

# PRACTICE

## A PATIENT'S JOURNEY

# Irreversible renal damage from accidental mushroom poisoning

Nicholas Evans, author of *The Horse Whisperer*, tells the story of his journey through acute renal failure to successful transplantation.

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

We were visiting family in the north of Scotland. We thought the mushrooms in the woods behind the house were ceps and chanterelles, but we were wrong. The “ceps” turned out to be *Cortinarius speciosissimus*, a cousin of the more widely known deadly webcap. I have picked mushrooms all my life and never before eaten anything without getting 100% confirmation from my two guide books. Our error with the supposed ceps was the result of two people each trusting the expertise of the other—and the consequences were catastrophic.

A blessing was that none of the children who sat down to lunch wanted to taste the mushrooms I'd so proudly cooked. Had they done so, they would almost certainly have died. The guide book, consulted only the next morning when their parents were starting to feel ill, showed a skull and crossbones. It said what we had eaten was “deadly poisonous.”

Within 48 hours my wife and I were in the local hospital, and by the end of the week we were in Aberdeen Royal Infirmary with tubes in our necks and having our first experience of dialysis. We had black diarrhoea and nausea and retched every few minutes until all that came was blood and bile. I thought we were going to die. And there were times, in the dark, early hours of another sleepless night, when but for the thought of my children, I rather wanted to. I called my solicitor and had him courier me a new draft of my will. After a few days, two of my older children flew up to take our young son home to Devon.

We remained in hospital in Aberdeen for about three weeks. Our nephrologist worked deep into the night deciphering Scandinavian and German medical papers on the treatment of

*C speciosissimus* poisoning. The toxin in this mushroom is only interested in the kidneys, and some research suggested that massive doses of antioxidants could prevent the total annihilation of the kidneys. We tried it, but it didn't do the trick. Our creatinine levels soared from the normal of around 70 µmol/L to well over 1000 µmol/L. Biopsies showed extensive cell necrosis. My wife retained a minimal amount of renal function, but I had eaten more of the mushrooms than she had, and I had almost none. I stopped peeing entirely. I used to have regular peeing dreams and wake up thinking I was cured.

We flew back home to Devon, where my kids had rigged up balloons and a big “welcome home” banner across the driveway. My wife and I had tried to hide the monstrous, Frankenstein tubes in our necks with bandanas but to no avail. I'll never forget the shock on our young son's face as he surveyed his new parents. We looked like the walking dead.

We started dialysis at the Royal Devon and Exeter Hospital, then in Newton Abbot, where the ancient dialysis unit, perched on top of a hill, overlooked the town's otherwise derelict hospital. We then moved to a new unit, in Torbay. Our consultant nephrologist and all the friendly staff there looked after us with great care and attention.

Life on haemodialysis is a gruelling business. Occasionally your blood pressure plummets and you tumble into a slough of nausea. I had to do five hours every other day. My wife found she could only bear three hours. At first I thought that 15 hours of enforced stillness a week would provide an excellent chance to finish my new novel. It didn't. Dialysis blurs the mind, making it hard to concentrate. I discovered that typing with only one hand (as I had one arm needled to the machine and out of action) disrupted the rhythm of my thoughts. Usually when I came home I felt too sick and disoriented to work.

In fact, you feel only half well all of the time. Even after all those hours on a machine, your blood is never more than a quarter cleaned of all the toxins that healthy kidneys normally get rid of. Your lifestyle is blighted too. If you want to travel, particularly at holiday times, you have to fix up dialysis for where you want to go many months in advance. The units are often unable to take you. Europe, in my experience, was fine. I've had dialysis in the Netherlands and Italy several times in good and friendly units—and free, with my European health insurance card. In the United States, where I used to travel often and widely, you have to pay for dialysis and it's extremely expensive. In New York it cost me \$1000 a session. It was a stark reminder of how marvellous our own NHS is.

However, there was always hope. I had no shortage of offers of a new kidney. All four children offered. But a parent's every instinct is to protect his children. Putting them at risk, however slight it might be, seemed unconscionable. Anyway, I had other offers. Seven friends, amazingly, offered me a kidney. It still moves me enormously that they should do so. Without knowing what I now know, would I have done the same for them? I'd like to think so, but I can't be sure.

But, one by one, they failed the tests. I'm blood group O, and oddly nearly all of them turned out to be group A. ABO incompatible transplants can be made to work but they are not ideal. And some of these wonderful friends found during the tests that they had medical problems of their own, which made it unwise to proceed.

I've always liked to keep active, but by the beginning of last year I found I couldn't run more than a few hundred yards without having to stop. My heart had always been healthy, but tests showed it was now being damaged, probably by the fistula. My pulse, normally about 45 beats per minute, was 70.

This was the moment when my daughter, Lauren, by now 29, said: "Dad, it's time to get serious. I want to give you one of my kidneys." I repeated what I'd been saying for two and half years: I couldn't do it. She said I shouldn't see it as a sacrifice on her part, that it was entirely selfish: she wanted me to live long enough to meet her children when she had them. She's a scientist and had done all the research. She said the risks were tiny. She had gone ahead and had herself tested.

