

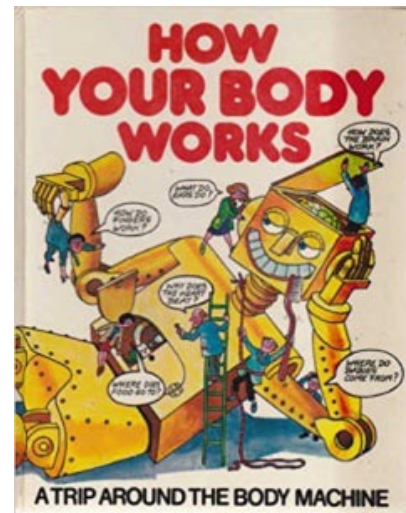
## LIVE KIDNEY DONORS ALTRUISTIC OR TO SOMEONE YOU KNOW

I'm a 47 year old male, an engineer, and just ordinary person. When I started on this journey I wanted to know as much as I could do, but I found that there didn't seem to be anything that really explained what I would be going through. I decided to write this down as I was going through it, to tell anyone who wants to read, what I went through and a lighter but still serious side of the whole process and things that I found that wasn't in the literature, these are my own thoughts and opinions, of my experience, independent to my live donor department or anyone else. I hope that some of it is some use to you, Thanks for reading.

**So where do I start**, a lot longer ago than you would imagine when my sister was pregnant, she had kidney problems and it was said she may have had to go on dialysis. It was joked around that she might need a transplant and it was jokingly asked if I would give her one of my kidneys, no problem I said, but I meant it seriously. Of course nothing more was said and after she'd given birth everything else was ok

My fear of needles goes way back to when I was young, I can't say that I'd had a bad experience with them, but we had a book at home called how your body works, and there was one picture that showed an inoculation. It showed a magnification of the end of a needle with green fuzzy germs coming out of the end of it, all drawn in cartoon. It must have had some sort of affect on me as I started having nightmares about being chased by a giant needle, and the source of my fear has been revealed.

A few years on and my sister got cancer, after seeing all the crap she went through, I decided to start donating blood, as my fear of needles seemed to be insignificant in comparison to what she was enduring



I controlled what happened, I chose the arm and I chose to have an anaesthetic I'm a chicken when it comes to needles but if it was under my instruction, and I felt in control, I didn't like it, I hated it and it scared me, and being honest about it, I would have quite happily stopped but for one thing. My sister told my mum that she was proud of what I was doing, that meant a lot, especially coming from someone who I regard as being incredibly brave. So even though she lost her fight with cancer, and even though I don't believe in an afterlife, I want to do something good in her memory. So 51 donations later I'm still doing it. They changed the procedure after my 49<sup>th</sup> donation, and stopped giving the anaesthetic, and if it hadn't have been after my 50<sup>th</sup> I would have not gone back again, such is my discomfort, but I thought I'd brave it out and just do the 50<sup>th</sup> and see how it went, it went so much better than I thought it would do.

After the 50<sup>th</sup> donation I found something on the web somewhere, I'm not even sure where it was, it could have been on an organ donor site or Facebook or even the blood donor site, and it just suggested that although live donors are used to give a kidney, or a part of a liver to family members, it's also possible to give a kidney to wherever it may be wanted. It's called an altruistic donation, a

word that I'd never heard of before, but I assume that as you don't get anything back from giving blood and am just doing it out of the goodness of your heart then blood donations are altruistic too. This peaked my interest, and I did some research had a look at the tests I would have to undergo and about the operation itself, there is so much information online but it's not necessarily easy to find, I will endeavour to add some shortcuts to the sites I find for the UK. I got in touch with the national referral centre at the NHS and they got back to me with a website that could put me in touch with my local transplant centre, so that's exactly what I did, I sent an email of to my local transplant centre and they put me in touch with my local hospital, and I was contacted within a couple of days with a telephone call from my local hospital, and an 'application form' was sent to me and an initial appointment was arranged.

### **FIRST APPOINTMENT**

I must admit I was a little anxious about meeting her, but Julie was very welcoming and serious about what she was doing, impressing on me that it would be a long procedure to go through, that there would be lots of tests to go through and what I could expect during them, also explaining the one choice I would have to make (I shall explain later, and my feelings towards that choice). She explained what would happen to me before, during and after the operation, and how my body would react to the operation, that they would only allow me to donate a kidney if my kidneys were working really well, they want to look after you as best they can and the donors health is paramount. She told me about the chemical changes to the body and how my remaining kidney would react to being all alone. How, that a live donor, who suffers from kidney failure would get preferential treatment regarding the transplant list (still not sure how I feel about that one). She also explained that during the tests that have been done on previous candidates, that a range of other illnesses have been discovered, one person found a cancer on their kidney, another cysts on their lung, and a third one found that they were diabetic, all things that, had they been left, could have had serious implications, to their health

She also explained to me about the law, that it's illegal to be coerced, bribed or forced to donate an organ, and also that it's illegal in the UK to profit from a donation. Also that there's a great possibility that I will never meet the recipient of the organ, but still the hardest thing was to be told, I need a urine sample, as that's not the easiest thing to do on demand.

I left there with a lot of information to take in, but with the comfort that no matter what, I can refuse the procedure at any point, unless I'm actually under anaesthetic, and that's only because of the communication issues LOL and that if I need to ask any questions, all I need do is call or email, nothing is too much trouble.

### **REACTIONS OF FAMILY, FRIENDS AND MEDICAL PROFESSIONALS**

Now that is a good one to discuss, I have had varying reactions, my parents weren't surprised, not necessarily overjoyed with the idea, but have never said anything negative to me because it wouldn't change my mind and I'd just do it anyway. I can understand why they are a little

apprehensive about me doing this, they've lost one child and no matter how you dress this up, it's a serious operation, but I've reassured them about how importantly the department take my health and my safety and about the right to say no at any time, and it seemed to placate them and since they've been interested in what I've been going through. My children seemed have taken it as an 'ok dads doing something loopy again' and have asked questions when they've wanted to know something, but other than that haven't said much.

My friends, well I've had 3 different reactions, one of them really doesn't want me to do it, and has honestly told me this and how she feels about it, I think that she is worried about me, and also worried about being without me, however she feels, I admire that she's told me, another is incredibly impressed and has said that if it wasn't for having a young child, then she'd be joining me on the journey, and donating herself, another one of my friends just burst into tears, gobsmacked that I would do something 'so nice' for a complete stranger and I get the same reaction from her every time its mentioned. Most have been supportive and have taken an interest in my journey.

The doctors and nurses that I've met have varying reactions, but without exception the first question they've asked is 'who are you giving a kidney to?' and when I've told them that I don't know, lots have been impressed with what I'm doing, lots have said they don't understand why I'm doing it, some have said they don't even give blood, others have said they wouldn't let people practice giving intravenous injections to them, I'll be honest with you, it came as a bit of a shock, I don't know what I expected from them, health care is a job you have the temperament for or you don't, you're a born carer or you're not, and to find out that they're normal people is comforting.

## **WHAT DO KIDNEYS DO?**

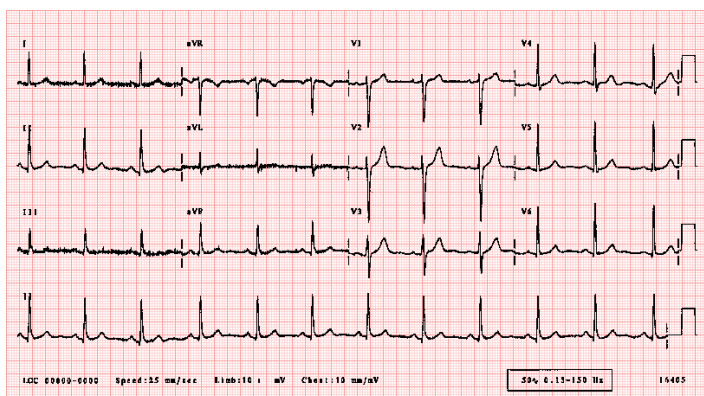
Most of us have 2 kidneys; they're about the size of your fist and live just under your rib cage at the back. They have a number of functions, but mainly to cleanse the blood of toxins, they filter around 200 litres of blood a day and produce up to 2 litres of urine to carry these toxins out of your body. The kidneys also regulate electrolytes and sodium content in the blood, and produce Hormones, Rennin, that regulates blood pressure, Erythropoietin, which regulated red blood cell production and vitamin D, for calcium absorption. Without your kidneys you'll feel weak, your bones will be weak and soft and your body slowly poisons itself. If dialysis isn't available kidney failure is fatal. 60,000 people die prematurely because of kidney disease in the UK every year, 3,300 kidney transplants take place every year in the UK, but there are still over 5000 people on the waiting list.

## **FIRST SET OF TESTS AND MEETING WITH THE RENAL DOCTOR**

My first appointment consisted of an ECG, a height weight check, an ultra sound scan on my abdomen and some blood tests. I go for my ultrasound scan first. The ultra sound scan is pretty standard, laying there on the bed being covered in jelly and scanned I get to see my insides for the first time on a small screen next to the bed, a



picture of my kidney from one side, then the other and finally of my bladder. Then I go up to the outpatient department, I turn up at reception, they measure my weight, and my height, and take me to a little room where I'm attached to a machine to check my heart. I have wires going around my chest, on my ankles and my wrists, I lay there for a minute or so whilst the machine prints out a sheet, like the one below. From there I was taken to the doctors' waiting room and offered a coffee, which I accepted as I'd just come from work. I got to see the doctor in about 10 minutes, I sat at his desk whilst he talked to me. He asked about my reasons for giving a kidney to a stranger, I haven't gone into them fully but I will do in the next chapter. He asked what I thought the positives are for a recipient, I told him what I thought, and then he asked me what I thought the advantages were for me, I told him that I didn't think there were any, after looking at the things I'd read on the internet. He explained the benefits for the recipient, and that I was right about what I thought about the donor, other than I'll know that my body is working well.



