

UK's first eight-organ transplant survivor leading the way

"I would have done anything. It was just, get me on the table. If you kill me, you kill me. Don't worry just do what you got to do. I was putting myself up as a guinea pig."

Adam sat wide awake in a chair. He was dosed up to his eyeballs, connected to feeding tubes and a Hickman line which desperately tried to pump nutrients into his heart and stomach. His intestines had failed. He was completely obstructed, throwing up what should have been coming out elsewhere. Adam thought, "I could have knocked myself out on the wall because I was in so much pain." A doctor came over, holding a white sheet of paper, titled 'DNR.'

'Where do you want to die?'

In 2013, Adam Alderson, from Yorkshire Dales was diagnosed with pseudomyxoma peritonei (PMP) at the age of 34, a rare form of abdominal cancer, a disease which grows everywhere and then goes hard crushing all the organs until you die of organ failure. Unfortunately, for Adam his was so widespread - attacking all his major organs - that the usual psycho reductive surgery that strips back the disease and subsequent nine months of chemotherapy did little to reduce it. He was packed up with a feeding tube and given two years to live.

"Cancer is very levelling. Cancer doesn't matter who you are, how much money you got, or from where you are or what you do. Cancer is cancer. It doesn't pick and choose."

Adam is a survivor. He was not willing to give up and he was no stranger to the disease - it had killed his father.

Despite countless hospitals saying they could not help, he was determined to find a way to fight it.

"I am a lone ranger. I don't conform to orders or instructions. The more someone tells me not to do something the more I try and do it."

The Christie hospital had given up hope, but after a phone call to Basingstoke Adam was transported by blue lights. There he was told his only chance of survival was a multi visceral organ transplant, pioneering surgery which was first carried out on England Rugby league player Steve Prescott.

"I had never heard of a bowel transplant, let alone an eight-organ transplant. It was like someone was saying you were going to the moon."

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There is only one hospital in the UK that has attempted a multi-visceral transplant. By the time Oxford's Churchill Hospital approached Adam, they had attempted it twice, but the surgery brought risks. Mr Prescott and the second patient had both died from complications three weeks after undergoing the operation.

The process of organ transplant also does not occur overnight, it is long and complex. While they waited to be contacted by the hospital Adam was sent with his wife, Laura, to the intestinal failure unit in Newcastle. There, both Adam and Laura were trained in palliative care - end of life care – in order for them to go home.

Laura was Adam's lifeline. He heavily relied on her to administer pain relief drugs and change his feeding tubes to keep him alive. There was a lot of careful infection control. She had to ensure everything was sterile and cleaned to ensure no germs were introduced – if it did, it could have killed Adam. It was an exhausting process.

Laura gave up her career and became his full-time carer.

“She’s has been through the mill of it just as much as I have. Laura slept on the floor and cared for me. She’s seen and heard some really horrible things, and still does.”



Eventually, the long wait for the consultation ended. Adam met new, eager and positive doctors who would change his life for the better. It was an experience that he found refreshing. His attitude to keep fighting encouraged the doctors, and in turn built on Adam’s confidence to undergo the extensive surgery.

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However, the road to transplants is a tricky one, let alone the road to an eight-organ transplant. Adam’s health needed to improve and that meant a few weeks of tailored nutrition via his tube to his heart to allow him to be listed on the UK Transplant list.

For each proposed transplant, a meeting is held to establish if someone is fit for transplant and everyone there must agree.

That same day, Adam was added to the list as ‘high priority,’ as his health had rapidly deteriorated. Laura called a Doctor out.

“I was lying on the sofa in so much pain. If I had a gun, I would have shot myself.

“The doctor said: ‘There is no more we can do.’ I was on maximum pain relief. He pulled Laura out of my ear shot and said ‘He is shutting down. Adam is dying now. We don’t have long.’

“Everyone was prepared to watch me go.

“Would you believe it, I don’t believe in miracles but by chance about eight hours after that conversation, we got a phone call and they said they had found a donor. I was only actually on the list for 30 hours, which is unheard of.”

That day, Adam was not the only patient called into hospital – across the same ward waited another patient, who went through the same process of blood tests, ECGs and health checks.

The other patient was called in as a back-up recipient. For each transplant operation this happens, and both are evaluated to establish who is the best match. The majority of patients experience this multiple times; to be prepped for theatre only to be sent home. This is known as the dreaded 'dummy run'.

Luckily for Adam he was a perfect match, but for the patient across the hall it was another dummy run and a longer wait until surgery.

