Kidney Concerns

News for Kidney Patients and Their Families

Fall 2019

Informed, Empowered, Engaged

In this issue...

Transplant Considerations

One of the hardest decisions I have ever had to make was whether or not to pursue a kidney transplant. Does that sound silly? Does it sound like a no-brainer? Well it wasn't. There were a lot of things for me to think about and a lot of fears to overcome.

Fear holds some patients back from pursuing a kidney transplant. Will I be accepted? What do I have to do? How long will it take? What is it going to cost? What if it fails? What are the side effects of the immunosuppressant drugs? Will I be better off if I do this? Or should I just stay on dialysis forever? That is a whole lot of fear wrapped up in those questions.

In this issue, we are going to address some of those fears and provide some answers to your questions. There are answers to many of those questions, however, the fear is something you are going to have to face and overcome. Your feelings are justified and valid. Some kidney transplants don't work, but most of them do. The quality of life that a kidney transplant offers you is awesome. I know because I faced my fears, and my kidney transplant is now 22 years old. Don't let the fear stop you.

Maggie Carey,

Consumer Committee Chair

Midwest Kidney Network

Understanding Kidney Transplantation

For over two years, Midwest Kidney Network has worked to increase kidney transplants for people with end stage renal disease. By working with kidney patients and kidney care providers, we have identified educational needs and ways to improve patient-provider communication.

The Knowledge Assessment of Renal Transplant (KART) tool was developed by subject matter experts to measure patient understanding of the risks and benefits of kidney transplant. We used this tool in our project. Dialysis staff and patients found the tool valuable and were surprised by what they did and did not know.

To test your knowledge and learn more about the development of the KART tool, visit our website at www.midwestkidneynetwork.org/kart

Here are some sample questions from the KART tool.

1. A patient on dialysis has the same level of kidney functioning as a patient with a transplanted kidney? ____ True ____False
2. About what percentage of all transplanted kidneys function for at least 1 year?

   ____ 50% _____ 75% _____90%
3. After a transplant, how long does the US Government pay for most of the costs of transplant medications? ____ 1 year ____3 years _____10 years _____ Rest of life

Answers: 1 = FALSE, 2= 90%, 3= 3 years (currently)

Immunization for Kidney Patients

All patients with chronic kidney disease (CKD) have a lowered resistance to infections. Vaccines lower your chance of getting and spreading certain diseases and disease complications. Vaccines are one of the safest ways to protect your health and your family's health. Talk to your healthcare team in the dialysis unit or at your doctor's office. They will discuss what you need and let you know how to receive the vaccinations.

	Why?	When?
Influenza (Flu)	The Flu is a lung infection that may lead to hospitalization and pneumonia. It can be easily spread to others.	Flu vaccinations are given once each year, usually in the late summer or early fall.
Hepatitis B	Hepatitis B is a liver disease that is no longer as common due in large part to the development of a Hepatitis B vaccine. Not receiving this vaccination could lead to a new outbreak of the disease.	Hepatitis B vaccination is given in 3 or 4 injections over the course of 6-8 months. Boosters may be given depending on how well patients respond to the vaccine.
Pneumonia	About 400,000 people are hospitalized each year due to pneumonia, and 5-7% of those people die from the disease.	Two vaccines can help to prevent pneumonia. They are given in two different injections, usually 8 weeks apart.

Patient Voices About Kidney Transplantation

Financial Concerns

We kidney patients face challenges medically, physically, psychologically, and financially. Kidney transplant is an appealing option for many people, especially living donor transplants. If you are on a kidney transplant waiting list, you may have to wait 3 to 7 years for a kidney transplant. While you are on dialysis, take time to research your cost of a transplant. Everyone's circumstance will likely be different. Costs to individuals/out-of-pocket costs will be dependent on individual health insurance coverage.

Transplantliving.org is a valuable resource to help with understanding multiple aspects of kidney transplant. The website was developed by United Network for Organ Sharing (UNOS), a private, non-profit organization that manages the nation's organ transplant system under contract with the federal government. Specifically, I recommend the section on understanding transplant costs (**transplantliving.org/financing-a-transplant**). The site provides a 10-point medical cost check list and a 6-point non-medical checklist along with many other links including financial assistance. Another resource is the National Living Donor Assistance Program at **livingdonorassistance.org**.

As you work with a transplant center to discuss candidacy, contact your health insurance provider and the transplant center's financial coordinator. They can help to determine your personal costs based on your procedure, the transplant center's policies, and individual insurance coverage. Understanding your insurance coverage and its limits is key (deductible, co-pays, annual and lifetime caps). Note, insurance coverages can change over time so you will have to keep an eye on this, and notify your financial coordinator immediately of any changes. Take your time, breathe, and get help with financial planning research and documentation if needed. Above all, get and stay healthy while waiting. It may reduce your costs! ***-Shared by Gary***

Immunosuppressant Drugs

The effects of immunosuppressant drugs on transplanted patients can at times worry a person taking these medications. A patient on these medications may worry about being exposed to people with colds or viruses because the patient's immune system cannot fight off the diseases. Sometimes there also is a fear of how long you have to be on the medications. Fear of the unknown causes us to worry unnecessarily. Once the medication is stabilized in your system, it is much easier to handle. The right frame of mind is the key to transplants altogether. Think of the medication as your lifeline to living long and having a better life.Taking care of your health properly, such as, eating the right foods, exercising, taking medications on time,and keeping doctor appointments may increase your life span. ***-Shared by Marguerita***

Rejection

My fears of a kidney transplant changed as I went through the stages of kidney failure. My first fear was the one most people hear about – rejection. When I applied to be a transplant candidate, I learned what rejection is, how transplant centers work hard to minimize the chances of rejection, and what treatments are available. After learning these things, I wasn't so worried. My next fear was whether I'd get a transplant at all – type O transplants have some of the longest wait lists. But if you stay healthy, follow doctor's orders and a dialysis program, if you're on one, you should be successful in getting a kidney transplant. ***-Shared by Jeff***

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About Midwest Kidney Network

Who are we?

Midwest Kidney Network is a nonprofit organization founded to improve care for people with end stage renal disease (ESRD). We monitor the care provided to kidney patients in Michigan, Minnesota, North Dakota, South Dakota, and Wisconsin. We are one of 18 ESRD Networks in the United States.

How do we help kidney patients?

We enable patients to voice concerns about the care they receive to an objective third party. If you have a concern about the quality of your care or access to kidney care services, we care. We want to know.

We provide a complaint and grievance process. If you want to have a confidential discussion about your ESRD care or services, we encourage you to contact us.

1-800-973-ESRD (3773)
info@midwestkidneynetwork.org

We also provide information on living well with kidney disease, and contact information for other agencies that help patients with kidney disease.

Visit us online at **midwestkidneynetwork.org** and **facebook.com/midwestkidneynetwork**