



FEATURE

PATIENT COMMENTARY

My three livers: how transplants gave me my life back

By the time **Erin Walker** turned 20 she was on her third liver, after a second transplant. Seventeen years on she reflects how organ donation has enabled her to experience many of life's rites of passage

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In 1979 the immunosuppressant ciclosporin had been developed, radically improving survival rates after organ transplantation. In 1983 transplantation was approved to treat end stage liver disease.¹

In January 1986, aged 4 and with primary sclerosing cholangitis, I had a liver transplant in Boston, USA. We lived in Ottawa, Canada, and I'd been on three waiting lists because my health was so poor.

Waiting had been a time of grief and anguish. One liver came up for me around Christmas 1985, but I had an infection, and the transplantation could not go ahead. My parents thought that this had been my only chance, but another came soon after.

I'm unsure what I remember from that time and what my parents have told me since. It was a profound experience for my whole family. My parents were just 30 and 31. I'm the youngest of four siblings. My identical twin sister was, and has remained, healthy.

Nearly brown with jaundice

I remember feeling fear and trying to be brave for my parents. I've seen photos of a cheerful looking little girl, abdomen bloated with ascites and nearly brown with jaundice, but I have little recollection of her. What's striking is the juxtaposition with photos of my twin—rosy faced, bright eyed, and half a foot taller.

My childhood after transplantation was quite healthy. I caught up with my twin sister in cognitive and physical development. But worries about rejection plagued us occasionally.

At age 17 I developed chronic ductopenic rejection and was told that I'd need another transplant. I had thought that my transplant in 1986 had been curative.

I experienced profound depression and symptoms of liver failure. I dropped out of high school. But, with support and adjustment to my drugs, I caught up with my peers.

My health continued to decline, however, and I dropped out of university after a year or so. As I waited for another transplant I experienced another episode of major depression and debilitating fatigue. I would not have made it through that time without my family.

I became convinced that a liver wouldn't become available in time—that I'd die without experiencing most of life's rites of passage. Seven months later a suitable liver became available: it was September 2002, and I was only 20.

The happiest girl in the world

I described myself then as the happiest girl in the world. After recovery I returned to university full time, worked part time, and had a regular 20 year old's social life.

But I was devastated to have recurrent primary sclerosing cholangitis diagnosed the day I turned 24, in 2005. I'd suddenly become itchy: the pruritis with liver failure is striking. A doctor confirmed bacterial cholangitis and diagnosed recurrent liver disease. I felt dread, then desperation, and then depression again.

In the 14 years since then my health has fluctuated. I still have primary sclerosing cholangitis, and my liver is atrophying. I also have ulcerative colitis and chronic neuropathic pain. I continue to experience depression and have developed generalised anxiety disorder.

But, thanks to transplantation, I completed that undergraduate degree, a masters degree, and then a doctoral degree on quality of life for liver transplant patients. I moved to the UK, got married, bought a house, worked full time (I still do), and became an auntie. I've undergone many of life's rites of passage, and I'm happy.

Celebrating "liversaries"

No statistics are routinely collected for survivors 30 years after transplantation, but I suspect that the numbers are small. I am

one, however, and every year my family and I celebrate my two liver transplant anniversaries, or “liversaries.”

I often worry how long my current (third) liver will last and whether I’ll have a third liversary to add to those two. It feels like a ticking bomb. I don’t know that my mental health will be strong enough when I’m put on a waiting list. I don’t want my family to have to care for me through another transplant operation, and I’m aware that outcomes become worse with increasing transplants.

People die every day waiting for a transplant because organ donation rates do not meet demand. Without a liver transplant

I would have died in 1986. I’m extremely grateful for these extra 33 years, for most of which I’ve lived a normal and happy life.

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1 Zarrinpar A, Busuttill RW. Liver transplantation: past, present and future. *Nat Rev Gastroenterol Hepatol* 2013;10:434-40. 10.1038/nrgastro.2013.88 23752825

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