We're quite alike and have always been very close. It was no surprise to discover she was an excellent match. Four out of the six criteria boxes were now ticked.

Reluctantly, I went with her to the Hammersmith Hospital in west London, where a nephrologist spent many hours with us patiently going through the research. My greatest worry, despite several studies showing no risk to conception or childbirth, was that it might reduce Lauren's ability to have kids. We were put in touch with a young woman who had given her mother a kidney and gone on to have two healthy children with no complications. I spoke to the mother (who'd had all the same

misgivings) and Lauren spoke to the daughter. They were immensely positive and reassuring.

"So, Dad, shall we do it?" Lauren said, as we left the hospital, my arm around her shoulders. I couldn't speak. We were both in tears. I hugged her and managed to nod and whisper okay.

The transplant procedures took place in July 2011. The surgeon had told us what to expect, and the first few days were a bit of an ordeal for both of us. I got very sick and Lauren was in a lot of pain. But the good news was that her kidney, nestling on the right in my lower abdomen, was working like a Ferrari. I had not peed for three years, so my poor, shrivelled, old bladder took quite a while to get up to speed.

Lauren went home after about a week, and I stayed about a week longer. It took her about three or four weeks of rest and recuperation to feel well again. A couple of weeks more and she was out running again. My recovery took a little longer. I caught a couple of minor infections that put me back in hospital for a few days each time. But within seven or eight weeks I was feeling well and increasingly mobile.

Now, a year later, my daughter is living in Kenya doing fieldwork for a PhD. She is fit and strong, runs every day, and has 100% kidney function. Her one kidney has grown and is doing the same work that two did before. We talk almost every day. The bond between us is stronger than ever. As for me, I feel every bit as well as I did before the poisoning. I run about 12 miles a week, I can eat anything I like (nuts, bananas—all those high potassium foods that were banned on dialysis). On my son's 10th birthday, I even went down the "death slide" at our local theme park.

I recently went back to the dialysis unit. In one year, six dear friends there have died. Some people manage dialysis for 20 years, but the average life expectancy on dialysis is five to eight years. And as I now know, being on dialysis isn't really a life. It's not even half a life.

Just over 12 months after my transplant, my wife also had one—from a family friend. She is doing well. Four years after the poisoning, we have our lives back. We have learnt a lot about our families and friends and the extraordinary generosity at large in the world. It has been quite a journey.

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### A medical perspective

Nicholas Evans eloquently describes the devastating consequences of poisoning by the mushroom *Cortinarius speciosissimus*. The toxin from the mushroom causes severe acute tubular necrosis, which meant that Nicholas became dependent on dialysis within a few days. The renal damage is irreversible; renal transplantation was his only option if he wanted to get off dialysis and improve his quality of life. Reading Nicholas's article, I was struck by how physically and mentally overwhelming his "crash land" on to dialysis was, going from health to organ failure in a matter of days.

Patients who have a slow decline in their renal function have the benefit of an early referral to a nephrology clinic and time to adjust to their situation, symptoms, and psychological state, aided by the multidisciplinary team.

The value of predialysis education is enormous in preparing patients. Some element of choice is introduced in terms of modality. Indeed, the procedure of having a fistula constructed or a peritoneal dialysis catheter placed is a psychological milestone in the journey towards dialysis. A home visit from a specialist nurse, in the patient's own environment rather than a sterile clinic room, can help the patient think about the practicalities of renal replacement therapy: showering with a tunnelled line; parking and transport at the dialysis unit; what happens if it snows? These conversations may be better held with front line staff, who appreciate the social perspectives without a clinician's agenda in mind. Patients have an opportunity to visit a dialysis unit and to speak to other, more experienced patients as part of their preparation process.

"Crash landers" have none of these benefits, and a multitude of uncertainties, including recovery, finance concerns, and temporary access to dialysis that may be suboptimal.

Nicholas describes dialysis as gruelling. He would have been an obvious candidate for home haemodialysis. In a satellite dialysis unit some patients build a new social network, having dialysis in the same slots week in and week out, and become friendly with the staff and other patients—even romantic unions can take place. Home haemodialysis might have given Nicholas more control over his dialysis but perhaps less engagement with the dialysis community. Haemodialysis requires "ultra pure" water, and unfortunately the age, rurality, water supply, and sewerage of his home made this impractical to achieve.

Another option would have been peritoneal dialysis, which in Nicholas's case might have been less of a burden on his cardiovascular system, and given him far greater independence and travel possibilities.

Unfortunately no renal replacement therapy is perfect, but, as with many of our patients, transplantation became the preferred aim for Nicholas. Transplantation, whether living or cadaveric, remains an ideal way of avoiding the need for dialysis (along with its complications) and providing a cost effective long term solution. Clearly no patient has a completely unchequered course after transplantation, but Nicholas's piece emphasises the benefits for him of a live donation.

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### Useful resources

- Give a Kidney, One's Enough ([www.giveakidney.org](http://www.giveakidney.org))—A charity promoting altruistic living kidney donation
- Kidney Research UK ([www.kidneyresearchuk.org](http://www.kidneyresearchuk.org))—A charity that funds research aimed at finding better treatments, and ultimately a cure, for kidney disease