He explained to me what the tests were fully, what they involved, what results they were looking for and the order in which they were done, and why they were done in that order. He also told me that my heart was ok, that I have two kidneys, (1 in 750 people are born with only one kidney) and that they and my bladder looked in good health. He also explained how the

operation is performed and what scars would be left and worst case scenario. Including that they prefer to take the left kidney as the veins and arteries are longer but there could be a side effect of my testicle swelling due to the way that the veins are set out. After meeting with him I went and gave half a dozen blood samples, one needle several vials to fill.

The doctor and nurse coordinator that sort out my tests give me all of the information in such a way that, if I hadn't already made up my mind, it would really make me think about what I'm doing, but at the same time they're being encouraging, it's a fine line they walk and they walk it really well. I was also told on my first appointment that they would prefer you not to have any tattoos or piercings until after the procedures have been completed.

#### THE ORDER OF THE TESTS ARE AS FOLLOWS

- Ultrasound scan
- ECG
- Blood tests
- Psychological examination
- CT scan to determine my veins and arterial layout
- GFR (kidney filtration test)
- DMSA scan (determining the work load of each kidney)
- Meeting at the donor coordination centre with the surgeon
- HTA (Human Tissue Authority) independent assessment process

## **MY REASONS FOR DONATING**

The initial reason I took interested in live donating in the first place was because of my sister, but as I thought about what I was doing, I couldn't see any disadvantages. Ok there's going to be pain and I'm going to be immobile, I won't be able to ride my motorbike for a long while and ill have a few scars but...

In my opinion, I've had a really good life with my kids, I've been all over on holidays, my kids have had holidays and have had lots of times where we've spent time together. They've grown up now, they've got their own homes, and they're self-sufficient. They don't need their fathers input as much as they did, both they and I have been lucky. Imagine if things had been different, if as a father I thought that every year could be my last one, if I was tied to a hospital every other day, or had to sleep hooked up to a machine every night, if I couldn't take my kids on holiday ever, or had to miss things that my kids did because I had to go to dialysis, I have been lucky. I can carry on my life with one kidney, and ok it may cost me a bit of pain but just look what someone else gets back, and it's not just one person's life that will change, the whole family's will, that, to me, makes it all worthwhile.

On the other side of things, if I don't manage to get to the operation point, then will have failed one of the tests and although I won't have changed someone else's life, I will have found out something about myself that may have implications on my future health, and enable me to live a longer life.

No matter what happens, it's positive, for either me or someone else, and their or my family.

## **RISKS AND REASONS WHY**

There are risks to all surgery and this is a major operation, so there are going to be risks, and it's important that you know these. From start to finish, there is a 1 in 3500 chance of dying, this is about the same as having your appendix out. There's a 3% chance that you may need a blood transfusion. You may get an infection, have bleeding, or suffer with pain due to the operation but this the same risk with all operations. There's a risk of increased blood pressure, but this can be controlled by tablets. There's an increased risk of having a hernia, because of the incision. The reason the kidney is removed from the waistline incision is because if it is removed from a side incision there's a chance of pneumonia because your lung won't inflate properly because of the pain. There's no need to shave before the operation, this is done in theatre, and this is to reduce the chance of infection. Kidney donors have less of a risk of developing kidney disease than the general population, and no increase to end stage renal failure. Whilst most women have no problems with pregnancy there is a very small increased chance of hypertension or pre-eclampsia.

## **THE PSYCHOLOGICAL EXAMINATION**

For me this was the most daunting of the tests, I'm not sure why it just worried me, maybe because it's one that I had some sort of control over. The answers that I give can stop this journey, and I have control over the answers. Whereas the biological exams, I have no control over at all, if I failed on them there's nothing I could do about it. Also because I do suffer from depression and although I have sought help and I'm stable, they may see this negatively. So after trying to find a parking spot for quarter of an hour, and you know what that's like for stressing you out. So I arrived on time

instead of early, and I hate it when I'm not early. So I registered at reception and within 5 minutes a doctor came out and took me to an interview room, she was very nice and polite, that scared me even more. I sat down and she introduced herself and then another doctor came in and introduced himself too. She was a psychologist from Hull, and he was a Psychologist from the altruistic donor department, coming to speak to me and to assess the other doctor. It seemed like there were 2 of us under the cosh.

They told me that they don't trust altruistic donors, there is a lack of understanding of why people would do something like that, which shows what this world is coming to when you can't do something positive for no reason without someone questioning your motives. They told me that organ donation would be the ideal way to satisfy the needs of certain mental disorders, so they're looking for Munchausen's and schizophrenia, again everything they ask is just to protect you, from yourself I suppose.

So they start with the first question, 'why do you want to donate a kidney?' so I explain the reasons above, but they don't understand the positives, 'when was the last time you gave a urine or blood sample for testing?' I ask, I know they can't answer, so I continue 'I've had several lots of blood taken and a couple of urine samples, I know my kidneys are working, I know I don't have any of the diseases they've tested for, do you?', they finally understand that, and after I tell them I've given 50 donations of blood, he asks 'if you like to help people, why don't you help out at a soup kitchen?' I actually thought this was a good question, and went into the whole 'people who can help themselves and don't', and ones that can't help themselves. Then they went through everything in my life, from birth, my childhood, my kids and everything, and dissected it completely, you've got to answer truthfully, you have no choice, they try and trip you up, just to make sure you're being truthful

After the interview was over, then they tell me they can't tell me what they think, and that it has to go to be spoken about with other psychologists, then they'll get in touch with my doctor and let me know the outcome. So after the worst 2 hours I've had ever I have to wait until the end of the month before I find out if I'm stable enough to go through with the procedure. I passed!

## **NUCLEAR TESTING**

As I have found out there is a bunch of tests that come under the heading of nuclear tests. These carry some sort of risk, and sometimes side effects, so these are done after the non invasive tests are done. These tests involve the introduction of a radioactive substance into the body to enhance scans of various organs and vessels. Without exception the scanning machines are a tube, and if you look at them on the internet they always show that the patient going in them head first, with these scans that is not the case, every one that I had I went in feet first, and my chest, arms, shoulders and head always remained out of the scanner. The scanners were not claustrophobic, and weren't noisy and definitely don't hurt.

## **CT SCAN TO DETERMINE BLOOD VESSEL POSITIONS**

Quick anatomy lesson, your kidneys are fed from the renal artery and vein, these in turn are branched from the vena cava and the aorta, the two main blood vessels to and from the heart, and in the average person the renal vein and artery go straight to the kidney and then split up inside the

kidney. The thing about the average person is that, they're not the same as everyone else and the renal vein and artery can branch out before it reaches the kidney, if it branches too many times, it can complicate the operation and in some cases make it impossible to do. So they do a scan, but to enable the scan to be enhanced, you're injected with an iodine based tracer, this flows through your blood vessels and highlights them during the scan. And it comes out with a pretty picture like the one below.



The procedure is simple, it's not a tube, well it is but you don't go in it too far and it's only a small tunnel. You lay on a bed, and you get asked the usual stuff, name, address and DOB.

Then they put a cannula in your arm, flush it through with saline, and then attach you to a machine that will inject you remotely with an iodine based clear liquid. So with your arms above your head and all metal items of your clothing removed from the scan area. The radiographers go and hide in their booth, and the procedure begins, they make sure you know what's happening every step of the way, there's a small speaker on the machine that links to them, they can hear you all of the time and you can hear them. You're moved into the hoop up to your kidneys and the process begins, but it's important to know you go in feet first. The machine starts and it sounds like a fast whirling, you're



asked to breathe normally and then asked to hold your breath for 15 seconds. And this reoccurs 3 or 4 times. Now it's the time for the injection, it's not painful, but it is a different sensation to anything that I've ever felt before. You hear the auto-injector start and as the fluid is injected you can feel it going inside you. Everywhere the liquid goes gets warm, and it's a nice warm. You feel it going up your arm and into your chest, you feel the warmth all over your chest before it spreads up your neck and down your arms, into your hands and your fingers, as its doing this you can feel it in your stomach and down your legs, and giving you a strange but not unpleasant sensation everywhere, I personally enjoyed it, I found it strange but relaxing at the same time, and definitely not claustrophobic, the whole scanning procedure take no more than 20 minutes,

then there is a 20 minute waiting time afterwards, whilst they examine the scans, and see if they require more. You have your cannula removed and time to go home. It's always better to be really hydrated whenever you have an injection, it makes it easier to find a vein. So plenty of water before you go.

### **GFR (KIDNEY FILTRATION TEST)**

Yet another nuclear test, when you go for the nuclear tests you may notice that the syringes they use are always in a thick metal shroud, don't be worried about this, the injections we get are of a

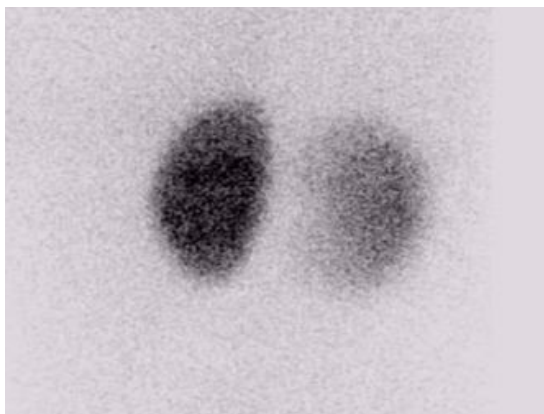
very low dose, and they spend a short amount of time in your body. But the nurses that you come in contact with do this job day in day out, they constantly handle these syringes, so they need to limit their contact. So the thick metal syringes are for the nurses' protection.

