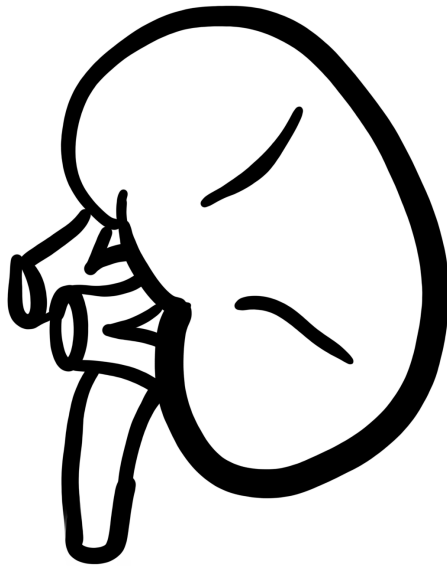


SPILLING YOUR
GUTS
(A LIVING DONATION
JOURNEY)



BY DYLAN ORCHARD

WITH THANKS TO...

My family for supporting me completely, even when they thought my decisions were daft ones. I love you all. Promise I won't do it again, for a while at least.

Everyone at Guy's Hospital, support workers, nurses, doctors, consultants - everyone. Nothing happens without you and you're there every day for all of us.

The NHS - for so many people at so many times the NHS is the most important service there is, whether it's saving lives or just being there when things are hardest. Anyone who wants to undermine it wants to undermine us all.

INTRODUCTION

I don't remember when I definitely, absolutely, definitively made my mind up to donate my kidney to a stranger. I guess there must have been a moment where I went from thinking 'that's a nice thing to do' to 'that's a thing I'm actually doing' but it certainly wasn't a revelatory one. In fact, if anything, it feels more like something I drifted into than actively set a course for. Not that it wasn't my choice, of course, but as with so many things I sort of circled around the idea until, eventually, I found myself at the centre of it.

I donated in May of 2022 at Guy's Hospital in London. It was some time in the morning and my most abiding memory of that day is being left alone before surgery to change into the hospital gown. It isn't a memory that stands out because of any particularly profound feelings, there was no particular fear or pride there - it was too early for either for one thing, I don't function well before mid-day at the best of times. It was still a strange experience though, waiting to go down to surgery, it was at once completely routine - there's nowhere more practical than a hospital ward - and also... I don't know, to this day I can't really nail down the feeling. Perhaps it was surreal? Bizarre? Weirdly anti-climactic? Whatever you may think from a distance donating an organ is a surprisingly low key experience, at least it was for me. While the whole process has an air of oddness about it, because you are making a free choice to have a chunk of yourself cut out without any pressing need to do so, I think it's also like most good things you do in life. Contributing something positive is very rarely about a big moment or a grand gesture (although some might say kidney donation is one of those, not me though), instead it's more often about a long list of dragging tasks that, hopefully, come to a positive end.

My donation was never about that one morning waiting for surgery. It was about the form filling, blood tests, urine tests, Nuclear scans, X-Rays, ECGs, long waits in hospitals, long talks with doctors, nurses and psychiatrists... It was about putting the deeply routine effort into small things which allowed for the build up to something good at the end. And not to get too grand or preachy but I think that's the best any of us can aim for. Aim for a positive end, absolutely, but make the job of doing something positive a day to day one, a routine one, a not-particularly-remarkable one. It was certainly that mundane goodness that got me through, from doctors, nurses, friends, family, support staff and everyone else involved.

I wrote the updates compiled in this book between the 9th of November 2021, just before my first hospital appointment and the 4th of August 2022, a couple of months after my surgery (on the May 26th). I didn't have anything in mind for them, certainly not any audience, but I felt the process should be documented in some way at least. I'm sharing them now mostly on the offchance that other potential donors might get some value from my experiences, or at least a long (and sometimes rambling) outline of what to expect.

If you are thinking of donating then I think the best bits of advice I can offer are 1: Don't be afraid to mash that drug button afterwards and 2: Have a nice long sit down when you're done, you deserve a break.

PART ONE: IN THE BEGINNING...