Finding a donor who is biologically similar to the recipient is key to a successful transplant. Our immune system are designed to seek out and destroy foreign organisms. This function is great for fighting bacteria and other pathogens but makes it difficult when an organ is being transferred from one person into another. Critical to that match is a collection of markers on the outside of nearly all our cells – Human Leukocyte Antigens (HLA's). The immune system uses these markers to recognise which cells belong in your body and which do not. An identical line-up of HLA is not possible, but doctors typically want a minimum of six HLA markers to be confident of a successful transplant.

Other factors include: time on waiting list, age difference between the donor and recipient, the rarity of the HLA profile, and whether a patient's immune system has developed antibodies to certain tissue types – all form part of the regularly revised algorithm that is used to match a donor to a recipient.



Brendan Moran (left) and Tom Cecil (Right) – the surgeons who removed his tumour and performed transplant

For 17-hours, thirty people worked in shifts to remove eight of Adam's organs: his stomach, large and small bowel, gallbladder, pancreas, appendix, abdominal wall, spleen and a tumour which weighed 10kg. Five donor organs were transplanted into him.

The operation was a complete success, and when Adam woke three days later he could scarcely believe his ears as Laura told him the tumour was gone; he had to go and get a doctor to confirm it for him.

While the operation went beyond expectations, the stress of having eight successive transplants was phenomenal, severely impacting Adam's body. For three months he had to remain in hospital.

The road to recovery was long and hard.

"Just to put one foot in front of the other was like climbing Everest."

However, slowly tubes were taken out each day, and soon he was able to get out of the hospital chair, and eventually walked out the hospital doors when he was discharged.

Usually, recipients are gently reminded of living with the gift of someone else's organ(s) by a surgical scar. For Adam, he is gently reminded everyday by multiple scars.

"I have what is called an abdominal wall draft, which is my donor's skin from my sternum to the pubic bone in the shape of a big plate. I have her belly button, her pubic hair and even her caesarean scar. I know it sounds strange but it's like putting a pie lid on everything. There was a huge void because when they did the operation I was massively extended. They had taken all this fluid out and nothing was back as it should. They took the skin to put a closing lid on.



Adam's abdominal wall draft

"Also, it acts as a warning window. If I reject or get an infection, I will get some spots or a rash on the donor's skin. Therefore, they instantly know to hook me up to anti-rejection drugs and put me back to sleep, to take biopsies. It is like a plug of skin.

"I have no feeling in that skin, you could cut me up now and I wouldn't feel a thing."

Initially, Adam found it daunting living with someone else's skin and belly button, but now he finds it comforting because it protects him buying him precious time. It has saved his life three times already.

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Each year about 6,000 people have their lives put on hold, waiting for a life-saving organ transplant.

For Adam, it was a miracle to only be on the waiting register for thirty hours, especially when he was not just receiving one organ but five. People needing organs often wait much longer – an average of 706 days for a kidney and 1,085 days for a non-urgent heart transplant. Many people do not make it.

Each year, 400 people die while waiting for an organ, with more than 700 a year taken off the list because they are no longer well enough for a transplant.

However, from 20th May this year, a new law – known as Max and Keira's law – will automatically enrol all adults as organ donors unless they choose to opt out. It is hoped that this system of 'deemed consent' will tackle the perennial shortage of transplants on the NHS.

The heart, liver, kidneys, lungs, pancreas, small intestines, bone, corneas, skin, and nervous tissue will all be considered for routine transplants.

It is hoped that the opt-out method, could see up to 700 extra transplants a year by 2023, according to the government.

There will be exemptions; children under 18, individuals who lack the capacity to understand the changes and people who have lived in England for less than 12 months before their death.

However, the jury is still out whether this move to "presumed consent" will increase the number of organs available for transplant, as families will still have the last word on whether donation goes ahead.

While many experts are welcoming the change, they are not convinced it will be enough to deal with England's organ shortage.

"We need to make it a normal conversation at all stages of life," says Dr Gill Fargher, Chair of the Organ Donation Committee at the Medway NHS Trust.

Dr Fargher explained that this new system will be a "soft" opt out. Like with the current system, bereaved families will still have the final say on their deceased loved one's organs and can refuse for them to be donated, even if they're signed up to the donor register.



Dr Gill Fargher, Chair of the Organ Donation Committee at the Medway NHS Trust

Currently, more than three families a week say no to organ donation because they don't know their loved ones' wishes. That's despite more than 80% of the population saying they would definitely donate or consider donating their organs, according to NHS Blood and Transplant (NHSBT).