The test is to show how quickly your kidneys filter out things from your blood. It's an easy set of tests, but the preparation is difficult, well it was for me. There's a caffeine ban, as it affects the test results. Like me you probably think no coffee, so no problem, it's not quite that simple, when they say caffeine ban, they mean a total caffeine ban. No coffee, tea, decaf stuff, or chocolate, you have to be totally caffeine free for over 12 hours. So if like me you need something to wake you up, or to relax or sooth you, everything like that is banned, after you get over that shock everything else is a breeze.

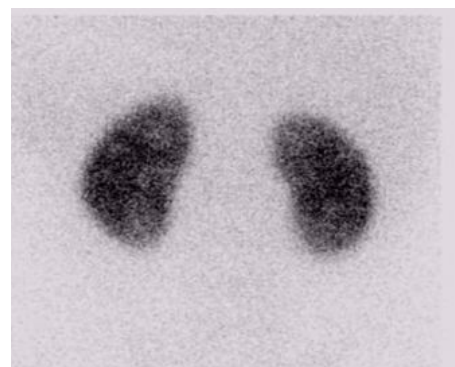
Preparation is key, be well hydrated and have a light breakfast, bring a book or tablet or something to do, you're there for a long while. It's a simple procedure, you sit in a chair and have a cannula put into one arm, this is flushed through with saline, you're then injected with a radioactive tracer. To ensure that the tracer is in your veins a radiation detection machine is passed over the injection site, and the nurse takes a reading and then takes a reading from the other arm, the readings should be about the same, if they are the same everything is as it should be, if not its come back again next week and try again. Then it's the long wait, there are three blood tests that need to be taken, the first one after 2 hours, then after 1 hour and the final one after another hour. When that it's done you can treat yourself to tea, coffee, or anything else that your heart desires. The blood tests show what amount of the tracer is left in your system and thus how efficiently your kidneys are working. Before you leave you are given a care sheet, it's a list of do's and don'ts, and warning to other medical professionals. You shouldn't be handling small children; you should flush the toilet twice and ensure you wash your hands well. For medical professionals it's a warning of what you've had injected into you and what precautions they should take. There doesn't seem to be any side effects, but I did have a bit of a headache.

### **DMSA KIDNEY FUNCTION TEST**

The DMSA test is to discover how hard each of your kidneys is working, you're injected with a marker that stays in your kidney for a short term and then is harmlessly excreted through your urine. Whilst it is your kidney photograph is taken with a gamma camera, and depending on the concentration of the marker as to how dark the picture turns out, if they're both the same colour it means they're working equally as hard as each other (illustration to the right),



however if it comes out like the other

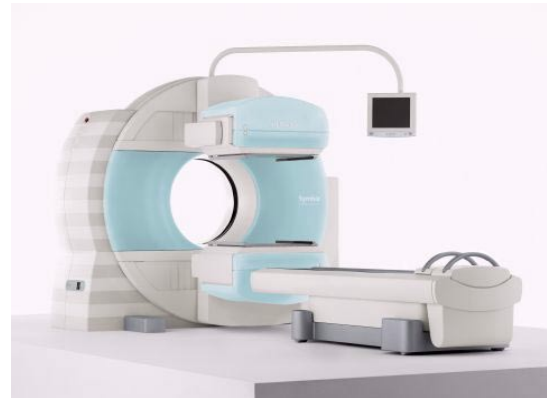


picture (on the left) it means that one kidney is working better than the other.

This is last of the nuclear tests and the easiest of them, no dietary restrictions, again being well hydrated helps as there is another injection. You



attend the hospital and then are called to a room where a metal syringe is taken from a metal box, (but we all know that's standard by now and nothing to worry about), you're fitted with a cannula and it's flushed through with saline, and then you're injected with the marker. You're given the do's and don'ts paper again, and then allowed to do what you want for the next 3 hours, you can go home, for a meal or like I did go to the cinema. Upon your return, its photograph time, with the Gamma camera (right) you get to lay on the bed and have a Velcro strap across your waist, this is just so you keep still, being still is the important part. The photographs take 13 minutes to take, and if you're lucky you're able to see them slowly develop on the screen above your head as the marker is seen by the camera. I had three photographs taken in total, around 45 minutes in length. The camera is completely silent, so much so that I managed to get a little sleep whilst I was being scanned. When I woke up it was all done and off I went home, again I had a slight headache, but nothing bad.



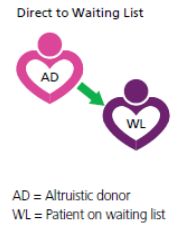
## **TEST RESULTS**

With me being an impatient person, the fortnight between having the tests and finding out what the doctor thought of the results was a nightmare. I tried asking the various doctors, nurses and radiologists that performed the scans what they thought but they specialise in what tests they do and then it's up to the renal doctor to interpret the results. You don't have a clue as to what the renal doctor will say, just remember that if you don't manage to pass all of the tests then it isn't the end of the world. If you have one kidney that works harder than the other that's alright, you managed so far without problems, and if the doctor finds some problems, it's something that's been found earlier than it would have been, a slight adjustment in lifestyle, or starting to take some type of medication could make the world of difference to you. I received a call from the transplant coordinator, telling me that my test results have been seen by the renal doctor and I've been referred to the main transplant centre in my region to see the surgeon. Please remember that even if you can't be a living donor, you can still help someone after your death, by carrying a donor card and telling all of your family of your wishes.

## **DECISIONS DECISIONS**

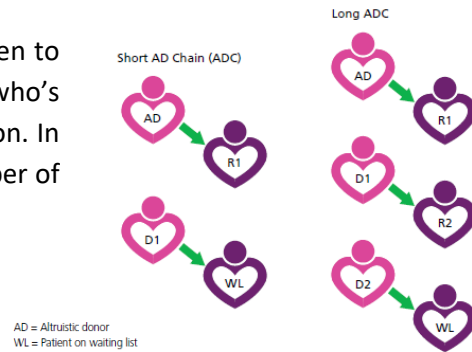
Quite obviously if you're donating to a specific family member or friend or someone in that circle, you know who you're donating to. If you're being an altruistic donor you have no choice or knowledge as to where your kidney is going to, it could be a man or woman of any creed, colour, sexual orientation or religion. You do, however, get one choice and it's a choice that needs some thought. The two choices are;

**National transplant list donation**, this is where your kidney is matched with a person on the transplant list and the kidney goes directly to that patient.



Or

**Paired/pooled donation**, this is where your kidney is given to someone, who's sister would donate to someone else who's brother would donate a kidney to someone else and so on. In theory the chain could carry on forever and a large number of people could have their quality of life improved.



For me this was a really difficult choice, or maybe I just over thought it. I had a thought in my head originally that I wanted my kidney to go to the next person on the transplant register. I had this idea that anyone who didn't have family and friends that were willing to donate so that their partner or family member had the advantage over other people who didn't have family that were able to do this for them, and I didn't think this was fair, but having forgotten about it for the time that I was having the other tests, I was asked the question again by my local transplant coordinator, and I came to this conclusion, no matter what you think, the more kidneys that come from live donors, then there are more kidneys from deceased donors, in other words there are more kidneys, and that increases everyone who needs one a better chance of getting one. In the end, a pair/pooled system is better for everyone, everything can be planned, and live donations have a slightly better chance of success, after all the over thinking it's really quite a simple choice. I have since found from the transplant coordinator that even if I have signed up for the pooled donation, if there is a perfect match that has been on the transplant list for a long time, because a suitable donor hasn't been found then that person will receive my kidney

### MEETING AT THE TRANSPLANT CENTRE, WITH YOUR SURGEON

My transplant centre is in Leeds, this is where my operation will be done. Today I've been to the transplant centre to meet my surgeon and have a talk with him. I was met by the transplant coordinator who introduced me to my surgeon. One of the first things he said to me is 'I know what I have to say to you, and I can repeat anything you need to hear again, but if you think of a question please interrupt me and ask me, I won't forget what I have to tell you but you may forget your question, and ask as many questions as you want to ask'.

The whole idea of the meeting is for you to have all of your questions answered and for all of the risks to be imparted onto you, I was told which kidney would be removed and the reason why. How the operation would proceed and how things were done, what would happen before the operation and what would be the best things for me to do to recover in the best possible way; and roughly the timeframe I could expect for a full recovery, and on a very serious note the things that could happen

and why certain things are done. In short, if there is anything you didn't know about the pre op, the operation and the recovery before you met the surgeon, you do now and it was reiterated again and again, that my safety and recovery was at the forefront of everything that was being done.

One of the things that was discussed was what happens if my kidney recipient couldn't have the operation after my kidney had been removed, i.e. if after the intended recipient has problems after being put under anaesthetic. There are a few options to consider, and you are asked to make a decision as to your choice. You are given impartial information and any questions can be asked, but you will not be given any opinion from anyone on the transplant team.

- That my kidney is replaced back in my body, not in its original position but in the transplant position, it would then have to remain there, and I wouldn't be able to donate it again.
- That my kidney is taken for scientific research and testing.
- That my kidney is given to the next person on the transplant list.
- The kidney is disposed of without any of the above happening.

As an altruistic donor I do not know, nor am I bothered as to who gets my kidney once it is removed, as long as the kidney is used, so decided that if the organised donation cannot go ahead then my kidney is to be given to the next person on the transplant list. This is documented and you have the document to sign for your wishes. I did ask if it could be devilled and served with nice Chianti, but apparently this isn't one of the options. I left there feeling comfortable with everyone I met, confident with my surgeon, plus he is a likable person. I felt happy with every thing that's going to happen.