In two minds over whether to write about this really, it's of interest to me but like most things people do in life it's probably of zero interest to anyone else. Still, as an exercise in self reflection it is interesting to me at least so why not?

Anyway, what is 'it' anyway? Well 'it' is living organ donation and the organ in question is my kidney (insert joke about donating other 'organs' here ((insert joke about 'inserting' here))). To clarify – what I'm planning to do is called Non-Directed Altruistic Donation, which basically means that I offer up a kidney and, assuming I'm mostly fit and sane, someone out there will get it when they need it.

At the moment I'm only at the stage where the fit and sane part has yet to be established. Paperwork is filed and my first meeting and blood test is on Friday so that is, I suppose, when the process becomes a real one rather than just speculative form filling. Although even with that it's still feeling a bit abstract, to me at least.

Why do it? A few reasons I suppose. The idea first crossed my mind years back when I was driving with a friend in the US, they had some PBS style talk radio piece on about altruistic donors and the concept stuck with me. I think the programme was actually about whether true altruism existed at all or if even the most selfless acts were, ultimately, self serving in some respect. A discussion I couldn't answer then and still have no concrete conclusions to. Although I incline to optimism when it comes to human behaviour, as far as reality will let me. Anyway, that was the genesis of the idea I think but the logic in following through on it is a bit more convoluted.

To be honest it's probably easiest for me to start by saying 'why not do it?'. The potential to save a life – or dramatically improve one – is, to me, a self evident good after all so the real question isn't so much what motivation there is to try and do it but what risks are there that might stop you. And there are risks, of course there are. For one thing some stranger with a knife is going to slice you open and take an important bit out, for another there are slightly raised risks of future problems. But then the majority of my life choices to date have the same true of them, the smoking, drinking, poor diet, lack of exercise – any/all of them could lead to complications down the way and the decision to do any of them was no decision at all. They were unthinking grabs for what felt good, or what was easiest, or frankly whatever was put in front of me. Not that I'm lamenting any of that, there's no self condemnation or straight edge turn in this but if those risks were acceptable to me for no real gain to anyone then a slight increase in risk to do something that'd be a real gain for someone? Well, why not? Just taking it as that kind of pragmatic choice it seems right to me, never mind any higher or more profound logic than that.

Another downside is that I may never be able to box or do full contact sports again apparently, which as anyone who's met me can attest will be a genuine loss to the worlds of UFC and rugby.

Reactions to my choice so far have been mixed. To be honest I'm trying to avoid talking about it too much, with sporadic success. It's a very personal thing to do really and it's hard not to sound like a bit of a prick discussing it, as if I'm showing off in some way. That said though it's also a thing that's happening and taking up a chunk of my head space at the moment so it's hard not to want to talk about it even if it's only in the same terms as talking about the cat having fleas, or gearing up for my busy work period at Christmas. Dull but it is what's happening at the moment.

Most people are, vaguely, positive so far. Most find it a bit weird really, or at least that's the impression I get and fair enough. That I can justify it for myself in no way extends to expecting or wanting anyone else to do the same because by a lot of lights it is a weird choice. Certainly an extreme one in its way. Most of my life choices always have been though so that one at least I don't find it hard to live with. Some people have been negative about it, which I've less patience for. Indifference is more than fair but to take offence at the idea, especially when it's someone else's choice just seems like a bad sign in itself. 'Nobody would do it for you' or 'I'd just look after myself' are shitty takes to have whatever the topic really, even if you do believe the former and I'd say the fact that people are altruistic donors shows that it isn't necessarily true. More on that sort of thing another time though maybe.

Anyway, as I said this is, I suspect, mostly just of interest to me but as I go down the road with it I might write more stuff. Or who knows? Come Friday they might let me know that I'm a physical wreck myself and in urgent need of going straight on the recipient list. There's plenty of medical and mental stuff to go through yet after all. We shall see.



PART TWO: KIDNEY BUSINESS...

Just back from my first proper, in person bit of kidney donation business. Was up at Guy's Hospital this morning pissing in cups, giving blood and being told I'm average height (fair enough), not fat (good to know) and my BMI is decent. Also sitting down and talking to the Consultant for a couple of hours getting a solid info dump which I mostly didn't glaze over for.

