



The Waiting Game: How to Endure the Transplant Wait List


By **Kirsten Weir**, a freelance writer based in Minneapolis

If you are on the organ transplant waiting list (or hoping to be listed soon), you have probably experienced all kinds of emotions: Excitement, nervousness, anxiety, fear, joy, guilt. Maybe all in one day!

The average time spent on the waiting list for a kidney varies from region to region. But for most patients, that wait is measured in years, not months. As the years go by, some people go about their daily lives and forget they are waiting for a life-changing call. Others feel mounting anxiety and hopelessness.

All of those feelings are completely normal, says Heather Ambrosion, Psy.D. a psychologist and postdoctoral fellow at University of North Carolina Transplant Clinic. "Initially, there is usually excitement to get on the wait list. After you settle back into the daily grind, that excitement wears off," she says. "It is very normal to have mood changes while you are going through this process."





The good news is that there are steps you can take to make the wait a little less stressful.

Don't hide your feelings. Many people on the transplant list put on a brave face, even if they are struggling inside. Some are even afraid to tell their providers what they are feeling, for fear it will hurt their chances of receiving an organ. "Some people think they might be taken off the wait list if they are feeling depressed or anxious, because their doctors will think they are not a good candidate," Ambrosion says. "But that is not the case." Ask for professional help. Most dialysis centers and transplant centers have trained psychologists and/or social workers on staff. They can help you navigate the turbulent emotions that go along with the uncertainty of waiting. If such an expert is not readily available, chances are your doctor can recommend one in your community. Talk to people who have been through it. It can be a relief to connect with another person who has walked in your shoes. Look for support groups at your transplant center, or ask your doctor if he or she can put you in touch with a former patient.



Many transplant centers have mentorship programs that pair post-transplant patients with those who are waiting for an organ.

Help your family help you. Your family and friends might be extremely helpful, or they might not realize how much you need. Wherever they fall on that spectrum, it is less frustrating for everyone if you learn to be upfront about how they can help. “A lot of patients do not like to ask for help. They might already feel like a burden,” Ambrosion says. If you are clear and honest about what you need, everyone is likely to be less frustrated.

It is also a good idea to bring family members to your transplant appointments so they have realistic expectations. Hearing it directly from your medical team can help family members better understand what you can and can’t do. “If your family is educated about the transplant process, it is better for everybody,” says Kristin Kuntz, Ph. D., a transplant psychologist at The Ohio State University Wexner Medical Center.

Reset your expectations. While you wait for a kidney transplant, your health may decline. You might not be able to do the everyday tasks that you used to do. That can take a toll on your mood and your self-esteem. “You have to be willing to change your expectations about what you

physically can or can not do,” Ambrosion says.

Try setting new, smaller goals for things to achieve each day. You might not be able to go for a jog, but you can set a goal of taking a 10-minute walk. “Be gentle with yourself. You might have to find a temporary new normal while you are going through this,” Ambrosion adds.

Take control. When you are living on dialysis and waiting for a transplant, life can feel full of uncertainty. Regain control by focusing on the things within your power. You can determine what you eat, how often you are physically active, and whether you take your medications. You can also prepare your home for post-surgery. Make sure you have supplies you will need, like a pill box, a blood pressure cuff, and a notebook to record medical information. “Focus on what you can do instead of worrying about the things that are out of your hands,” Kuntz says.

Focusing on the things you can control will help you feel calmer now, and ensure things go more smoothly in the future, Ambrosion adds. “Anything you can do to take care of yourself during the wait list process will help you after the transplant,” she says. “The better your physical condition, the more prepared you are, and the more support and coping skills you have going into the surgery, the better you will recover.” ●