

Preparing for Life After an Organ Transplant

Introduction

The Patient Voice is a report designed to share the wisdom, sentiments and experiences of patients like you. In this edition, we focus on some of the key challenges for patients following an [organ transplant](#). What do patients wish they'd known earlier? What kinds of unexpected expenses have they encountered? Read on to learn what post-transplant life is like in the real world.

Meet The Patients

In 2011, PatientsLikeMe hosted an online discussion with 32 organ transplant recipients from [the PatientsLikeMe community](#). Men and women were equally represented with ages ranging from 25 to 60 years old.

In partnership with [Novartis](#), this special research initiative called PatientsLikeMeLeaders™ connected our group of patients with industry representatives to share their transplant experiences. All together, our 32 participants had undergone 43 organ transplants, more than half of which were kidney transplants. Liver, lung, pancreas and heart transplants were also represented.

Managing Expectations and Finances

It may be hard to imagine life after transplantation, especially since the wait for a new organ can be so long. The 32 patients in this research group averaged 27 months pre-waitlist (the time from learning of the need for a transplant to being placed on the waitlist) and 14 months on the waitlist, which in total averages over three years of waiting for a new organ.



What Will I Learn About in This Report?

- Anti-rejection medication side effects
- Ongoing expenses following transplantation
- Post-transplant adjustments and challenges
- How to find other transplant patients

Waitlist	22%	19%	11%	15%	- 0%	33%
Pre-waitlist	33%	7%	15%	11%	- 0%	33%

<3 months
 3-5 months
 6-8 months
 9-11 months
 12-14 months
 15+ months

With this extensive wait – as well as a post-transplant hospital stay of two weeks or more for 45% of these patients – it would seem that there would be plenty of opportunity to discuss life after transplantation with providers. Yet many patients felt they would have benefited from better expectation management. As one person stated, “Patients need more information on lifetime costs and requirements so we have a better understanding of what is coming our way.”

What advice do patients have now that they've gone through it? Here are the top three themes that emerged:

1. Be aware of the short- and long-term side effects of anti-rejection medications

One of the biggest adjustments following transplantation is coming to terms with taking anti-rejection medications for the rest of your life. Most of our patients' negative experiences with transplantation centered on their anti-rejection drugs, not their surgery. As a result, many expressed a desire to better understand these medications, which suppress the immune system to prevent organ rejection.

Where Have You Found the Most Useful Information About Your Anti-Rejection Medications? (n=12 participants)



"CellCept causes me nausea and diarrhea. Prograf seems to make me have hand tremors and anxiety."

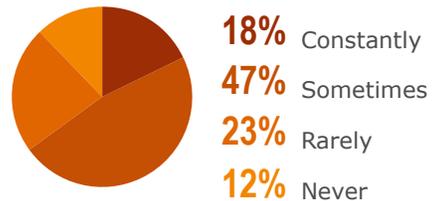
"What gave me the most problems was the prednisone. I am extremely unhappy with the associated weight gain."

"One of the questions for which I have never received an answer: what are the potential long-term side effects?"

2. Prepare not just for surgery costs – but for ongoing costs too

Our patients said they expected their transplant surgery and recovery process to be expensive. For some, however, they did not expect the ongoing costs, particularly for anti-rejection medications, to be so expensive. As a result, many felt that a financial road map would have helped them feel more secure about the future.

Frequency of Feeling Surprised by the Costs of Transplantation (n=17 participants)



"I have been appalled by the cost of the anti-rejection drugs - \$1,500-\$3,500 a month!"

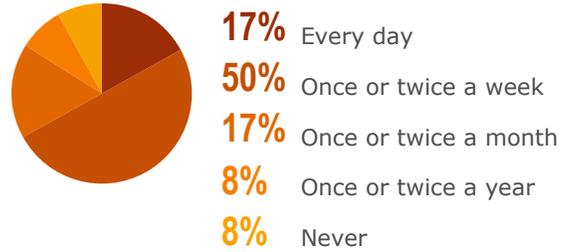
"Paying for medications is a long-term problem. The out-of-pocket costs for my Rapamune would be impossible for me to cover without their [assistance] program."

"The costs associated with traveling, labs and doctor visits are overwhelming to think of, especially considering that I hope to live at least another 2-3 decades."

3. Establish “a new normal” for your post-transplant life

While many of our participants say post-transplant life is not what they expected, they don't regret the experience. They just wish they'd known earlier how best to prepare. In addition, these patients revealed that while a transplant resolves serious worries, it also creates new ones. The key is accepting that life doesn't just “return to normal.”