## **BLOOD DONORS**

Blood donors please remember to tell your blood donor team what you're doing, even ring them on 0300 123 23 23 or contact them on their contact page <https://secure.blood.co.uk/ContactUs> they'll get back to you and let you know if you can donate or not, I was informed that I could donate 6-8 weeks after the nuclear tests, also let your transplant centre know that you give blood and they'll advise you appropriately too. When I spoke to my Surgeon he asked me not to donate blood any more until after my operation.

## **MEETING WITH THE HUMAN TRANSPLANT AUTHORITY**

Before your details are put into the computer to find a match, there is one more legal hoop to jump through, you have to be interviewed by a representative of the HTA (Human Transplant Authority), a report is written and during a meeting, your case is heard at a later date and approval is given or denied. The meeting is to confirm a few things,

- That you have the mental capacity to consent to the operation
- that you understand the seriousness of the operation,
- you understand what the operation entails, and how it can deviate from the plan
- the risks of the operation and what can go wrong
- that you're not being paid, monetarily or otherwise
- that you're not been forced or blackmailed to donate

These are the things that ensure that everything conforms to the legal framework that is the Human Tissue Act 2004.

so basically it's a 30 minute sit down and talk over coffee with the representative from HTA s/he has various things that she has to ask you, but also is there to get to know you a bit and your story. For me this was a breeze, but I'm not giving my kidney to anyone I know. If I were then both the donor and the recipient would be interviewed, to make sure no one is being cajoled into the donation, and to see the relationship between the two people and how they interact. The person I met was really, friendly and great to talk to, she was a nurse and understands all about the operation and what happens, again if you have any questions, she's there to help, and she's there to make sure you understand everything, and know what you're undertaking. When the report has been written and HTA board have approved or denied your operation your transplant coordinator will contact you with the decision.

### **HTA DECISION**

Got a call from my live donor co-ordinator, private number that I didn't recognise, so I nearly never answered it, with the great news that the HTA have approved me for donation, to say I'm happy is an understatement. So what happens now? There's a quarterly match run of all live donors, I'll be added to that list on the 10<sup>th</sup> of January, and the computerised match will take place on the 17<sup>th</sup> of January. After they find a match, then it's time to go to have more bloods taken, probably in my local hospital.

### **SET BACK**

I've got a call from my live donor co-ordinator today, with the decision from the HTA being delayed by the Christmas period, and because of the order of tests that are carried out, there won't be time to do the tissue typing blood test before the current match run. This test is the most expensive of the tests and hence the reason it is left until last. The information from this test is fed into a computer and is matched to potential recipients, and consequently if there's no test I can't be put in for a match. I am a little disappointed, I'd got all set up for everything but I only have to wait another couple of months for the next run. So I've had my blood test today, and then I have to have a verification blood test taken by an independent person, I chose my doctors surgery, had that done there and sent it off to the transplant hospital. So now I'm waiting until March for a call from the hospital.

### **THE MATCHING PROCESS**

There are three tests that are done to see if donors and recipients are compatible. These are blood type, cross match and HLA.

**Blood type;** There are 4 different blood types, O,A,B & AB. The blood type of the donor must be compatible with the recipient. The rules for blood type in transplantation are the same as they are for blood transfusion. Some blood types can give to others and some may not. Blood type O is considered the universal donor. People with blood type O can give to any other blood type. Blood type AB is called the universal recipient because they can receive an organ or blood from people with any blood type. The chart below shows which blood type can donate to which.

<b>If your blood type is:</b>	<b>You can donate to these blood types:</b>
TYPE O	TYPE O, A, B, AB
TYPE A	TYPE A, AB
TYPE B	TYPE B, AB
TYPE AB	TYPE AB

Certain blood groups can only be given to people with certain other blood groups, so blood typing is done first, my kidney can be given to people of 2 other blood groups, but the preference is same blood group. Then tissue typing is carried out, this is to identify if the white blood cells are compatible. Cross matching, a blood test is taken from the donor. The results of the first two tests are fed into a computer, and a scoring system is used to decide the most needed recipient of the organ, when they are found, the cross match test is done, and then repeated just before the operation.

**HLA Typing;** is also called "tissue typing". HLA stands for **human leukocyte antigen**. Antigens are proteins on the cells in the body. Out of over 100 different antigens that have been identified, there are six that have been shown to be the most important in organ transplantation. Of these six antigens, we inherit three from each parent. Except in cases of identical twins and some siblings, it is rare to get a six-antigen match between two people, especially if they are unrelated. Kidneys are very successfully transplanted between two people with no matching antigens. A person can make antibodies against another person's HLA antigens. Antibodies can result from blood transfusions, pregnancy, infections or even a viral illness. Having one of these events does not mean a person will make antibodies but they could. If a recipient has strong antibodies against a donor's HLA, the risk of rejection is high and a donor would be declined for that recipient.

**Live donor Cross-Match Testing ;** The crossmatch test is a very important part of the living donor work-up and is repeated again just before the transplant surgery. Blood from the donor and recipient are mixed together to see if they will react with each other. If the recipient's cells react with the donor cells, the crossmatch is considered positive. This means the recipient has antibodies "against" the donor's cells which would result in the kidney being rejected straight away. If the crossmatch is negative, the pair is considered compatible.

## **BACK ON COURSE**

I got an email today to say that I'm going to be put on the matching run on the 25<sup>th</sup>, and everything is back on track. Was definitely a boost to me, and I dare say it is to the recipient, that doesn't even know it yet.

## **ANXIOUS**

I'd been getting a little anxious, not heard anything at all from my transplant coordinator, or from the transplant hospital, was hoping that I hadn't been missed off the matching run. So I dropped my coordinator an email just to ask, so what happens, the same as it always does when you're wanting someone to get in touch or you're waiting for a phone call or something. The Phone rings, it's my

coordinator, I don't hear it, for 2 reasons. One, because I'd forgotten to take my phone off silent (good move eh?), and two, I was in the shower when she called and wouldn't have heard it even if my phone wasn't on silent. Anyway, as usual when I miss one of her calls, she leaves me a message and I call her back. It's good news on two fronts, I have a potential match, I am so happy to hear this, but there's no information as to whether it's a straight donation or if it's a paired or pooled donation, the other good news was that the delay was because there were a lot of donors so there's a lot of meetings and discussions that have to take place first before people can be contacted, anyway the meeting about my kidney is tomorrow and I hopefully will find something out in the next couple of days.

### **GOING FORWARD AGAIN**

My living donor coordinator emailed me to tell me that the matching run was on the 25<sup>th</sup> and I was on it and not only that but I have a potential match, they've compared scans of my kidney at the recipients hospital, and figured that my kidney will fit comfortably inside the recipients body, obviously you're going to struggle to put a fully grown mans kidney in a child, so size is a big factor in the choice of recipient, Because of the physical fit, could I come in for blood tests. Today that's what I did, I went into ward 50 of Hull Royal Infirmary, and spoke to Julie, she told me that she knew nothing about the potential recipient, sometimes she'll be told something but not for my recipient.

They needed a lot of blood this time, around 10 vials, because although the 'computer says yes' they still need to do what would be a bit of an archaic test, but never the less, the most important test of all. If you think that my kidney is going to be put in someone else's body, and our cells/bloods are going to mix, then the best way to test this is to take blood from me and take blood from the potential recipient, mix it together and see what happens. To see whether the bloods mix with no problems, or to see if a reaction occurs and something from alien pops out of the test tube, ok maybe not that bad, but if the bloods react against each other, then my kidney will have a tougher chance of survival, if not an impossible chance. The potential recipient is told that there may be a chance of a donated kidney, but that is all.

### **HAPPINESS!**

I got an email from my coordinator, the bloods have mixed well, by the looks of things, which is great, I got home with this thought on my mind, there's someone out there that could have been waiting for years for a kidney, having to go through dialysis 3 times a week, not eating or drinking what they wanted to, living in hope, and losing hope, maybe being told that there's a potential donor, only to be told that the kidney isn't viable. This time is different, they've been told there's a chance, they've had the tests, they know it's a viable match, and now after, potentially, years there is an end in sight for them and their life will change, I know that this isn't a cure, I know that what I'm doing isn't anything more than a stopgap, but I can imagine that any amount of relief from kidney disease would be welcome, and it makes me smile just to think that someone is starting the beginning of the end of their journey. I feel like I have an immense responsibility now to stay healthy, and look after myself, I have someone else who is banking on me now.

## **RESEARCH**

I got an email from my local donor coordinator, asking if I'd be interested to take part in a study entitled, **Understanding barriers and outcomes of unspecified (altruistic) kidney donation (BOUnD)**. It's a study led by research teams from Guy's and St. Thomas' Hospitals and Plymouth University. It would involve 4 questionnaires at various parts of the donation process. From the initial interview, 2 weeks before donation, and 3 & 12 months after donation. It is to help understand the psychosocial factors, (stress and anxiety) of the donation process. Either if it was a successful donation or if you were unable to proceed with the donation. By taking part I'll be contributing to the understanding of the process of unspecified donation in the UK, and contribute to new recommendations to improve services to the development of helpful resources for both donors and transplant professionals. For me it's a no brainer, the one reason I started this story was because I didn't think that there was the right amount of information from the correct sources. There really was a lot of information but most of it medical and statistical, but not a lot of firsthand experience available or the procedure explained without really looking for it, so to have an input in this study to possibly improve things for people like me is something I am more than happy to do.