Dr Fargher adds: "We know now that if families know the decisions of their loved ones, they will consent in 90% of situations. If they don't know they will only consent in 50%.

"That's a lot of donors being lost."

For Dr Fargher, her devotion and time spent to raise awareness on this issue, is a battle that comes from the heart. Her husband, Tris, suddenly died in 2015, from a cardiac arrest at the age of 56. He was in intensive care for 12 days before he died. He had no history of heart disease and no prior health issues.

"When I knew he was going to die, I desperately wanted something positive to come from his untimely death.

"I am immensely grateful that Tris and I had spoken about organ donation."

Already, opt-out has shown encouraging results in Wales, which now has the highest organ consent rate of all the UK nations, having climbed from 58% in 2015 before the law changed to almost 80%.

Currently, Spain holds the highest rate of deceased organ donation in the world, which is often attributed to the 'opt out' system, which they adopted in 1979, with 46.9 donors per million as opposed to 24.4 per million in England.

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Speaking to Adam on the phone five years after defying all odds, he is weary and fatigued, but because he has tired himself out after training for the 10km Steve Prescott charity run, which is in two-weeks' time.



Adam and Laura with the vehicle they travelled to Mongolia in

In the past five years, Adam has become a notorious ambassador for charities which supported him through his illness and recovery from PMP, including Macmillan and Pelican Cancer Foundation. He has embarked on a number of challenges along with his wife Laura, after setting up a fundraising team called Yorkshire Yaks. In 2017, the couple attempted to complete the Mongol Rally, which saw them drive a Suzuki Jimney, in a 10,000-mile race from Leyburn to Mongolia. Six weeks in Adam fell ill with kidney failure in Kazakhstan and was flown home from Russia. Refusing to give up, he returned to Mongolia along with a friend and drove back to Yorkshire raising £25,000.

Adam said: “We proved to the medical world that this procedure is a viable option to patients with cancer when there are no good options. Some patients get to end of life care where there is nowhere to go with it. It has revolutionised the whole thing.”

We have all been touched by cancer. It is a word that lingers and hangs over us like a dark cloud. Yet, as I listened to Adam pause in thought and contemplate his achievements and adventures, it was almost as if I could see him smiling – as he questioned himself over whether he’d have the life he has



Adam and Laura on their mini motorbikes

today, if not for his cancer. The answer was no. It was reassuring to hear that after all the torment he has endured, that the illness has not broken him but has given him a new life.

“Going through what I have been through shows me that you have got to do the stuff you want to do. You must take risks in life.

“I don’t know how long I have got to live. I certainly won’t live a full life, I’ll still die young, but we don’t know when that will be.”

Last year, the couple rode mini-motorbikes 2,000 miles across the Pyrenees to Santander. Adam laughed as he said they remind him of something a clown would ride in a circus.

Along with his adventures, Adam travels the country speaking at charity events and medical conferences talking to thousands of people about palliative care and multi-visceral transplant.

“If someone said to me four years ago you will be on the speaker scene, I would have laughed because I was actually quite a nervous person.

“But I have found my passion. It’s great.”



Adam speaking at Marks and Spencer's two-day Retail Live event March 2019

While cancer is now a thing of the past, Adam will have to take immunosuppressants – drugs which will ensure his body does not reject the transplanted organs – for the rest of his life. Also, every six months he must go for scans to ensure he is cancer-free.

His gratitude to the team at Oxford is genuine and heartfelt. Adam says he hopes to continue to give back and show his appreciation to those who helped him through his illness. This will include the reappearance of the mini-motorbikes to celebrate Laura’s 40th birthday.

“I am the world’s first. I am leading the way. But as far as I am aware everything is fine at the minute and we will keep going as long as we can.

“I will keep continuing to cram as much crazy stuff into my life as I can.”

Adam is believed to be only the fourth person in the world to survive the operation, and the first in the UK.

But there is also the selfless decision by one donor and their family. That person's death gave Adam the gift of a new life. He knows it was a young woman, and through the hospital he was able to write to her family to express his gratitude. While he did not tell me entirely what he wrote, he did share with me that he said it finally allowed him to marry Laura two years later.

"I don't think donor families know just how us recipients think about them and try to respect them. We are so grateful for that decision that they have donated their organs. It's a huge thing to do."

For more information about the change in law and organ donation please visit:

www.organdonation.nhs.uk