

ARTICLE

## Notes from an Organ Recipient: Once is Enough

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### Abstract

In this paper, the author describes her personal experiences with liver disease and the challenges both before and after receiving an organ transplant. She describes how organs are currently allocated and offers her perspective on what fairness entails in situations where organs fail and patients need multiple organs.

**Keywords:** organ transplantation; liver transplants; MELD score; organ allocation fairness

I was diagnosed with primary sclerosing cholangitis (PSC), which is an autoimmune liver disease, when I was in my early 20s. I clearly remember the appointment with my primary care doctor who told me, and my parents who were with me, the diagnosis. He said it was a progressive liver disease. My first response was “Okay, what do we do about it?” He said there were medications that could be somewhat helpful, but that it would get worse and in about 10 or 12 years, I would need a transplant or I would die.

So, at an early age, I was faced with the knowledge that I was going to need a transplant. As it turned out, I was very fortunate at some levels. I went 6 years with no complications; and, during that time, I went back to school, got my first job and married my husband. Despite the fact I took medication every day, there was nothing to stop the progression of the disease. It is like a freight train coming right at you. There was nothing else for me to do but live my life.

And then, when I was 27, I started feeling sick. The lab tests that had been done over the years showed the disease was progressing; although, I had never really had side effects other than itchy skin. This time I knew there was a change and something more serious was going on.

Luckily, I had a friend who was also a PSC patient and she urged me to switch to a more proactive doctor, which I did. When I met my new physician, he looked at my numbers and said I had about 6 months to live. He talked about trying a procedure—endoscopic retrograde cholangiopancreatography (ERCP). It was followed by a stent placed in the biliary ducts to allow for drainage. Although the procedure is usually a hit or miss proposition, I responded well and went back to my life.

I had hit a valley and came back up, even having the unexpected benefit of a child. I went back to work, lived a busy life and then, about 10 years later, had another flare up and began to get sicker again. I had already well exceeded the original prediction of 10 to 12 years.

At this time, we had moved to Florida for my husband’s work and my doctors said I needed to either get serious about coming back to California and getting listed for a transplant or establish care in Florida. We moved back to the Bay Area and I went through the necessary work up and evaluation for a transplant, knowing I would need it in the future.

Although I was getting progressively sicker and having to have stents placed, I was fortunate to go another 3 years. I had spent my whole life wanting to prove the doctors wrong, that I would never need a transplant. All along, I had been determined to live on my terms in my own way. I think it was an attempt to beat the odds and stay motivated and not give in to the disease. So, for a lot of years, I had done really well; but, over those last 3 years, little things had begun to chisel away at my ability to cope; and, I was able to do less and less. It got harder to eat certain foods without upsetting my gastrointestinal tract. It also got

harder to exercise, to keep weight on, and more difficult to keep my protein intake right. I was constantly making adjustments along with trips to the hospital to undergo procedures, including removing fluid from around my lungs so that I could breathe.

Finally, I remember sitting in a hospital room looking at my doctor and saying, “Okay, I’m ready to do the transplant. I’ve done everything I can do to stave it off. And now I’m just ready.” I know some people, for lots of reasons, never get there; but I finally came to the realization that I could not do this by myself anymore. I had to give in and let the process take me wherever it was going to take me.

Next, I had to face the realities of the unfairness of the transplant system in the United States. Because there are so many sick people and not enough organs, those who do not have a Model for End-Stage Liver Disease (MELD) score that is high enough to deem transplantation necessary will never get an organ. A brutal fact is that very rarely in patients with autoimmune liver disease will there be a high MELD score. In my case, living in California, there was no way I was going to be able to get a transplant and I would have died if I had stayed.

There is much discussion around how the system could be made fairer. That is a hard question, and not being a doctor, I do not have an answer. However, as someone who has lived through the current system, I do have two suggestions: One, I think that for people who, through no fault of their own, are born with a genetic condition that causes them to become so sick, that they cannot live their life—and yet cannot reach a MELD score necessary to win them a place on the transplant list—deserve to have their special circumstances considered. In my case, I was so much sicker than my MELD score indicated; I could not walk my dog or take a four-block walk with my son without not being able to catch my breath.