It was a fairly full on experience given that I didn't know what to expect at all. First thing I knew after arriving I was being taken off into a room to be measured and weighed, which wasn't unexpected but there was very little by way of details given on what this first meeting would entail. So bit of a whirlwind process. Then a bit of sitting around before going in to get the full rundown on things.

It was a discussion really, not an interrogation, although there were plenty of questions in there and space for me to ask my own. That was probably more daunting than the rest to be honest. I've done a fair bit of research on the process already and the Consultant seemed pretty happy with that but there's still a lot I've not thought of and trying to conjure questions up on the spot isn't particularly easy. That said though it was good to test my reasons for going through with this on someone who's seen it all before. After all, sitting at home thinking about it, or explaining it to friends and family is one thing but there's no objective measure of the right reasons/time to donate and it's good to express your own out loud and know that a: they aren't unique and b: they make sense.

One thing it did bring home to me though is how much mental preparation can/should go into a choice like this though. Once you step into that clinical world there's a focus about things which means one question -> one answer. Fair enough, obviously, but few decisions in life are

summed up that easily. My choice to donate certainly isn't, I can happily bore the arse off of anyone who asks by exploring the thought processes involved not just in this choice but the life experiences, beliefs and philosophy that lead up to it. And that's important in itself, I think you need to do some deep thinking before you move forward and you need to be comfortable with each aspect of the process yourself before you even go in to discuss it. Helpful as people are I can imagine struggling to offer up those finally packaged answers if you haven't done the mental/emotional/philosophical leg work yourself first. As an example I was asked about the anonymity aspect of things – you don't get to know anything about the person you donate to, they don't know anything about you, although they can write if they want to. I had my views on that already formed to be honest, generally I prefer the donor to be an abstract entity rather than a real person, for all sorts of reasons, so the anonymity is fine with me. But if you're not confident of your position and motivations then that can be a difficult aspect to remind a person of.

Anyway, if there was any downside to the experience it was pretty quickly resolved. Prior to attending I had, as I mentioned, very little idea about what this visit would actually entail. I've read up enough to know about the various steps involved in the whole process but as to their order I was pretty lost. The Consultant was ready for that though, they had a full roadmap for how that particular unit processed things which solved the problem in itself really. She also asked how the whole thing could be improved and seemed happy to find a solution to my confusion. So, not a complaint at all really.

One final note to end on – sitting in the waiting room I was in amongst people who were (mostly) there about being recipients. That was a bit of an odd one. As I mentioned I view the end result of my own donation as a bit of an abstract thing – I know there's a person who'd benefit, I'm very glad of that, but as far as I'm concerned they have no face or identity. Only on the day, in the place, they do.

Lots of them in fact. Lots of people all at various stages of the process, one of whom might end up with my kidney, or being part of the same chain of donations as mine. I mean, they probably won't, the waiting list is long and there weren't thousands of people in there but still, it's a thing. Also got talking to one woman who'd had a donated kidney already, she was there for a check up. Think she assumed I had kidney problems at first, maybe picked up on my confusion and started to chat with me. Rushed, maybe a bit too quickly, to clear up that confusion – felt vaguely dishonest to even be mistaken for someone who needed help, but then also felt a little bit odd to say 'yeah, I'm grand, just a donor' when I (at that point) wasn't sure of her condition. She was nice about it though, very positive about my choice and that was good. Still, it's a small moment of oddness in the day, a bit of human interaction in a process that, to me, is a vaguely mechanical one. Felt good I suppose, in a roundabout way, to know that there was a human effect to it all which I generally don't focus on too much.

Anyway, will leave it at that for now. The last post and this one are both a bit rambly to be honest, in future I might try to focus on particular aspects of what's happening and keep it more coherent but who knows? The process is a long one and there's no obligation to make this semi-journal serve any particular purpose.

PART THREE: KEEPING IT RENAL...

Tuesday was the first really big step on the path to giving up one of my (lovely) kidneys to a stranger. At least it felt like it to me. My last visit to Guy's Hospital was for some quick blood tests and a long talk with a consultant. A step definitely, but it still felt a bit speculative – the transplant staff and me both feeling the thing out rather than doing the serious business. This one though was all serious business.