## **LET'S SET A DATE**

So whilst I'm at work, I get a phone call, that I missed of course, because that's what I do, I miss calls, all the time, but it's ok because they left a voice mail. 'Hello, this is Rachel from St James hospital in Leeds, I'm the Kidney donor coordinator, ill ring you back later or you can ring me on 0115 2000???' and on the last number the phone hisses, and it was indecipherable. I take the phone to a different area and the same thing happens, and again in a different area, that's when I figure that the problem is on the caller's phone and I'll never get the number from the answer phone. So I call my coordinator at my local hospital and she's busy and I get her answer phone, eventually I get through to St James, and through to the coordinator, yay! 'We have a date for your operation, we're sorry it's taken so long to sort out but we've had a number of hospitals to coordinate as your donation has created a chain of 3 other donors' the news is better than I expected, I wanted to help improve one person's life, but a domino effect has happened and three people will be having their lives improved if everything goes well. I really am happy but also I now have a month to look after myself, keep myself healthy, as I have more than one person banking on me. By law I also have to have a full health screening a maximum 14 days before the operation, so I have an appointment for a chest x-ray, a cardiograph and blood tests, this just confirms the donor/recipient match. Let's see how much weight I can lose before my operation, gives me something else to focus on. I shall receive a phone call on the morning of the day before to let me know what time they want me to come into the hospital, and then it'll be admission and starvation lol, and that's the thing I'm not looking forward to.

## **OTHER THOUGHTS**

With everything medical there's always some form of risk, and I have had lots of offers of help from lots of my friends and family, but I have refused every one. If something does go wrong, I wouldn't want anyone blaming anything that they've done for me, and feeling guilty, I've listened to everything that everyone has said to me, both encouraging and not and other people's concerns,

granted there hasn't been that many people saying 'why would you do that?' and it's been positive, there has been one person that has actually said 'I don't want you to do this' and I really respect her for that, but like everyone else has said to me, 'you're so stubborn, once you've decided to do something you do it and nothing anyone will say will change your mind' which is spot on. Since I've got my date, I've spoke to my son, who has been very approving, and he's said to me that he's worried, and although I know that I have his full backing it has made me think, not change my mind at all just made me think.

My friend who asked me not to do it, today asked me if she could pick me up from the hospital, when I said I would think about it, she added that she'd bring the dogs for me to cuddle and that we could stop off for McDonalds on the way home, I gotta say that is very tempting. I've decided to take her up on her offer.

## **THOUGHTS**

Well I've had a couple of weeks for everything to sink in, I'm letting my friend bring me home from the hospital, less stress for my parents, and she's being supportive, which is really good. Have been on a different shift at work and I was asked if I'd heard anything from the hospital, told them what date id be going in for the operation, I was asked 'are you was nervous? Cos I'd be bricking it if I was you' and it got me thinking, I'm not nervous at all and I'm not sure if that's ok or not? Do I have that much faith in the people around me? Or am I really that stupid that I'm not nervous? It confused me somewhat as I'm a bit of a control freak and yet I'm completely ok with everything that's going on around me. I look at my twitter feed, and other social media sites that I'm on, and due to me doing research, I've joined a number of pages to do with transplants, and people that have received them. The only thing I can come up with is that 'what will be will be' there are so many people out there that have suffered for years because they need a transplant, waiting for someone to die so they can live, because they caught a cold or something as innocuous as that, I don't care what people say, accepting someone's death is bad enough at any time, but to accept it so that you can live must be really hard, to know that someone has done this for no other reason other than 'because they can' must be easier. I've seen posts from people who have received organs and they are so very grateful to have an opportunity to be able to live again, they see the world through different eyes than the rest of us healthy people. They appreciate the small things, the insignificant stuff that passes us by, but it's always tinged with sadness that someone had to die. There has to be confidentiality between donor and recipient in an altruistic donation, and if there was to be communication then both parties have to give express permission for it and what information is shared. I'm not doing this for thanks, for praise or for any other reason, and to be honest, I'm not sure whether I would want to meet the recipient, for that very same reason, but am I denying that person of closure? and is that selfish of me?

The one thing I do know is this, what I'm doing is the right thing to do, I'm not saying it's for everyone, but it is the right thing for me, and because of that I'm not worried, I'm focused. Oh and I'm a bit mad

## **PRE OPERATION MEDICAL AND MEETING**

No need to be worried about this one, there's nothing here that you haven't already done before. I met the transplant coordinator from the hospital where I'm having the operation, she went through everything with me, from start to finish, I found out that the surgeon that I've previously met is going to be the one that's doing my operation, I'm pleased with that, I have no doubt that he is a



brilliant surgeon as they all are, but having talked to this guy, I like him, and that makes a difference. I was told about the process, pre, during and post operation. Pre operation I shall be admitted the day before at 19:30, where I'll stay til the morning, where I'll be nil by mouth, in the morning I'll be getting up early, shower, be issued with my surgical stockings and 'special pants' (I'm looking forward to seeing them LOL). I'll be taken down to theatre, and as for some reason they don't use the anaesthesia room in the theatre I'm going into, I'll be going straight into the operating theatre, and getting to see the full set up that will be used on me. I'll have a drip put in the back of my hand, and then its sleepy time, and after I'm asleep I shall be intubated, (a tube put down my throat to help breathing). The operation will be carried out, when my kidney is removed it'll be covered in the normal fatty tissue in the human body, taken to one side and cleaned, packed on ice and then taken by paramedics in and ambulance with blue lights and sirens to the hospital where it will be 'installed' into its new owner. I've asked if I can have a photo of my kidney after its been removed (I know it sounds macabre but I'd like to know what I look like from the inside). When I'm waking up the tube will be removed, but I won't be aware of it or remember it, afterwards I'll be taken to the recovery room for a couple of hours, just so they can keep an eye on my for a couple of hours. My coordinator told me that she'll come around to see me and have a conversation with me, that I won't remember. I'll be hooked up to a bag of saline to rehydrate me, and also a supply and demand push button Pain relief machine, these will be in for 24 hours, I'll be encouraged to get up and walk around in the evening, which suits me as I really don't want to go to toilet whilst I'm laid in a bed, and I'm not one for laying in bed. I shall be ok to leave the hospital the day after my operation. One of my coordinators will call me around a week after my operation, and maybe a couple more times to before I get my 6 week check up to see how things are going, again the emphasis is put on the, 'if you need us, call us, we're here for you'. I also asked if I could send an anonymous card, wishing them Good Luck, my coordinator said it was ok and she'd never been asked if a card could be sent with the kidney before.



I've had a chest x-ray, and an ECG today, no stresses, no hassles. I've had my weight measured and also my height, and I've found that I've grown by a centimetre and have lost a couple of kilo, I'm pretty happy about that. I made sure that I had a lot to drink before my appointment, as I know I'd have to give some blood samples, I just didn't know there'd be that many lol, they have everything to check again, to make sure everything is ready to go on the day of the operation, I've had lots of blood taken and a few urine samples too. So the drinks worked two fold. I've also been tested for MRSA (Methicillin-resistant Staphylococcus aureus) it's a bacterium that's known to cause infections that are hard to treat, but it quite happily lives in the nose and ears of around 25% of the population, quite harmlessly I might add. So you're swabbed in your nose, under your armpits and in the groin area for it, but either way you're treat for the infection no matter what the results, you're given a cream to be rubbed in the inside of your nose for 5 consecutive days before your operation, and also

a special shower gel to be used for 5 consecutive days before your operation, the last shower is just before your operation.

Lastly I got to speak to a member of the surgical team that shall carry out my operation, he's explained everything to me that I've heard before, which is good, as there's bound to be something that I'll forget, and you get to sign the consent form for the operation.

Again when speaking to everyone I've seen today the emphasis is on your safety and the main points is that you can ask questions whenever you want and as many as you want.

**2 Weeks and Counting**, and I'm genuinely not worried, scared or nervous.

## **THOUGHTS**

I'm not allowed to know anything personal about my donor, which is understandable, but there are things that I do know, I know that I've started a chain of 3 donations, and I've found out that the person that shall be receiving their kidney from me has been on the waiting list for a long while. I am so glad to be able to do this for them. I was told by the coordinator today that if you asked anyone on the transplant list, that they would give anything for a few weeks of not having to be on dialysis, and also that the hospital is having a 40 year transplant birthday for a kidney this year. No matter the outcome, it's worth it.

## **OH NO! TURNS TO OH YES**

Well I did it again, I need to get a louder ringtone, missed a phone call again, the Coordinator from the transplant hospital, Voicemail 'can you call me as soon as you get this message please.' So with no thought of anything, I give her a call, 'hi, we've got a problem with one of your tests, you have too much creatinine in your urine, is there any chance you can bring another sample into your local hospital? Don't worry about it as all your other tests have been fine, it's just a glitch' 'of course', is my immediate reaction. I'm at work though, but I'm doing overtime and we're not that busy so I figure I can go home no problem. Off I pop home and do my samples, you tend to have a couple of sample pots around when you're constantly being asked for a sample. The thing about work is the limited opportunity to have a drink at any time and I know I'm dehydrated. I do my sample and let's just say 'it doesn't look good'. I decide seen as it's a wonderfully sunny day that going by motorbike just might be the best thing, it probably wasn't but any excuse eh? I drop my sample off and pick up another couple of sample bottles and go home. That's when it hits me, I flown all the way through these tests with no problems, could this stop the whole thing? I bloody hope not, I've got people relying on me, not just one, but three, and the one that's getting my kidney has been waiting for a very long time for it. I don't want to let these people down, its different now, if I'd have not passed a test in the early stages then that's different, but now I feel like I'm living with one kidney and the other one is one that I'm looking after for someone else, it's no longer mine its theirs, and I've got to take special care of it. To say I had a sleepless night is an understatement. I've been bingeing on water since I git back from the hospital just in case I need to give another sample, if I do this one would be mainly H2O.

I hadn't heard anything from my coordinator until 2pm the next day, when she told me that the new test was fine, such a relief.