How Often Do You Think About Your Transplanted Organ? (n=12 participants)



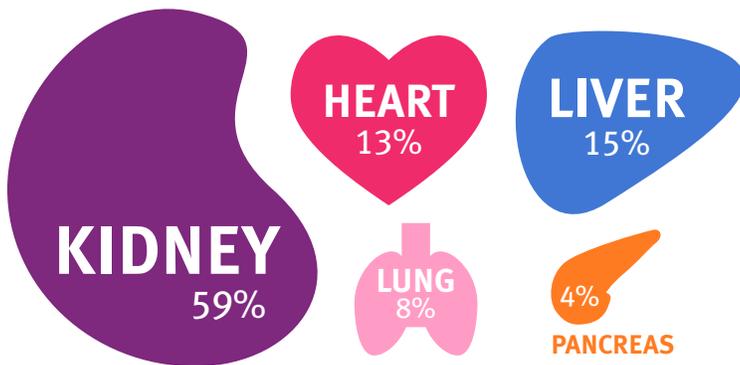
"The one thing they stressed over and over was a transplant is not a cure."

"I had a very good job as a machinist, which I can no longer do. I have restrictions I wish I didn't have, but given the alternative, I am good."

"I am concerned about aging with this condition. As we age, the odds of being placed back on the [wait] list if we reject diminish."

Finding Support and Understanding

Many patients said they've benefited from interacting with other transplant patients. In addition, all participants (100%) were willing to mentor another patient through the transplant journey.



Transplant Patients You'll Find on PatientsLikeMe
Of all the patients who report having an organ transplant, these are the most commonly reported types.

Would you like to find another patient like you? There are [more than 3,000 patients](#) at all stages of transplantation in the PatientsLikeMe community, including patients who have undergone – or are awaiting – a [kidney transplant](#), [heart transplant](#), [liver transplant](#), [lung transplant](#) or [pancreas transplant](#).



"No one understands more than someone who has had a transplant."

"It is very comforting to know what other patients are experiencing."

Questions to Ask: A Quick Reference Guide

Here's a printable summary of some of the questions you may want to ask as you prepare for life after transplantation.



Ask Your Doctor

Medications

- How many anti-rejection medications will I need to take?
- Will my medication regimen change over time, and if so, how?
- How do my anti-rejection medications keep my organ healthy?

Side Effects

- What are the potential side effects of my anti-rejection medications and what can I do to reduce those side effects?
- What long-term risks might I face due to a suppressed immune system and what can I do to reduce those risks?
- What over-the-counter products (e.g. heartburn relievers) may interfere with my anti-rejection medications?

Post-transplant Life

- What will my lifestyle restrictions be post-transplant?
- Will I be able to continue in my current occupation?
- How often will I need lab work and doctor monitoring?

Seeing your care team soon? Our [Doctor Visit Sheet](#) is a great way to get your provider up to speed quickly.



Ask Other Patients

Side Effects

- What medication side effects have you experienced? On which medications? Have they changed over time?
- How have you coped with the side effects (or if possible, resolved them)?
- If you gained weight, how did you lose it – and how long did it take?

Post-transplant Life

- What was recovery like – and how long did it take for you?
- What were the biggest challenges for you and your family post-transplant?
- How do you cope with long-term concerns about organ rejection?

There's much more that you can learn from [other patients](#), though. Join the conversation in [our forum](#).



Other Financial Planning Questions

Insurance Provider

- What will my out-of-pocket costs be for my anti-rejection medications?
- What could cause these costs to change over time? Does my employment status or income have an impact?
- Will I have to use generic anti-rejection medications? If so, how can I request brand-name medications if that's what I want?

Medication Manufacturer

- Do I qualify for your patient assistance program? If so, how do I enroll?
- Do I qualify for other forms of financial assistance? If so, how do I enroll?
- What other financial or non-financial resources do you offer a patient like me?

PatientsLikeMe (www.patientslikeme.com) is the leading online health community for patients with life-changing conditions. PatientsLikeMe creates new knowledge by charting the real-world course of disease through the shared experiences of patients. While patients interact to help improve their outcomes, the data they provide helps researchers learn how these diseases act in the real world. PatientsLikeMe endeavors to create the largest repository of real-world disease information to help accelerate the discovery of new, more effective treatments.