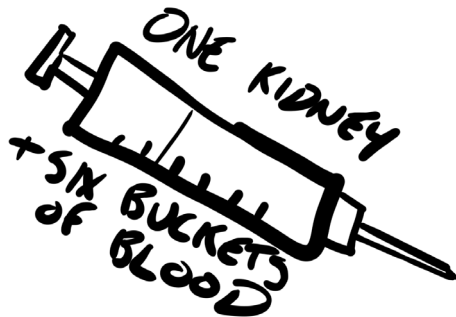
It was a long day, loaded with waiting around, tests and crap coffee. I had a CT scan, (lots) more blood taken, more pissing in pots, x-rays and something in the Nuclear Medicine department which I still don't entirely understand. They also gave me an ECG and, as far as I'm concerned, confirmed that my hairy tits are indeed pure electric.

It was an exhausting one, was wiped out for most of the next day although whether that was all the injections and blood letting, the waiting around or the Guinness I had immediately afterwards I'm not sure. Was also a rewarding one though, I was mostly just being bounced from department to department where there was only a vague awareness of why I was there but it did a lot to solidify the process in my mind. And on top of that the results that come from all those tests will be the main factor in whether or not I get to go ahead and actually donate. That part is a bit stressful to be honest, it's not exactly something where I can say I 'did well', there were no cheerful thumbs up after they'd taken the 4th blood sample of the day. Instead it all goes off to a consultant who has a good long stare at a load of incomprehensible results and decides if I can get by on one kidney for long enough to take the risk. A decision I won't get to hear about until my next meeting on the 18th. So until then it's a great unknown really.

In the meantime a couple of observations though. If you ever do consider donating then rest assured, the medical preamble of tests is no great trial. It's boring and a little uncomfortable (especially the 'warm injection') but it's all easy enough. The various teams at Guy's were all good, friendly and full of answers even if I hadn't asked the questions. My position on anything technical is that if I don't care enough to learn myself then I've minimal interest in being told about it, but fair play for making sure a person doesn't feel left out.

I'm also (still) a bit uncomfortable talking about doing it. I've a lot to say about the process and my reasons for undertaking it but it's awkward to be honest. I'm still acutely aware that it may not happen, although the signs so far have all been good and it still feels like saying it out loud is tempting fate a bit. I might not be healthy enough to do it after all. And if it falls through then ultimately I've done nothing of any real value. At the hospital especially I'm nervy on that front. Another guy was on the same schedule of tests as I was and we chatted a bit. He was doing it for his wife, so the whole issue of donation was a lot more immediate for him. By comparison my reasons, good as I think they are, still don't count for much next to his immediate personal experience. I can afford a detachment he can't and that shuts me up a bit. Writing here helps with that but the process of being open about it is an ongoing one.

Anyway, as a final thought – you can see the logic but they should never have closed down that big McDonald's next to the hospital.



PART FOUR: SPILLING MY GUTS...

Been a while since my last post on the kidney donation process and a fair bit has happened over the last couple of months. All of it, fortunately, good.

The first big step after my last post, or at least the first one that comes to mind, is the mental health interview I had. Like most non-blood taking meetings in this process it was done remotely thanks to the joys of Covid, this time over the phone.

It was just about my biggest worry as far as the process of applying to donate goes. I'm lucky enough not to have any particularly dramatic history of mental health issues but, as with most people, there have been hard times. Although to be honest the prospect of going over them really wasn't what concerned me. For the most part I think I'm a fairly honest and emotionally articulate person, where I've struggled in the past I'm generally aware of the causes and have no real issue explaining them. Which is essential with this stage of the donation process I think, you need to be honest during the interview because ultimately as a donor you're unavoidably stepping into unknown territory. It's not enough to assume that you can deal with the potential hurdles and outcomes of the process, although self confidence is certainly a key factor, you need to measure your own expectations against the expertise and experience of others.