## **AN EMOTIONAL JOURNEY**

In general I'm not bothered what people think of me, but I wouldn't want someone thinking that I'd let them down. No matter what anyone says, the whole journey is highly emotional and does get more emotional the further on it goes. From what I've experienced, people don't seem to get how emotionally committed you are.

When I first started this journey, I'd read up on things and knew what was happening, and I was good with that. By the time I'd had a couple of tests and spoke to the renal doctor and found I was healthy enough to carry on to the psychological interview, I'd already invested so much of myself, that that interview was so stressful for me, mainly because I had control of my answers, and I could 'blow it'. With the medical stuff if I failed a test then I couldn't help that, it was just my body not doing what it does. As the tests went on, they became so very important, a big part of my life around that time, I wanted to be relaxed when I went there, and to be able to do the tests with the best frame of mind I could have. It would have really bothered me if I hadn't got all through the tests.

I would have found it hard to cope with being told that I had a potential match only to find out one of the subsequent tests say that it wouldn't work, I know that they would have been disappointed, but I would have been just as gutted for them.

The biggest compliment I've had in such a long time is when the coordinator at the transplant hospital told me as she was reading my file 'wow, you have fantastic kidney function' I know that sounds silly but, my initial thought was pride followed by 'my recipient is getting a good one' followed by 'I'm going to be ok too'

I'm pretty certain that only people that have or are doing this will understand, that you're invested in saving/improving the life of someone you don't know, and that anything that happens that's slightly negative affects you more than you thought it would do, a big surprise to me!

Through talking to people about what I'm doing and trying to highlight how good it is to sign up for organ donation, blood donation and bone marrow donation. How a few minutes of discomfort can literally mean life to someone else. I've had so many people tell me what a wonderful thing I'm doing, from friends, and family to nurses and even surgeons, now I don't know what other altruistic donors think about what they're doing, but I don't think of it like that, I don't think of it in any other way than it being something I can do so why shouldn't I? I'm not looking for thanks or recognition, I'll be happy enough knowing that it worked how it's supposed to. I'm no 'goody two shoes' I've done things I'm not proud of, but neither am I looking for redemption either, as I'm an atheist. I just want to live up to my blood group and 'Be Positive' I don't want to be seen as anything else but me.

## **IT'S GETTING CLOSER, THE WEEK BEFORE**

I'm getting close to the date of my operation now, still not worried, really quite relaxed about it. What I'm finding funny is that there seems to be a lot of people who'd like my company for coffee at some point soon, so I seem to be busy drinking coffee and reassuring people that everything is going to be just fine, it's something I already know, but there again I've spoken to a lot of people about it.

I've been trying to do a 'Christmas clean' of my house, I'm staying at my parents for the first 2 weeks of my recovery, and when I do get back home I'd like it to be as clean as an empty house can be. Just

so I can relax, and only do things if I want to do them. I've also filled my fridge with drinks, not because I'm expecting a drought, but because they're heavy, and where as I can carry bread and ham, because they're light, I think I'd struggle carrying 30 cans coke (other soft drinks are available).

I've packed my case for hospital which has probably got more in it then I'll ever need, but you can't be too careful. I've also tried on my new pyjamas, apparently if you have a chest the size that I have then your stomach should be the size of a lorry inner tube, off to the shops I go again.

I've sorted out work and not only are they happy for me to have the time off, they're also happy to pay me, and I thank them immensely for this, everyone there has been very supportive. I work shifts and I've got 2 shifts to go before I go to hospital, which I suppose I could have taken off but I've decide to work one full day and a half day. I'm going to finish half way through the day, grab a shower, pick up my case and go and catch the train. I could have taken the day off but I think I'd be better off keeping my mind busy rather than thinking about the lack of food before my operation. I might just pop in for a manicure if I have time, and something nice to eat.

I have started my preventative MRSA treatment, although I've been swabbed for MRSA, and it's come back negative, I'm being treat as if I have I have got it. I've got cream that I have to spread on the inside of my nostrils three times a day, much to the amusement of my friends daughter, 'who gets told off for that and wants to know why a nurse said it's ok for me to do it'. I've just been for my second shower with the MRSA shower gel, the routine is that for 5 days in a row I have a shower with the soap the hospital provided and for 2 of those I clean every part of me from top to toe. As they've provided a huge amount of the soap, I don't see there been a problem with me doing a top to toe every day, so that's what I'm doing. I also have a sheet to fill in, I sign this every time I use the cream and the soap, and this is brought to the hospital when I go for my operation.

I've found out that my friend who really didn't want me to go ahead with the operation, isn't worried about the operation itself, just worried about me living with only one kidney, I'm preparing all of the info for her to look at to show that I can live perfectly happily on one kidney and I'll be checked up on every year.

Just checking the train times to my transplant hospital too I'll be home from work at 11, shower, shave, and then the walk to the station, before a 2 hour journey and an hours bus ride to the hospital.

### **PREPARATION FOR HOSPITAL**

So what do you need to take to the hospital? I didn't know what to take so I seemed to pack for a week in Spain, but there are some things that I think you may need. A couple of changes of nightwear, slippers, something with a loose elasticated waist to wear home and a baggy T-shirt, peppermint tea, mints, a long charging lead for your phone (sockets are usually behind the bed in hospitals) and wet wipes.

Your incision site is very well securely stitched, good enough to cope with the worst sneezing or coughing fit, but even when you know this, a lot of people tend to worry (including me) I found it really comforting to have a small cushion to hold against me, a barrier if you like, it served no practical use, but psychologically it did the trick.

The other thing you should be aware of is the noise and lights that there are in a hospital, if you're a light sleeper then maybe consider taking an eye mask and ear plugs. Entertainment wise, most hospitals have individual TV/internet screens where you can pay for extra TV channels, but there are free channels and radio usually. Headphones are usually available but I took my own. After my operation, I found that listening to music that I liked helped me sleep, but I didn't have the concentration to follow a TV program or movie, so watching TV that didn't require thinking was good for me.

### **THE DAY BEFORE THE OPERATION**

Ok, I need a little bit of help here, I'm still not nervous, I don't feel it, and I don't think I am. I didn't sleep well, and I know what you're going to say, but with it being 27 degrees in my bedroom with all the windows open, can you blame me? So am I unusual or have I completely lost my marbles?

I got up for work as usual, then got a fault on a machine that seemed simple but ended up being a bit of a head scratcher. I had a nice big full English breakfast. One of my friends at work asked me when my operation was, and when I told her, she replied with 'don't worry about it, he's watching over you', I replied that I don't believe in god, her answer was 'it doesn't matter whether you believe in him or not, he's still watching over you' it must be nice to have faith like that, to be able to believe in something without any proof, I believe in the surgical team that are carrying out my operation, and also a different surgical team that are installing the kidney in its new owner, but I am so very grateful to my friend for her kind words and thoughts.



I've shut down my house as if I'm going on holiday, fridge is empty, and lots of things have been turned off. I've had a phone call from the donor coordinator and she's told me there is a bed for me and where it was, and I forgot almost instantly, so she's emailed me the details and they're on my phone. I've had my final shower at home with the wonderful red scrub stuff, packed that for tomorrow, and put some cream up my nose before leaving for the station. I will have forgotten something though, I'll come back to half a mouldy cucumber hiding at the back of the fridge. I picked up my case, then went back and got my phone. It hasn't got any cooler I can literally feel the seat running down my back as I walk to the station, I picked up my ticket, waited 5 minutes for the train, and got a nice seat with a table, had to change trains half an hour later, straight off

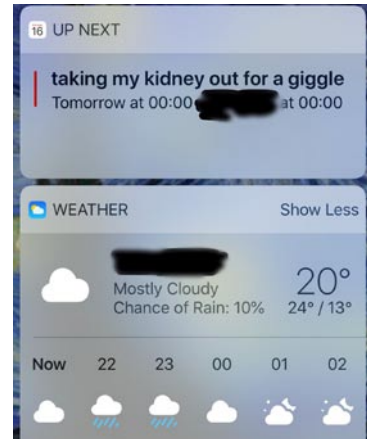
one train and straight onto the other, it couldn't have been an easier journey if I tried to be honest. So now I'm sat in Costas, just had a latte and a chocolate brownie, then I'm going to have a little walk and find a McDonald's, before I try and find a way to the hospital LOL, but I think.

Well I got bored walking around, so I took a walk to the hospital just over a mile and a half, and arrived at the hospital an hour early, my bed had been ready for ages, the nurses are wonderful, I've treated myself to the full sky package on the TV. I'm nil by mouth from midnight so I've had a coffee too, I'm not hungry, but if I was there are sandwiches if I want them. I've had my blood taken again, this is to cross match for 4 units in case I need them during the operation, I'm happy and chilled, and so is everyone around me too. I'm relaxing, watching a movie, Sherlock Holmes. I'm in a good place both mentally and the hospital I'm in, I'm in a mens ward where we've all either had or are going to have operations, there's a fair bit of banter going around too, the male nurse is taking my blood pressure

every few hours, and he's a funny guy, full of jokes, treating the mind as he's doing his job, it's things like that that I didn't realise until after I left hospital, but something I am grateful for now.

## DAY OF THE OPERATION

Marked up on my calendar as 'taking my kidney out for a giggle' I'm not making light of it, it's my way of coping for something I thought I'd be nervous of, but I've found out I'm not, I expect to become nervous as the morning goes on. I got up in the morning and showered, scrubbed myself from top to toe in MRSA shower gel, put on my DVT pop socks my rip off pants and my theatre gown, and sat on my bed. My coordinator came to see me, asked how I was, all comforting and supportive as she always has been, then my surgeon and anaesthesiologist, all explaining what's happening, and again being supportive. As much as it's nice to hear all of this, but because of the way that they've been, since the very first meeting,



ensuring you know that you are the most important person in this whole journey. I was not nervous and I think that surprised me more than a little. One of the surgical team came to see me and asked if I knew what operation I was having and which side was being operated on, and when I answered he removed a sterile black marker from its packet and drew a large arrow on my side, I was marked for surgery.

