

Kidney Concerns

News for Kidney Patients and Their Families

Fall 2016

Informed, Empowered, Engaged

In this issue...

I was recently on an airline flight and I took special note of the flight attendant's emergency instructions. "If you are traveling with a child, or someone who requires assistance, secure your mask first and then assist the other person."

I was paying close attention because there was a family with young children in front of me. I wondered if the parents would actually be able to secure their own masks before they took care of their children. Would I be able to do so in their situation?

I understand how important it is to make sure you are conscious and able to take care of your loved ones. But how often in daily life do we ignore our own health and well-being when we are caring for someone else?

This is a common occurrence for caregivers, those wonderful heroes who give so much of themselves to help us cope with our kidney disease.

In this issue of *Kidney Concerns*, we will explore ways that caregivers can make sure they are taking care of their own needs.

We will also talk about ways to ask family and friends to consider donating a kidney. This is often a very difficult topic to bring up with our loved ones. We are hoping this issue of *Kidney Concerns* will help answer questions and open up conversations on living kidney donation.

Maggie Carey,

Consumer Committee Chair



**Midwest
Kidney Network**

Caregiving: Challenges and Solutions

Many of you have the role of a caregiver to someone or perhaps have a caregiver who helps take care of you. Caregiving can be hard work and is often balanced with several other responsibilities, such as being a spouse, a parent, or an employee.

Tips for Caregivers

- Taking care of you is important, such as getting good sleep and proper nutrition.
- When you are caregiving it is imperative to continue to engage in activities that replenish you and give you energy.
- Be kind to yourself.
- Spend time with trusted people who care about you and with whom you can talk or problem solve.
- Find resources for your specific needs by asking others in your situation what resources they use. You can seek out resources online or within your local community.
- Set limits within your abilities. You cannot meet everyone's needs all the time. Focus on the task at hand and don't beat yourself up when you can't do everything. Set realistic expectations of yourself and the person you are caring for.
- Get help when you need it. Don't be afraid to admit you need help and then ask for it.



Emergency Preparedness

You as a dialysis or transplant patient need no interruptions in your life-sustaining treatments and medications. It is vital that you are prepared in the event of an emergency. This is a good time of year to review your emergency plans.

- Gather and update important medical and contact information.
- Speak with your dialysis provider about what steps you need to take in an emergency.
- Prepare an emergency kit with supplies, food, and medicines.

You may find it helpful to review the booklet *Emergency Preparedness for Dialysis Patients*. For a free copy, contact Midwest Kidney Network at 1-800-973-3773 or visit us online at www.midwestkidneynetwork.org.

Taking Care of Me

One caregiver, Renee, who helps her husband with his home dialysis, says that the support systems in her life have made an important difference to her building her confidence.

She also engages in meaningful work on the family horse farm with therapeutic riding for special need riders. That job helps replenish her energy and makes her happy.

She credits proper nutrition through a biotech company she works with for helping her feel strong and positive. She also is willing to ask for help when she needs it.

She reports the local dialysis clinic with the nurses and doctors have always been supportive, helpful, and very competent. The home dialysis 24 hour helpline personnel have always been available by phone within a minute of any call! That has always been comforting to her.

My Living-Related Donor Experience

During the spring of 2005, I reconnected with my cousin Allen. While growing up, Allen was bigger than life at 6'5" and 360 pounds. But now Allen was a shadow of his former self weighing around 220 pounds. Undetected heart disease and diabetes had taken their toll on Allen. The ashen color of his skin confirmed that he only had 10% of his kidney function. After my visit with Allen, I began to think about his prospects waiting on the kidney donor list for the next 2-3 years.

As I started to research living kidney donation, I realized the threat to me was minimal and the reward to Allen was live-giving. Although Allen never asked me to consider kidney donation, his openness about his need provided an opportunity for me to respond. After numerous tests and physical exams, I was deemed healthy enough to donate a kidney, and Allen and I were a perfect match. It's been eleven years since I donated a kidney to Allen. It was one of the most rewarding experiences of my life, and I have no regrets.

"Although Allen never asked me to consider kidney donation, his openness about his need provided an opportunity for me to respond."

Conversations About Living Kidney Donation

Kidney patients are often reluctant to ask someone else to donate and wonder if they should ask and how would they ask others to consider donating a kidney. More and more people are receiving living kidneys from friends, relatives – and even complete strangers.

Donation of a living kidney usually has a very good outcome. Donors are carefully screened and in good health; surgeries are coordinated with the donor and the recipient. The more people who know about living donation, the more potential for people to come forward as donors.

Tell your story

- Some patients are using social media to tell the story of living donation. Consider your church, community groups and your employer as places to tell your story too!
- Ask your transplant center for brochures on living donation; this information has talking points on living donation that help you tell your story for you.
- If you don't feel comfortable telling your story; maybe a relative or a friend will tell it for you and spread the word of the need. The National Kidney Foundation has a very good section on *The Big Ask* on their website, www.kidney.org.

Educate

- Make the story bigger than you. There are over 100,000 people waiting for a kidney. Instead of asking, it may be helpful to be telling people you know the story of living donation.
- Tell them that kidneys from living donors are more successful. The health risks are very low for someone who donates their kidney.
- Let people know about different living donor types such as, living-related donors and non-related donors, non-directed or altruistic donors.
- Explain that if a potential donor does not match you there is the possibility of paired exchange donation, an exchange with another donor/recipient.

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Resources for Caregivers

The Caregiver Helpbook: Powerful Tools for Caregivers

by Vicki L Schmall available at Amazon.com

AARP: 1-877-333-5885 (1-888-971-2013 in Spanish)

Share, get and give advice with other caregivers on AARP's Online Caregiving Community.

Eldercare Locator: eldercare.gov

A public service of the Administration on Aging, U.S. Department of Health and Human Services, this nationwide service connects older Americans and their caregivers with information on senior services.

Family Caregive Alliance: caregiver.org

(National Center on Caregiving) works to improve the quality of life for caregivers and those they care for through information, services, and advocacy.

Midwest Kidney Network: midwestkidneynetwork.org/patients/living-well

Find state-specific resources on housing, legal services, assistive technology, and more.