For example one of the questions was about potentially comparable experiences I'd had in the past and how I'd dealt with them. Initially I said there were none. To have gotten this far I've had to prove that I'm pretty healthy (even if I'm completely out of shape) so while I vaguely assumed I could deal with any issues that might come up I didn't think I'd been through any problems relatable to surgery and the potential

complications following it. Talking it out though – and having the psychiatrist overtly state it – I realised that I probably did have a greater frame of reference for what might happen than I assumed. I have, unfortunately, had experience with episodic Cluster Headaches, aka Suicide Headaches. Episodes are mercifully few and far between, once every couple of years maybe but when they come they're a pretty dismal thing to endure. A month or so with 4-5 crippling headaches a day, like some evil bastard driving a screw driver through your face from the inside. I've been diagnosed so there's some relief to be found in the donkey strength pills they give me when the bad times come but still, it's a thing. It isn't, however, a thing I give much thought to unless I have to. I certainly don't consider it some sign of my ability to endure suffering though, I don't view going through those periods as a marker of inner strength or anything like that. But within the context of donating I suppose it is and having someone else push me to acknowledge that is helpful in a way.

Sure, I think taking that sort of view of your own experiences can be helpful to most people because in my experience we seldom see what we go through as anything greater than what it is. Be it mental or physical problems we tend to face them as immediate obstacles and not reflect on what they change or expose about us. We forget how much just keeping going can be a measure of personal strength. In fact even as I talk to people about my own plan to donate I've heard people infinitely stronger and more capable than myself say they couldn't do it, or that I'm brave for going through it all. Always comes as a surprise to me because from where I stand a lot of people go through vastly more than me and to donate a kidney would be a walk in the park by comparison. Not that I'd ever suggest that anyone else should do it of course, it's an entirely personal choice.

Anyway, that aside I still found this call to be the most daunting one so far. If there's a downside to the way the process of being an Altruistic Donor is dealt with it's in the vagueries of the details. From more or less day one I knew this meeting was something that would happen but up until I was on the call I had very little idea of what it actually involved. The purpose of it is to establish whether someone is competent to make the decision to donate, isn't being pressured and will be capable of dealing with any complications that may arise. Asked how I could prove any of those things before that phone rang I'd have said I had absolutely no fucking idea. I've certainly thought a lot about what I'm doing but I still had only the faintest of ideas of what a psychiatric review would entail. How do you prove that you're competent? How can you judge whether past experiences are relevant, which of them are going to be a positive or a negative, what possible issues arising from the surgery and recovery they want you to show yourself aware of and able to deal with? To be fair there's nothing you can really tell a person about this stage to prepare them, it's a conversation, not a test. But it is also a test, if you see what I mean, and there's no escaping that no matter how reassuring and encouraging those involved are. So I suppose there's no way not to have nerves about it, especially in comparison to nice easy blood tests and x-rays.

Take my word for it though, the inevitable nervousness only lasts until you're in the interview and while it may feel a lot more demanding than the practical medical tests it's ultimately more or less the same. You need to be honest and the outcome will be the outcome, you can no more pretend to be right for donation than you can pretend to have a healthy kidney and while the questions are definitely probing they're not being asked to catch you out.

I'll leave this there I think. Having left it so long since the last update I've plenty more to add but I'll save that for next time rather than ramble on for too long.

PART FIVE: SPILLING MY GUTS PART II...

After my psych interview the next (and last) big step on my adventure in kidney donation was the HTA interview. The HTA is the Human Tissue Authority and, when you're going in as a Non-Directed Altruistic Donor (giving a kidney to a stranger) they're the ones with the final say on whether you get the go ahead.

As with the psych interview there was a fairly nerve racking wait for this one if only because it seemed to take so long to come. I mean, it didn't really, this whole process has been really efficient but when you know that there's only one major barrier to pass things do seem to drag a bit. Unlike the psych test though I felt a lot less uncertain about it. I more or less knew (and was reassured by the incredibly helpful Facebook donor group) that it was retreading a lot of old ground as far as the questions went and it would also be taking into account all the stuff I'd done so far. The HTA representative's job is more of a final once over than anything, an additional layer of confirmation that you know what you're doing, why and aren't being coerced or paid to do it. And while I'd be more than happy if anyone wants to slip me a few grand on the side I'm also good without and pretty clear on my reasons for going ahead.