My transplant coordinator came back to see me and said it's time to go to theatre, and we were going to walk there as there was nothing wrong with me, and I quite agree there was nothing wrong



with me, and I was quite alright with that I didn't think that I should be wasting hospital staffs time for something I can do myself. I was perfectly fine until I got to the lift, now I know this sounds really silly, considering what I was going to do, but I'm really not very good with lifts, not very good at all. Good job I was doing something important, I walked into the lift cool as hell and gripped the rail on the wall, my finger marks are probably still there to this day.

We walked in to the waiting area of theatre, all of the usual questions were asked of me, name, date of birth, when was the last time I ate and had a drink, what operation I was having etc, everyone was great again.

My coordinator and I walked to the theatre, she explained to me that the operating bed is pretty impressive, as the operation is performed with me laid on my side, the operating table is like a giant beanbag, and when I'm positioned in the correct place all the air is sucked out of the beanbag and it 'sets' solid and I wouldn't have been able to move if I wanted to. I walked into theatre and it was nice to see how bright it was, there was a bed in the middle and lots of machines on wheels around it, and a huge circular light above it, the light being a special design that doesn't give any shadow on the operating area. The anaesthetist introduced himself again, checked who I was again and put a cannula in the back of my hand, but he numbed the area first before putting the needle in, so I didn't even know it was there, my coordinator was with me all the time, she was the last person I saw

when I was counting up to 10 to my sleep, apparently I got to 12, and she was the first face I saw when I woke up, I know that she's had other things to do, as I know she prepares the kidney for transport after its taken out of me, and make sure it's packed correctly with ice and taken to the paramedics, who take the kidney to the recipient, with blue flashing lights and sirens blaring, it's a medical emergency.

So when I remember waking up she was the first person I saw, and when you're in a place that you don't know, seeing a smiling face that you recognise telling you everything's ok, don't worry just relax, I was so grateful to see her. My first thought was, 'that was a gooooood sleep' and then I realised where I was. I remember looking up at the clock and thinking it was 230pm and thinking that I wasn't in pain, and looking down under my cover to see that I was a little bloated. But I had plasters on so I knew

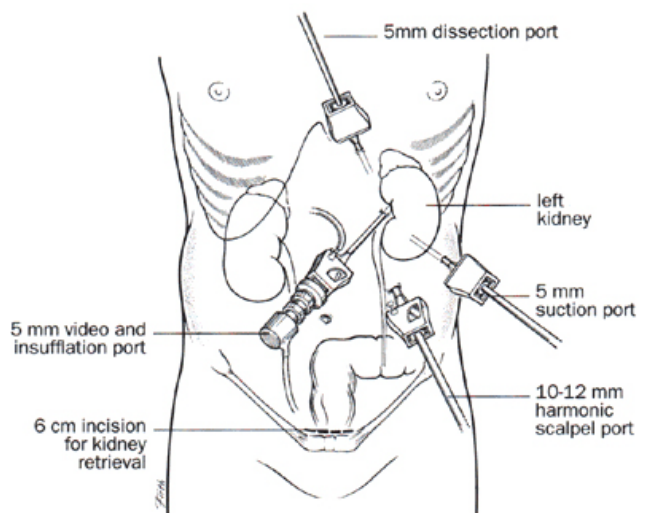


I'd had the operation. I went back to sleep, I remember coming round again and again each time a friendly smile was there, then the next time I was in the ward, in my normal place, familiar surroundings, and a push button in my hand, this was to operate my supply and demand pain relief.

If I press the button I get a dose of pain killer, it's on a timer, so you can only have so much in an allotted time. It's safe pain killer, whilst I was under I've had penicillin and also blood thinners to prevent deep vein thrombosis. I never used the pain killer in the whole of the time I was in hospital, I think I was really lucky or I've got a good pain threshold, I ached and that wasn't what I call pain, and I was bloated, again not painful just uncomfortable.

## THE OPERATION ITS SELF

The operation is performed with the patient on their side somewhat, a few small incisions are made for the instruments that are used and one for the video/viewing camera. After the incisions are made under the skin, intestines are separated to make a nice working space and the patient's stomach is filled with carbon dioxide to swell the stomach cavity and to create a space to work in. The renal vein and artery feed into the kidney, but they also feed the adrenal glands and some areas of the back and, in men the vein from left testicle. The vein is clamped off to the testical and the blood supply will return by other routes. The blood supply to the adrenal gland, which sits on top of the kidney and regulates your body when under stress, are rerouted. The renal vein and artery, and ureter are clamped and cut, and the kidney is removed in a ball of fat via a



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larger incision in the waist line. The kidney is taken to one side and the fat is removed and the kidney



cleaned up so it can be put straight into the recipient when it arrives at the theatre. The stomach muscles are stitched back together with dissolvable stitches and the same with the skin on your stomach. At the end it really is quite neat, one of the things my surgeon asked was if I had tattoos, if I had, we would have agreed to where my incision sites would be so my tattoos wouldn't be ruined, my surgeon's words not mine.

### **BACK ON THE WARD**

Back on the ward, I'm still relaxed, the nurses have put me on 1 hour observations, blood pressure, blood oxygen and pulse. I have a drip with saline, a tube with oxygen going up my nose and the morphine drip too. My stats are all good and after 12 hours I went onto 4 hour observations, still all good. I'm drinking ok and I'm feeling ok, the anaesthetic is slowly wearing off and at one point I was sick, but only the once. 8 hours later I was sat at the edge of the bed with my nurse from the night shift, helping me to stand up, (this is all with the blessing of my coordinator) and I made the short walk to the toilet, which was so good, and although it was a small thing it was a big thing for me and I was very happy with that. I'd messaged my family and friends to tell them I was ok, even sent them a selfie from the bathroom mirror, 10 minutes later it started,

'Are you sure you're in the hospital and not an all inclusive hotel?'

'Hospital for sure',

'I can see your red wrist band'

'It's because of my allergy to milk'

'Oh yeah ok, and now you'll be off to the water slides and pool bar, then the buffet restaurant'

It's the little things that your friends do that make a lot of difference, things like half a dozen messages, that are exactly the same as if you weren't in hospital, just wanting to make light of a situation and treating you normally, I was so grateful.

Later as I was watching TV a nurse came around with medication, checked to see what I've used from the morphine system, and to give me my blood thinner injection, I asked if I can do it myself as I would have to do 6 of them when I got back home. If you've read this from the start you'll know that I was really scared of needles, not so much now, I've got quite used to them, but giving myself an injection is a whole other thing. It was a lot simpler than I thought and the nurse was encouraging and I did it, and every one when I got home.

Whilst watching the TV, I wondered if my coordinator from my home town had being told that I'd had my operation, so I sent her an email, I had a reply from her by the morning. Saying how she didn't expect me to be up to sending emails already, and a 'take it easy' I know this wasn't advice, this was an order!



The anaesthetic seems to wear off on different parts of the body at different times, I was awake and lucid I could walk and physically feeling great, my prostrate hadn't woken up yet, I discovered this when I woke up wet, I was embarrassed to say the least, a called the nurse and she was fantastic, 'its the anaesthetic, it happens all the time, don't worry.' As soon as I'd gone to the bathroom to clean myself up and change, both the night nurses started on my bed, by the time I'd got out of the bathroom, both had gone, there was a perfectly changed bed and no embarrassment at all.

### **THE NEXT DAY**

I woke up in the morning, feeling great still no pain but I do feel uncomfortable and bloated, the gas that's in my system stays there for a fair few days it moves around your body and up to your shoulders, and that became the only pain that I have had, but only when I got home. I tried to lose myself in a couple of movies, I managed half of one before breakfast. I had some toast, but there was a choice of cereal too, I had orange juice, and the nurse got me a peppermint tea. Peppermint tea is amazing I've no idea what it does and I really don't like it **but** it helps dissipate the carbon dioxide in your body, and it works. I wasn't in pain but I did feel uncomfortable, one of the other things that needs kick starting is your digestive system, it shuts down the movement of waste out of your body, mine didn't start up again for 4 days, but after lots of Senna tablets at regular intervals, if you get offered laxatives, take them, don't get worried about getting caught short, it's not going to happen, you got to trust me on this.

You'll get in positions where you feel comfortable, not only for the position but for the psychological aspect of where you're sat. Sitting in the big chair next to the bed felt better for me than sat at the side of the bed, only because of armrests, it meant I could relax, and if I fell asleep, which I did a lot, I wasn't going anywhere at all. Sometimes just moving a couple of centimetres makes all the difference. My surgeon came down to see me and was more than happy with how I was doing, he explained to me that the operation went well although rearranging my blood vessels for my adrenal gland and my back was a challenge, but everything went well. He did say to me before the operation that he would only have to shave small patches around my incision sites, when I woke up I had half of my stomach shaved, he apologised for this and said he didn't know what had happened. I can only assume I'd upset the one with the razor LOL. It was good to see him, he's a really positive person, everyone I've met is.

I had a sandwich at dinner with more fruit juice, and bakewell tart and custard. Watched another movie and then I was visited by a wonderful lady who took my blood on my pre op appointment, another smiling face that I recognised, she sat and talked to me for a while, and asked if I wanted to have a walk outside, we had a slow walk out into the garden and sat in the sun and talked for a while, normality for 5 minutes, the best medicine ever, I was so very grateful. After I'd been back in the ward a while I had so many visitors, my surgeon to say I could go home if I wanted to, and he could sort my lucky bag of medical stuff for around 6 pm. They weren't pushing me out the door though, if I'd have wanted to stay there longer, that wouldn't have been a problem at all, it's when you feel comfortable to go home is when you go home, I was going to my parents for a while, and you know what mothers are like, so I knew I'd be well looked after.

