

# Kidney Concerns

News for Kidney Patients and Their Families

Spring 2018

Informed, Empowered, Engaged

## In this issue...

What I wish I knew...

This issue of Kidney Concerns is continuing the topic of self-management. Again, education is the key to effectively managing our health issues. But sometimes we become overwhelmed with all the information that we are handed, and we don't even know where to start.

So, we asked several experienced patients three questions:

1. What do you wish you had known earlier?
2. How would knowing this have changed your decisions or your quality of life?
3. What would you tell a new patient who is struggling?

In this issue, you will find the answers that were shared. Often, the words of other patients hold more meaning for us as we struggle to find our way. We hope that the knowledge shared by these patients gives you the power to live a better life.

*Maggie Carey,*

**Consumer Committee Chair**



**Midwest  
Kidney Network**

## What do you wish you had known earlier?

Ask more questions and know that staff were willing to answer my questions.

Educated myself:

- Regarding the importance of diet.
- Regarding lab values/obtained a copy of lab reports.
- Regarding key lab values for calcium, albumin, phosphorus, & Kt/V.
- Regarding available resources for understanding these matters.
- Regarding the consequences associated with improper lab values.

Taken better care of my health to feel better & increase my chances of getting a transplant.

Known dialysis wasn't such a struggle & realized how much better I would feel.

Requested updates regarding changes in procedures.

Known at what point I could consider dialysis or transplant.

Known what might disqualify me from getting a transplant.

## What would have changed?

My outlook...instilled hope, dispelled fear, & reduced anger.

The way I take care of myself.

I might have made lifestyle changes.

Signed up for adjustments in the length of dialysis treatments.

I might have felt better.

Improved my chances of getting a transplant.

Been on more than one transplant waitlist.

## Helpful Tips if you are Struggling

- Ask a lot of questions even if you need to repeat them.
- Self knowledge & personal action helps you to feel more in control.
- Ask someone to share their experience with you.
- Expand your support system with a peer mentor or support group.
- Make a list of your concerns and talk to the medical staff.
- Give it some time.



"Managing your fluid intake as a kidney patient, no matter which modality you choose, can be a challenge. Eating a low-salt diet can also make a big difference. Salty foods will make you thirstier and you'll naturally want to more to drink. By limiting your fluid intake you'll help make your dialysis treatments easier, especially the first one after a long weekend." ~Jeff



"I didn't know what to expect. Everything was going crazy for me. They need to teach people what to look for. They need to make the patients more informed about their health care." ~Beverly



"I have a team. Everyone is on my team, the dietitian, the cardiologist, etc... Everyone has to be on the same page." ~Willie

# Patient Voices



"To show up for dialysis is a key thing, you have to participate in your care. If you're going to live on dialysis and do it successfully you have to be compliant. Being compliant means you make sure you have your fluids right, you take your medication and that you're compliant coming to dialysis, you're not late." ~Charles

"I did feel very alone on dialysis. I had to focus on what I could do versus what I couldn't do. For me, I have a wellness plan and with that wellness plan, I do a variety of things between diet and exercise, and mental health, yoga, Pilates, and I have a dog I have trained to take into hospitals and clinics. So I got involved to give back. Set goals, they can be little goals, to find happiness and find what you enjoy and find joy in your life. Find something that you enjoy and keep active." ~Mary



"When I first started dialysis I really didn't understand the function of the kidneys and the function of dialysis. I didn't understand that you had to monitor your fluid intake. Without my kidneys eliminating the fluid out of my body, and still drinking as much fluid as I wanted to, I was overloading my body with fluid. I had a lot of fluid buildup in my hands, my feet and my lungs and heart. I didn't know I was causing it because of my fluid intake. I had to educate myself to be able to understand the fluid intake and the diet. Don't let your kidney disease beat you; you can beat it by your mental attitude. Keep pushing forward and staying healthy. You can overcome it." ~Mitzi



"When I started dialysis, I didn't know anyone else on it. I didn't how I was going to get through it. What worked the best for me was hearing other patients who were living good lives. Knowing that person had what I had and was still having a good life, that gave me hope. And I think hope is the biggest thing that you are missing at the beginning stages. If you can find that hope again then you can continue putting the next foot forward, and it gets better." ~Maggie



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# Informed, Empowered, Engaged

## Am I prepared for an emergency?

1. Do I have a current list of my emergency contacts?
2. Do I have instructions on how to find alternative arrangements for treatment in the event that I cannot get to my dialysis facility?
3. Do I have an emergency stock of supplies, food, and medicines?
4. Do I understand what to do if my dialysis must be delayed?
5. Do I have a copy of the booklet *Emergency Preparedness for Dialysis Patients* from the Midwest Kidney Network?

Did you answer no to any of these questions? Contact your dialysis provider, or us at Midwest Kidney Network, for a free copy of this emergency preparedness booklet. You can reach us at 1-800-973-3773 or [info@nw11.esrd.net](mailto:info@nw11.esrd.net).

### Emergency Preparedness for Dialysis Patients



1360 Energy Park Drive, Suite 200  
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1-800-973-3773  
[midwestkidneynetwork.org](http://midwestkidneynetwork.org)

If you have a question or a concern about your care, or you wish to file a grievance, we are here to help!  
1-800-973-3773