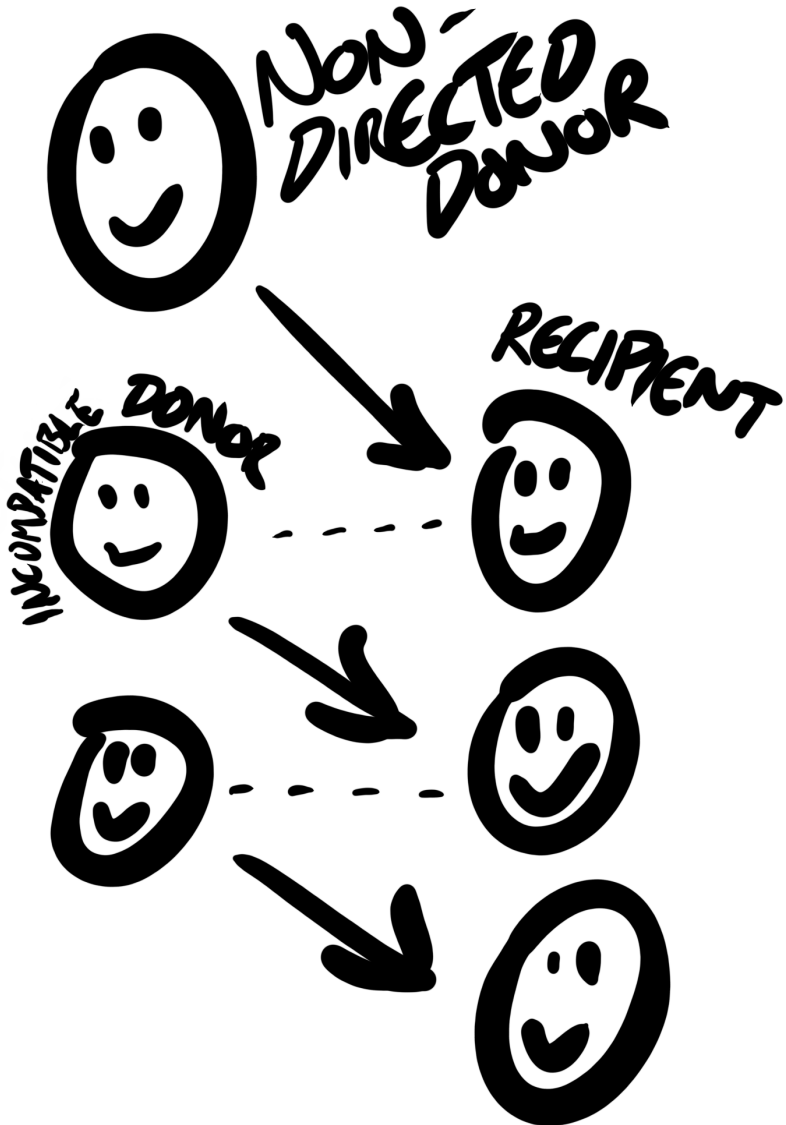
This interview was easy as really, it didn't take long, the interviewer was nice and friendly as well as being very positive about the whole thing. The only downside was that, yet again, it was a remote meeting and for some reason it was on a platform called Blue Jeans (or similar), which doesn't work on anything apparently. Still, technical issues aside we got through it and she told me that she was happy to give me the go ahead. Which brings my story up to date really. I'm currently waiting for

the HTA to process their paperwork, whatever that may be, and then I'll be going into the April matching cycle hopefully. Which means more medical tests to find me a match. What those tests are I'm still not sure and when the surgery will happen is similarly a mystery. Both the kidney unit and people who've donated have given me rough guides to when it might happen – late June onwards basically – but there's a lot of uncertainty around it all. Usually they try to get things lined up as quickly as they can but with so many moving parts it's hard to be too precise. I'll hopefully be going into a chain, which means that my donation will trigger others and that means that everyone involved has to stay healthy for the duration. If someone comes down with Covid (or anything) then surgery can be delayed, if I get sick, it can be delayed. In fact a week before I go under I'll have to quarantine regardless which will be fun I'm sure.

