



17 year old Simran has end stage kidney failure and needs a transplant so she may live a life free from dialysis.

“My name is Simran, but you can call me Sim. I have end stage kidney failure after being diagnosed with Chronic Kidney Disease at the age of 14.

Continuous urinary tract and kidney infections from my childhood had caused irreparable damage and scarring to both my kidneys. It was only by chance that I was diagnosed as I'd been feeling very tired and unwell after a normal day at school and even after a good night's rest. I felt so unwell that I knew something wasn't right and asked my parents to take me to have a blood test.

Overnight everything changed, my parents received a call from Birmingham Children's Hospital asking them to take me to ward 1, the renal ward immediately. At this stage we had no idea what was actually wrong with me, but I was admitted, put on a high dose of blood pressure medicines and monitored every hour throughout the night as my blood pressure wouldn't come down.

Over the next few days I had numerous blood tests, scans of my kidneys, bladder, chest and heart. It was while I was having one of the heart scans that the consultant told my mum that I had stage 5 renal failure/end stage kidney failure of both of my kidneys meaning that I would need dialysis and a transplant eventually.

Over the next few months, I was monitored frequently, and both of my parents were tested to see if they were a suitable match as a living kidney donor, unfortunately they were not a perfect match.

Although my mum was a perfect 6 out of 6 as a tissue match and my dad was a near perfect 4 out of 6, neither matched my blood group. My Mum has blood group A, and Dad has B, I inherited blood group O from them.

As part of the testing, both mum and dad's anti-antibodies for my tissue were measured and the doctors decided that my dad could be a potential living donor for me due to a procedure where they could wash my blood (plasmapheresis) of the antibodies that would react with his donor kidney tissue, a first ever tried procedure for Birmingham Children's Hospital. This would mean that I could receive a kidney from him potentially.

For the blood washing to happen I had to have a central line catheter fitted. This was a long plastic canula (thin tube) from the blood vessel in my neck right into the top chamber of my heart.

However, things are never straight forward with me and I wasn't aware it was a nil by mouth before this procedure so instead of having this done under a general anaesthetic and being asleep in theatre, I was fully awake and had it done under a local anaesthetic, again, a first for the fantastic surgeon at the Children's Hospital that did this. I wasn't worried because they let my dad wear some theatre scrubs and sit in with me.

Over the next 6 months he successfully underwent all the testing at the Queen Elizabeth Hospital, Birmingham and a date for both our operations was set. My first blood washing session out of three went well and things were looking positive, however at the 11th hour, everything came crashing down.

As I was getting ready for my second washing session, the surgeon asked for a quiet word with my Mum and Dad. It was here that they were told of quite a major complication that had been missed throughout my Dads testing.

Most people have one renal artery to each kidney which makes plumbing a donor kidney in relatively straight forward. However my dad had three arteries to each kidney which is much more rare and complicates the donation procedure in that the operation time doubles from 3-4 hours to 7-8 hours because of the time needed for reconstructing three arteries to marry into one, this in turn means the donor kidney is out of the body for much longer than it should be and this makes it highly likely to fail before being transplanted.

The surgeon did not think it was the right thing to do and it would be better to wait for the right kidney.

Gradually, over 24 months my kidney output decreased to less than 8%, and the time had come for me to undergo dialysis.

Since I was first diagnosed, I knew this moment would eventually arrive, but not even all this time had prepared me emotionally to take the news in that my kidneys were shutting down. All options were explained to me, I opted for Peritoneal Dialysis (PD) as it meant being able to do it at home, overnight while still being able to maintain as normal a life as possible.

Since March 2018 I have been on dialysis every night, for 10 hours.

If you were to see or meet me, from the outside you'd probably see a healthy teenager, but from the inside my kidneys are no longer able to clean toxins and waste product from my blood, produce enough hormone to make enough red blood cells or produce effective amounts of bone hormone.

Alongside this I take 8 different drugs every day to try to fight against some of the collateral issues caused by my poor kidney function alongside a monthly hormone injection to help me make sufficient haemoglobin.

This has kept me well up to now and allowed me to continue to attend school, do my GCSE's and now A Level's. I also hope to attend university, all being well to study child nursing.

Regular dialysis, even though very restrictive, does its job keeping me well, but a transplant would offer me the freedom to live longer and healthier and a more normal life."

Please [#ShareYourWishes](#) with your loved ones about your organ donation decision.

Follow [A Kidney 4 Simran](#) to follow her journey.

15th March 2020
Organ Donation Awareness
Event
#akidney4simran

Come and see us at

**Guru Nanak Gurdwara
West Bromwich Street
Walsall
WS1 4DE**

from

10am to 1pm



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