My coordinator came to see me, showed me a couple of pictures of my kidney that I'd asked if she could take. If you're expecting something from the butchers you'd be mistaken, it doesn't look like

that at all but she pointed out all of the important bits and I could see what it was. She was really happy about my progress and then told me that although it was a difficult operation, that my old kidney was working at the moment although it's early days, things are looking ok. I cannot describe how I felt at that time, all I can say was that it was a feeling that can only be rivalled by the birth of my children, all of the happiness and joy was overwhelming, and I tried to hold it back but couldn't, and I started to cry, but it was because I was happy, so very happy, and even writing this now I feel emotional. My coordinator made me promise that I would get in touch with her if I needed anything, absolutely anything, and I would, I would have no issue with that at all, she also asked if would consider being a buddy, someone who would talk to people who were considering donating a kidney, or were going through the process already, to share my experiences with other people.

Next I was visited by the transplant team, I was asked if it would be ok if they could take a picture of me and in a few months put my smiling mug on instagram, I'm more than happy about this, I don't want recognition and I don't want thanks, what I do want is to raise the profile of doing what I've done, of organ donation, of the good that it does and how little it takes to talk to your family about it. To be able to increase the amount of donor organs available. There is donor week coming up in a few months and although I won't be able to take part as they like you to have a year or so after donation before things like this, I will be going and supporting in my own way.

## LEAVING HOSPITAL

When it came time to leave everything was ready for me, all of my tablets, my spare dressings and my injections, was given information leaflets on everything I was given, a sharps bin for my used needles, and a phone number in case I wanted to ask questions. I was given spare dressings,



paracetamol and Naproxen, for pain relief, Movicol and senna to ease my stalled bowels, and 6 injections of innohep, a blood thinner to stop DVT

When I was picked up by my friend she carried my case and I was able to get myself in the car pretty well, couldn't reach to shut the door but I was in the car, the journey home for me was over 60miles. I will say this, short or long journey home, have a pain killer an hour before you leave and have a soft cushion to go under your seatbelt and over your large incision, trust me on this one, it will make a huge difference. The soft cushion also helps of you have pets or small children, it gives you that barrier, that makes you feel safe, and also for the psychological help when you cough or sneeze, we all know that you've been sewn together so that you can sneeze your head off, but it feels better when you hold a cushion around your waist.

On the road home it doesn't matter whether you go fast or slow, if you hit or avoid bumps, it is going to be uncomfortable. We stopped for a McD's on the way back, and it was good just to have a 10 minute break from driving and a drink to take my mind off things.

**So those would be my recommendations for coming home, pain killer, cushion and stop when you need it**

## HOME

I went to my parents instead of going home, partially because I didn't really know how I would be, but also because I know my parents, they would only stop worrying when they saw I was ok. I basically went to bed, then found that the bed I was sleeping in was really low and I couldn't actually get into it, so I got myself onto the recliner sofa and slept there, it was really comfortable, unfortunately I woke up early and I was cold, so after struggling for 20 minutes to get off the sofa, I crawled to the bed and managed to get in there. I found that when I was in the hospital that I found that I was more comfortable in bed, sat up with something under my knees, I slept with a few pillows around me and 2 under my knee. Heaven.

The next few days consisted of lots of sleeping and resting, walking around the garden and drinking coffee and flavoured water. I've found ways to be able to do things, get up off the sofa, get into bed, simple things that people take for granted, but can be difficult after an operation, don't get me wrong, recovery isn't fast, and it shouldn't be. You'll notice improvements in yourself every day, less aching, more strength, easier to get out of a chair, small things are good. If your body says sleep, then sleep, you've deserved it, and your body needs it, I've gone back to bed for 2 hours sleep after been awake for an hour in the morning, there's nothing wrong with it.

The only pain that I've had is in my shoulders from the gas I was filled with during the operation, and that subsided after 3 days. I've taken the laxatives every night and 4 days later I can report all waste management systems are working within acceptable levels, and I've also injected myself everyday at the same time with blood thinners, to prevent blood clots, this was the thing I wasn't looking forward to, but I managed it no problem. If you don't want to do it a family member or friend can be taught how to do it, or it can be arranged that a local nurse or doctor can do it for you. I removed the smaller dressings after 3 days, and the larger one after 5 days. My incisions look nice and clean, no redness, or any liquid from them, if there is go to your doctors straight away, no messing, you go and you wait until you're seen, or call up your coordinator, they'll sort you out

My sleeping position changes depending on how I feel, there's still a bit of swelling and aching, and different positions, help with different aches. I've also found that if I stand up for a couple of minutes that I can lay down more comfortably. My night time sleep of choice is on my non operation side with my operation side leg on a large pillow to support it. Eat what you fancy and when you fancy it. Most importantly take it easy, don't push yourself, recovery is not a race, take the time that you need, and do not lift anything heavy, 1) because you'll run the risk of a hernia until you're healed, 2) because you'll know about it with the pain. Some people are ready to go back to their office jobs after 2 weeks, others can walk to the end of the street and a really fatigued by it, both are completely normal, everyone heals at a different rate, so listen to your body and let it tell you what its ready to do.

## THE FUTURE

I'll be going back to see the coordination team in around 6 weeks, for blood and urine tests, to make sure that everything is going as planned, I had blood tests taken just before I left hospital so they have a comparison. 6 months after that I'll be called to my local coordinators for more tests, after that my local coordination team will invite me to see them every 12 months for more blood tests, to make sure you're doing ok.

## WHAT I'VE LEARNT

Honestly, I have learnt so much about myself, I've learnt to conquer my fears, not just cope with them but squash them flat! I've gone from someone who would visibly sweat at the thought of being injected, to someone who asked a nurse 'would you mind if I gave myself that injection?' I have learnt patience and humility, the times between tests and results was testing for me, but I've learnt that things cannot be rushed.

I've learnt that, no matter what, I am lucky to have had the health in my life that I have, to have had the life that I have, and to have the freedom to do what I want, and when I want. I always knew what I was doing was important for someone, I never realised how important. I didn't know how many people were on the list waiting for a kidney. That the vast majority would give the world to have a couple of weeks off dialysis, and that kidney disease can stop you doing anything at all. I've had a tweet from someone saying that she was so grateful to be able to play and bake with her children since having her kidney transplant, as most of her time previous to that was spent in bed.

They say that the operation is worse for the person who's donating than who's receiving a kidney, that's not true, their operation is far more invasive, but providing everything goes well, they start feeling better very soon after the operation, as they've been feeling so bad for so long, the pain would get swallowed up by the elation of just the chance of a normal life. We go for our operation in perfect health and come back to recover.

Am I proud that I've done this? You're damn right I am, it started off as a let's see if I can get through this, nothing ventured nothing gained, and if I don't make it to the end then it's because I've found something wrong with me. After a couple of tests it became obvious to me that I wanted to get through this but not for me, but for someone else, anyone else, anyone who can use my spare, and enjoy it. I've heard myself being called a hero by others, I've been told I'm amazing and very brave, when I rebuffed this to a member of my family, he said I was generous, I'll take that one, I can be generous and have no embarrassment about being told that. If you're going to talk about amazing, brave and heroic people, then look at the ones on dialysis, and their families, those are the words that describe these people, not me. All I did was take a couple of months off work to help someone out. I did something that 95% of you would do for a family member, I just did it for someone else's family.

If by some miracle I could grow another kidney would I do it again? Oh yes without, even thinking of the answer, there would be no hesitation. Is this the end of the journey for me? Not if I can help it, I've been asked if I can be a 'buddy' to talk to people who are thinking about doing this, to be a voice of the experience. Hopefully I can spread the wonderful thing that is donation and get more people on the donor register.

If it hadn't had worked would I still have felt the same? Yes I would, it's a high percentage success rate, and that still means there will be some failures, no matter how few. If it hadn't of worked I would have been sad and upset, but not for me. When you get to operation stage it stops being about you, you tend not to think about yourself. I would have been sad for the recipient that it didn't work for them and disappointed for them, gutted in fact, no thoughts for myself though, I did the best I can do. The system works, it's just one of those unfortunate things, and everyone tried as hard as they could to make it work, it just didn't.

I am so very thankful to all of the people I have seen in the medical profession during the past 18 months, they have been, without exception an amazing, underappreciated group of people, every nurse, doctor, surgeon, and especially the donor coordination team, they are so very supportive, they make sure you know what's happening at every step of the way, and they are always there for you, no matter what the question, no matter how insignificant you may think it is, they're there with the answer. I thank you all, so very much.

I am also so very grateful to my family and friends, the ones who have supported me, and looked after me, the ones that have worried about me, questioned my sanity, and asked questions, and have given me more questions to ask. I know that this was tough on my parents, but their support never wavered, thanks mum and dad.

#### **MY LAST BIT**

The last thing I want to say is this, I'm not asking for anyone to do what I've done, if you want to, then I've tried to put everything that I've experienced, done and had done to me on here just so that it may help someone somewhere.

#### **BUT**

I want to ask you this, please, please, please register to have your organs donated when you die, organ donation can improve the lives of 8 people with organs alone, and up to another 50 with tissue donation. The link is below, but registration isn't enough, you need to talk about it, as your family still have to give consent. Please talk to your family, explain to them the good it will do for other people, and that it's what you would like more than anything after you have gone. The organ donation form will only take you 2 minutes to fill in but will give life to so many people, let it be your legacy.

**[www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)**