

# Kidney Concerns

Informed, Empowered, Engaged

## In this Issue...

Transition of care is a hot topic. Simply stated, that means making it easier and safer for patients moving from one point of care to another. For example, moving from the hospital to a nursing home is one kind of care transition.

In our own world of kidney disease, it also includes moving from one form of dialysis to another. We have found that very little information exists on the transfer from transplant back to dialysis.

Care providers may think that people who lose a kidney transplant are familiar with the world of dialysis, but times change. Kidney transplant patients who are returning to dialysis need the most current information about their treatment options.

In this issue of *Kidney Concerns*, we start to look at this topic. As a kidney transplant patient myself, this topic is near and dear to my heart.

I also encourage you to visit us on Facebook and check out our new website at [www.midwestkidneynetwork.org](http://www.midwestkidneynetwork.org). Both contain the information and ideas to deal with the everyday challenges that face all of us with kidney disease.

As always, knowledge is a powerful tool.

*Maggie Carey,*

Renal Network 11 Consumer Committee Chair

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*Do you have a question or concern about your dialysis or kidney transplant care? Do you need to file a complaint or grievance?*

Contact Renal Network 11

1-800-973-3773

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# Dealing with Kidney Loss After a Transplant

*From Mitzi in Michigan*

Because your transplanted kidney becomes a part of you, the feelings are almost the same as if you lose a close family member. There are feelings of grief, anger, guilt, and mourning. While I was going through some health problems, I was very slowly losing my transplanted kidney function.

The process of the kidney loss took a little over a year. I went through colon cancer and also intestinal issues. Because I had a living donor transplant from a relative, I thought the kidney would last forever. It was very hard to accept that I needed to start dialysis again. I delayed it as long as I could.

Before I started dialysis, my feet were very swollen. Every day I had a very upset stomach. I was sent back to the transplant facility for five days of in-patient testing and treatment. When I had the transplant twelve years before, I thought that was my last dealing with the hemodialysis experience. The thoughts of why this happened plagued me every day.

After my health problems started, I developed an allergy to the anti-rejection medications. I feel the guilt of losing the kidney. The gift that the donor gave is now a loss. I am now on the transplant list for a kidney from a deceased donor. I have chosen to do in-center hemodialysis until that time comes. I have reached my third year on dialysis. I also work full time. I'm doing all I can to stay healthy to be able to receive the kidney when I get the call.



## Questions for Patients Transferring to Dialysis

1. Before your transplant, what was your experience with dialysis? What questions do you have now about dialysis?
2. What feelings are you having about going on dialysis?
3. How can we make this transition better for you?
4. What did your doctor tell you about home dialysis or getting another kidney transplant?
5. Would you like to speak with a patient who has been through this process?

## Transition from Transplant to Dialysis

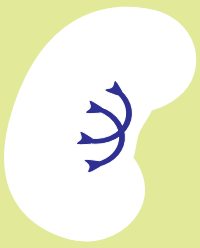
In 2013, there were almost 20,000 patients living with a kidney transplant in the Network 11 area. About 300 of these patients needed dialysis after their transplant failed.

During the transition from transplant to dialysis, patients have shared a variety of different feelings and responses. However, literature search shows little data regarding this transition process.

Sheila Jowsey-Gregoire, MD, from Mayo Clinic, reports the importance of patient resilience. She recommends the following that can help patients at this time.

- Optimism
- Problem Solving
- Flexibility
- Resilient Role Models
- Humor
- Helping others
- Moral compass/faith

Network 11 is working with our dialysis units and patients to learn what kinds of support will improve the transition from kidney transplant to dialysis.



## Dialysis: A Positive Outlook

Jessica Zeman, MSW

Cliff is a dialysis patient. When Cliff was diagnosed with renal failure, he felt nauseated and weak and had several hospitalizations within months. Although Cliff has a wonderful wife and a very supportive family, traveling and attending dialysis was difficult for him.

At the clinic where Cliff receives his dialysis, he has a nurse, Jennie, who is cheerful and outgoing. Jennie laughs with patients and thanks them for coming after every treatment. After over 13 years of working in dialysis, Jennie's motto is "Dialysis is Fun". More often than not, she gets a chuckle from her patients.



Cliff's family started using the phrase "Dialysis is Fun" to help him cope with this change in his life. Cliff's daughter was able to make Cliff a shirt with this phrase to help keep Cliff's spirits up. Of course, Jennie was thrilled to see such a shirt and shared this information with the rest of the dialysis team.

As a way to spread this optimistic outlook on dialysis, his dialysis social worker, Jessica, asked dialysis patients at her other dialysis units, to complete the phrase "Dialysis is..."

Inspired by Cliff's T-shirt, dialysis staff were able to have T-shirts made with "Dialysis Is..." on the front and the responses from our patients printed on the back. Staff are able to wear these shirts on specific dates in the dialysis unit to continue to promote a positive attitude for both patients and staff.

## How You Can Help Other Kidney Patients

Are you a dialysis or kidney transplant patient living in our 5-state area? We hope you will consider joining us and patients – many just like yourself – to gather and apply effective ideas for living well with kidney disease.

We are looking for people to serve on our Consumer Committee. The 13-person committee is made up of dialysis and kidney transplant patients from Michigan, Minnesota, North Dakota, South Dakota, and Wisconsin.

By volunteering your time, you will help us make care improvements that really matter to you and your family – and to future patients.

**If you would like more details about serving on this important Committee, please call 1-800-973-3773.**

Patients share their experience and optimism about dialysis.

Dialysis is \_\_\_\_\_

"Fun"

"Peaceful"

"Life-saving"

"Extending my life"

"Socialization"

"Magic"

"Getting Recharged"

"Crazy fun"

"What you make of it"

"A no-brainer"

"Relief"

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# Informed, Empowered, Engaged

## Tools for Transition from Kidney Transplant to Dialysis

*Sheila Maybanks, MSW*

When a dialysis patient gets a transplant, their team and fellow patients are thrilled for them. But when someone comes back to the clinic for dialysis after a transplant fails, everyone feels bad. The patient may feel worse physically. They may feel guilty even if there is no reason. They may be angry at themselves or the situation or life. They may be depressed.

How can people whose transplant has failed take care of themselves to get through this difficult time?

- Find someone who will listen to you, a loved one, another patient who's had a failed transplant, a social worker, a counselor. When you go through the trauma of losing your kidney, the act of talking about it helps you cope with the loss and get ready to move on.
- Take it easy; get as much rest as you can. If possible, keep the rest of your life peaceful. Don't try to do too much. Do something you enjoy, not just things you have to do.
- Remember, the disappointment and the sorrow is not forever. It is a phase of your life that you can move through.
- Make your time at dialysis as painless as possible. Bring things to make you comfortable, a blanket, books, laptop or a friend to sit with you for the first few treatments.
- Ask your healthcare team if home dialysis is a good option for you.