



HUMAN
ORGAN
FOR TRANSPLANT

Living Well on Dialysis

When a Kidney Transplant Fails

By **Jewel Edwards-Ashman**

After years, maybe a decade or even longer, of living with chronic kidney disease you finally get the call from your doctor letting you know that you'll receive a kidney transplant. If it's successful, you'll be able to quit your dialysis treatments. You'll have enough energy to run a marathon, or maybe just walk up a flight of stairs. You'll be able to do whatever you've been putting on hold because of your health. You're not even thinking about another round of kidney failure in the future, and most transplant recipients aren't. Organ failure, however,

is something most transplant recipients will likely face more than once in their lifetime.

I had very few complications in the first few years following my own kidney transplant. Then I became pregnant, miscarried in my second trimester, and ended up undergoing treatment for an acute episode of organ rejection. All of those events left me with decreased kidney function, and I soon learned that my transplanted kidney would likely fail after about five to seven years. My initial reaction: This is not how things were supposed to go. Since then, I've been trying to mentally and emotionally prepare myself for a second round of kidney failure.

Data show that I'm not alone. "The average lifespan of a kidney transplant is 12 years for a deceased donor, and 15 years if you have a living donor who is related", according to Jared L. Skillings, PhD, a transplant psychologist and Chief of Psychology for the Spectrum Health System in Grand Rapids, Michigan.

If you receive a kidney transplant, you'll likely be monitored closely for years by your nephrologists (i.e. kidney doctors) and transplant team, so any news of decreasing function shouldn't come as a surprise. "Patients I have talked to who have had a transplanted kidney for a long time, say 'I kind of knew it was coming,'" says Kristin Kuntz, PhD, a transplant psychologist at

The Ohio State University Wexner Medical Center.

However, some patients become acutely ill, or contract a virus or infection that leads to kidney failure. "For these patients, the failure of the kidney may seem out of the blue. It's sudden. The patient is not prepared for it. It's a very difficult adjustment. You had planned out your life and all of a sudden you're facing a return to dialysis," Kuntz says.

No matter what camp you fall in—prepared for the worst, or completely shocked—kidney failure is hard. Here are some tips for adjusting to the news.

Keep doing the things you enjoy doing and taking care of yourself.

After receiving a kidney transplant, you might go several years without feeling sick. Many of the symptoms of kidney failure will likely disappear and you'll find yourself doing things you wouldn't have done before your transplant. But finding out that your transplant is failing could put you in such a funk that having fun and pursuing new interests seem like a waste of time. Your second instinct might be to withdraw from your friends and family.

Try to keep doing things that you enjoy and spending time with people you care about. "Don't let feeling discouraged keep you from doing the things you like. You'll end up feeling worse, if you stop doing those things," Skillings says.

Also, don't slack off on good health behaviors, Kuntz advises.

Do what you can to stay healthy—eating right, exercising and taking your medications.

Take a step back and reflect on how you're feeling.

You might start worrying about the future or stressing about the next steps after hearing that you'll have kidney failure again. You may even start thinking ahead to your next transplant.



While it might seem like a good idea to start preparing immediately for dialysis or another transplant, Kuntz advises patients to hold off on creating an action plan. Take some time to think about how you're feeling. You'll probably experience a range of emotions, according to Skillings. "Feeling afraid is really normal. Knowing that your transplanted kidney is failing makes you nervous.

You might go through a period of grief where you're mourning the loss of your kidney function. There is a grief process of realizing that you are not well," Skillings say. Some patients also respond to the news with anger or avoidance, or they feel guilty thinking about all the things they could have done wrong.

Some transplant centers require patients to have a period of reflection before starting another transplant process. "The transplant team will probably ask about what you did well with your last transplant, what are some areas for improvement, what worked for you and what didn't work," Kuntz says.

Whether taking time for reflection is a requirement or not, understand that it's OK if you need some time to process everything that's happened. Let your transplant team know if you're taking a breather to prepare for what comes next, whether that's returning to dialysis or pursuing another transplant.

"If you decide to go on dialysis, there is always a chance to go back and do a transplant later, even if you're not ready right now," Skillings says.

Consider who you might tell and when.

It's not always easy to talk to friends, family members and other people you know about your health status. They might not understand why your transplant is failing, which can lead to lots of invasive questions. It's best to share this

information with people who have been supportive of you in the past. Talking about your kidney transplant may even be helpful for your close friends' and family members' emotional adjustment to the news, Kuntz says. If you do tell friends and family, and they are supportive, you'll be able to lean on them when you need help.

You might decide to tell your donor, assuming they are supportive, that the kidney is failing. These conversations can be emotional and difficult, so Skillings recommends writing a short "speech" or memorizing what you want to say beforehand.

You don't have to share the news with people who are toxic or have been unsupportive in the past. "It's OK to not tell someone, even if you're related to them, if you don't feel like it's safe," Skillings says.

Try counseling or get professional help if you need it.

For those of us with a chronic illness, some aspects of our health are out of our control. If the likelihood of kidney failure

is on the horizon, you may feel like there's no point in keeping up with your favorite activities or continuing to take your medications. Some people become depressed.

Seek help if you start feeling hopeless, depressed or are unable to cope with the news. Consider seeing a licensed psychologist, therapist or other mental health professional. Your transplant team or nephrologist will likely be able to refer you to a provider who can help you through this tough time.

Jewel Edwards-Ashman is the member communications manager in the Practice Directorate at the American Psychological Association. She was diagnosed with kidney disease (FSGS) in 2003 and received a kidney transplant in 2013. *This resource was developed jointly by the American Psychological Association (APA) and Dialysis Patient Citizens Education Center as part of a partnership to educate dialysis patients and their families on the psychological and emotional aspects of managing kidney disease* ●