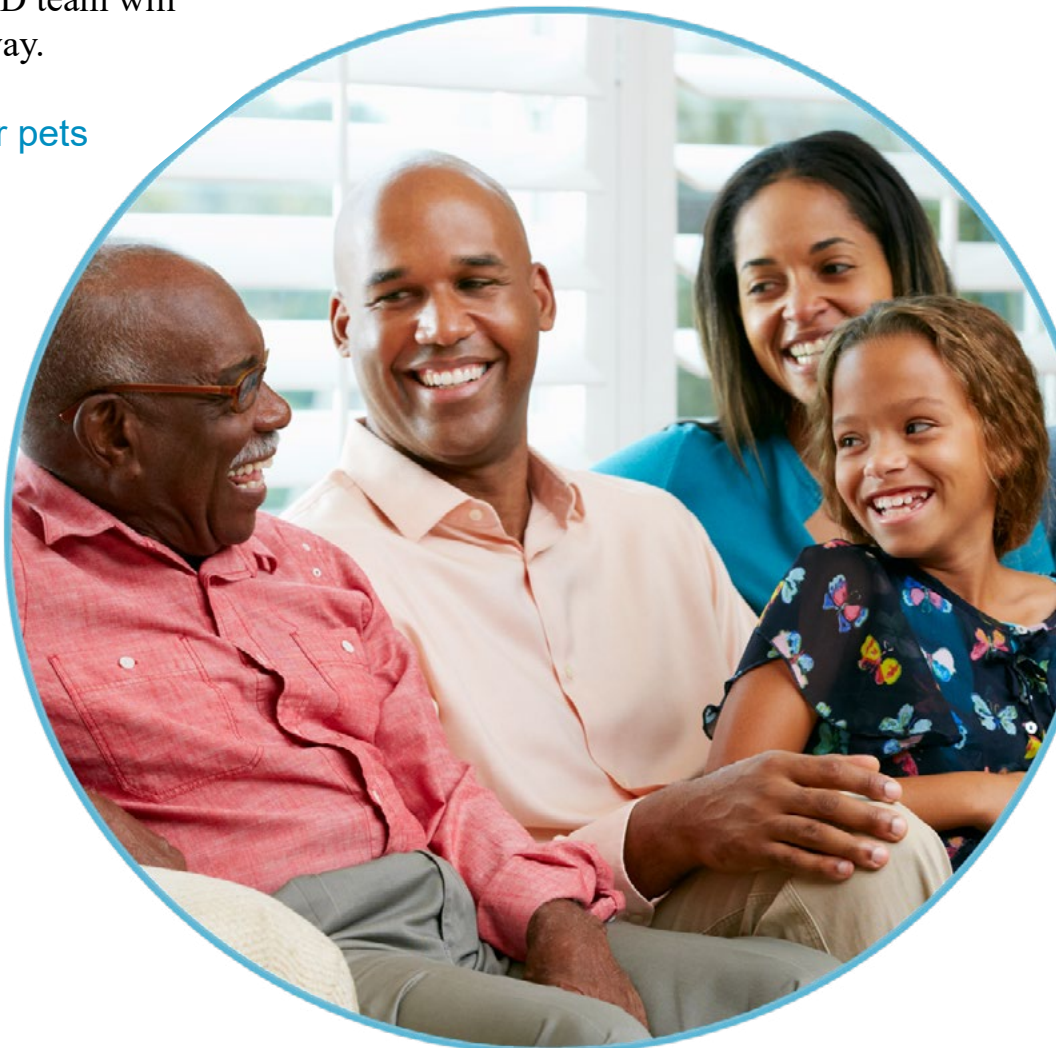
Fact: It's best if YOU do as much of your treatment as you can. Some people do home HD without a partner.

Myth: A home HD care partner needs to have a medical background.

Fact: No. The clinic will teach you and a partner (if they require one). No past medical training is needed.



**My Choices:
Home Dialysis**



NPR Spotlight: Jerry Ribbing



Pictured is Jerry Ribbing with Dori and Melinda, staff at Ozarks Dialysis.

Jerry Ribbing has hit the ground running as the new Network Patient Representative for Ozarks Dialysis in Monett, Missouri.

Jerry and the team at his dialysis clinic hosted their first picnic this May. The picnic included a potluck and games while providing a great opportunity for patients to get to know each other outside of dialysis. The picnic went so well that they plan to have it every year.

In June, Jerry, his fellow NPR, Randal and several volunteers kicked off a new support group. Their motto is “Working together for a healthier YOU”... they are definitely showing the power of teamwork!



**My Network: Network
Patient Representative**

Summer Recipe: Strawberry Sorbet

Servings: 4 Serving size: 1/2 cup

Ingredients

- 1 cup frozen or fresh strawberries (cleaned and stemmed)
- 1 tablespoon lemon juice
- 1/4 cup water
- 1 1/4 cup crushed or cubed ice
- Sugar substitute (to taste)

Preparation

1. Place ice in blender
2. Add all ingredients
3. Turn speed to crush or turn to liquid
4. Enjoy!

Also, try putting it into ice trays or popsicle holders and freeze.

Source: <http://www.davita.com/recipes/desserts/strawberry-sorbet/r/4980#>

Nutrients per serving:

Calories	22
Protein	0 g
Carbohydrates	5 g
Fat	0 g
Cholesterol	0 mg
Sodium	2 mg
Potassium	123 mg
Phosphorus	18 mg
Calcium	12 mg
Fiber	1.5 g