A second suggestion has to do with the problem that different states, and even centers, apply different standards in determining eligibility for recipients. In California, none of that was enough to gain me enough extra points in the MELD system to warrant an exception. As it is, patients with connections and means to travel have an advantage over those who do not. With health insurance that allowed me to move, and a supporting family willing to resettle, I began to look for options. My California physicians were invaluable in canvassing other programs, evaluating which would be best for me, and transferring records. The field narrowed down to New Orleans.

In New Orleans, I was put on the transplant list and we rented a house, assuming it would take 6 months to a year for an organ. I had been there 3 weeks when the call came that there was an available organ. It had been passed over initially because they needed a recipient close by. I said, “I’ll be there in 10 minutes.”

Not knowing if we would ever see each other again, my family and I said our goodbyes as I was being wheeled into the operating room. My next memories were waking up the following morning after transplant in the recovery room and feeling panicky at being intubated. Once I was extubated, it was amazing how quickly I felt better, and how quickly I healed. I stayed in New Orleans for three more weeks after surgery and then I flew back home to California and brought my care back to the physicians who had followed me for 20 years.

My recovery was not simple; there is no simple recovery. It takes time and it hurts; but it was never as bad as having been sick. Every day after transplant was a better day. With my disease, there is always a chance for recurrence. I have experienced an episode of rejection, which is very common; but, from a liver standpoint, I made steady progress.

We each have a life and part that it comes with illness, sickness, and death. Some people do not get as much of it as others; and, I do not want to lose what life is about. For me, life is not about living forever; it is about living the life I have. Now, I have this great liver that is working and I want to do what I can in the time I have. Because I am here, I want to grab what I can and just live it. I do not mean in a wild, carefree, sense. I have a job. I have a family, and I have responsibilities. I have no desire to throw caution to the wind and go skydiving or ski off mountaintops. I am responsible with my health; I do not do drugs or drink—never have nor ever will. I enthusiastically embrace what life has to offer; and, that involves helping others where I can. Physicians ask me to talk to their patients about my transplant experience; and, I am always glad to do so.

People sometimes ask how I feel about getting back in line again if the organ fails. I have strong views about that. There are alcoholics who went sober and were given organs. After transplant, they relapsed,

effectively destroying a second liver. Should they be allowed back in line for a third one? I would say “No.” With any organ, a person is lucky enough to receive, in order to be worthy; they must take care of it. It is like car maintenance, only more so. If you do not fill your car with gas, it is going to stop running. If organ recipients do not stay on top of their immunosuppressive drugs, the organ is going to stop running. For patients who neglect their responsibly in taking care of the organ, they have been fortunate enough to receive—whereas others have not been so lucky—I believe they have forfeited any chance for more repeats.

Compare that situation with the person who is transplanted; but the organ never really works. Right out of the gate, they never even had their shot. It is like a faulty engine, no good from the beginning. In those cases, I would say we should swap that organ out one more time. They are not culpable, they did nothing wrong, they were not neglectful and they deserve another place in line.

For myself, I do not want to die; but, if down the road the disease recurs, I know from past experience that the hardest thing I have had to face is being sick with liver disease. Comparatively, the transplant was easy. When I meet people who are sick with PSC and need organs, I think, “That was me.” I understand what they are going through as no one else could.

When I look at my life now, I am grateful to the surgery and that I have been healthy with no recurrence. That said, as glad as I am that I did it, I would not choose to go through another liver transplant. I have been given my second chance. I treasure it and I would not ask for more.

The way I look at life today is that I have been given this awesome responsibility, with someone else’s liver, to live out the life I have as best I can. If in the future the liver fails, I will not go back to the well in an attempt to extend my life. When I think about another transplant, I think there is someone else out there like I was 20 years ago who needs it. They have their whole life ahead of them and they are struggling with a condition they had no part in creating. Their disease is making their life a misery and I have had my turn. I am living it. I am doing it. Someone else should have that chance.

That is a very personal choice and not one that would necessarily suit others. I have friends who have been transplanted and whose disease is recurring. Fortunately, none of them has needed a second transplant yet. When the time comes, I do not know what they will decide; but, if they opted to go back in line, I could understand it for them. From my perspective, I would feel I was burning up something precious that could go to someone else.

For me, I am good; I am grateful—and that is enough.