

## The Truth about Transplants: How to Cope After Surgery

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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.

Ideally, receiving a kidney transplant is a totally transformative experience for patients. A successful transplant can mean an end to the agonizing uncertainty of the waitlist, relief from dialysis and its attendant complications, and—hopefully renewed energy, health and a return to "normal" life.

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But even people whose transplants go exactly as planned can experience anxiety, depression and difficult emotions related to their transplant. They may find it harder than expected to adhere to new medication routines, or have transportation issues that affect their ability to keep medical appointments. Their relationships may be strained. They may have trouble returning to their prior work, or adjusting to new professional roles. Some may struggle with ongoing mental health issues or substance use, or be in financial distress as a result of their medical costs.

You probably already know that these problems can affect your quality of life and the function of your new kidney. But with the help of your transplant team, there are steps you can take to protect your physical and emotional health.

**Be prepared to adjust your expectations.** Staying positive is important, but be careful about pinning your hopes on a dramatic, immediate transformation. You should be prepared for the possibility of complications, says Jody L. Jones, Ph.D., a transplant psychologist with the University of lowa Hospitals and Clinics.

"When you're feeling hopeful, and when all you want is for dialysis to end, it can be hard to absorb that you may not have a smooth course," Jones says. "But I try to help patients stay present in the moment, and focus on taking care of themselves as best as they can."

Even if you don't experience medical complications or have any trouble adhering to post-transplant routines, there may be other challenges. For example, it may take longer than you planned to return to work or other activities—and you may



not be able to return to them at all. Your transplant team can help you manage expectations and set realistic goals.

**Find opportunities for growth.** This can be an opportunity to learn about yourself, especially if you need to identify new pathways to earning a living.

"Use this time to look at what you can do with your life. You can move forward," Jones says. "It may be in a direction you weren't anticipating, but that's okay. Feel inspired by the challenge, not stricken by it."

That might mean going back to school, learning a trade, or getting some other kind of training. "This may be a time to try something new, to focus and learn," Jones says.

**Let go of guilt and shame.** These feelings can come up at many points along the timeline of your transplant experience, says Audrey A. Krause, Ph.D., a transplant psychologist with the Indiana University School of Medicine and IU Health.

For one, it's common for patients receiving kidneys from deceased donors to worry that someone had to die in order for them to get better. They may feel bad about being grateful for another's loss.

Krause helps patients reframe those feelings, suggesting that they think of it this way: "A grieving family has lost a loved one, and you are bringing them additional meaning to that loss."

Patients who receive kidneys from living donors can wrestle with feelings of guilt, too, especially if the donor is a relative. Underlying dynamics—such as those between parents and children—can be a source of stress, though Krause says that usually the relationships between recipients and donors are strengthened through the transplant process.

Feelings of guilt and shame are also common for people

who need another transplant, especially if they weren't compliant with post-transplant medical regimens. People in that situation may feel like they made a mistake and don't "deserve" another kidney.

Krause meets these feelings with compassion, and it's likely that your team will, too. A mental health professional can help you navigate those feelings, as well as help you overcome emotional, psychological, and practical barriers to success.

"You're only human. No one expects you to be more than that," Krause says.

**Rely on your transplant team, and be open with them about your struggles.** Remember that your team is there to support you and wants you to succeed.

Fundamentally, it's their job to educate you about maintaining your health, set realistic expectations, and help you get support systems in place. They can help you if you're struggling with anxiety, depression or other mental health issues.

They also may be able to help if you have problems with your insurance coverage or finances. "If you can't afford your medications, you may be embarrassed and feel like you can't share that," Jones says. "But it's not your fault, and please don't be ashamed. Often, we can connect you with medical assistance programs or tap into other sources of support." The key, though, is to communicate.

"In order for us to help, you have to let us know if you're struggling," Krause says. "We can problem-solve with you and help you get over all kinds of stumbling blocks, so please speak up."