So, that's a little annoying. I've never been a great one for uncertainty, I like to know what's happening when, which runs a bit contrary to how I live my life – basically as one long act of procrastination, but there you go. Things will be going ahead though, all being well and I'm trying to remind myself that beyond waiting and not obsessing about it there's nothing at all I can do to speed things up so no point worrying about it.

On a side note, for the uninitiated, a 'Chain' means that when I donate a load more people do to. Basically a lot of people who need a kidney have friends or family who are willing to donate one. That doesn't mean they'll be a match though. So instead of donating to their friend/partner/parent/sibling those willing people say they'll donate to a stranger when their friend/partner/parent/sibling gets their own kidney. The person they donate to then has someone do the same, so you can build a line of transplants that goes through a fair few people. The starting point for that process though is the feckless likes of me, with our free, non-directed kidney. So my donation, with a bit of luck, will trigger a chain. Of course it might not, there's also the possibility that there'll just be a match for me who needs a kidney in a hurry and that'll be that.

Doesn't much matter either way from my point of view, someone's getting a high quality, barely used, one-careful-owner kidney whatever the case. Also, here's a picture to (maybe) explain it better than I have...



So there you go. That's where things stand at the moment, I'm waiting for news on the next step and, gradually, trying to organise myself for it. Sorting work out will be a big thing, the NHS does cover loss of earnings but being self employed means that's always a matter of luck as much as anything. I'll have to submit earnings from a comparable period so we'll see. I also need to plan out my recovery period, figure out how best to look after myself. Some people can, apparently, get back to work and life in next to no time. As my job involves a fair bit of physical work I have to err on the side of caution a bit more though, might be off for up to 3 months even if the recovery all goes well. Certainly can't do any heavy lifting for a while and that's unavoidable with what I do. Still, worse things in the world than doing nowt for a while. Something to think about though.

I'll finish up with a listening suggestion which, next time, I might write some thoughts about. It's over on BBC Sounds and it's called 'The Anatomy of Kindness'. It's not specifically about Altruistic Donation but it does include an interview with a kidney donor and a fair bit of related stuff. It's interesting although I wouldn't say I'm entirely sold on some of the conclusions/theories involved. Still, more on that another time.

PART SIX: THE COUNTDOWN STARTS...

Well, the balloon has gone up, the bomb has dropped, the cat's out of the bag and other such nonsense. I have a match and I have a date, my kidney has a new home to go to.

After all the waiting these final steps have come around dizzyingly fast. I got a call in the middle of last week telling me that they had a match from the recipient list and asking if they could book me in for surgery. I'd been expecting a call although getting a positive match was still in doubt and the wait to hear was... a thing.

I should probably mention the bit just before that call first though really. The week before they'd called me and said they wanted to test me for a potential match from Tier A, which means someone who's waited a (very) long time or who has other issues that have led to previous/potential rejections of donor kidneys. That was a confusing turn along the path to be honest, going in I think I'd researched and expected to be part of the standard matching cycle and then the start of a donation chain. In fact, daft as it is, I'd started getting a little bit... I don't know really, competitive? Not with anyone because I'm doing no more than others, but the prospect of being part of an extended chain of donations seemed like a bigger thing than a direct match, where you donate to one person in isolation.

Absurd, I know, but thoughts come as they come and that was one of them. It's a bit like the low level arrogance of doing a manual job or something, sometimes you create an arbitrary measure of it like speed, or how much you ache afterwards and get the vague idea that by being quicker or more wiped out you're doing something above and beyond. When all anyone else looks at is whether the boxes got shifted or the hole got dug. Only it's considerably more ridiculous than that, because

I'm only donating one kidney and effecting one life, a chain would have had zero effect on or relevance to that. But there you go, we're all daft in our own way, that was mine.

Anyway, I went in for the initial blood test, had a long week of waiting and then got the call. It was an interesting one. My co-ordinator confirmed the match and then, to be honest, I blanked out for a bit. I've got another appointment before the big day comes, a meeting with the surgeon and I think someone else too – part of the medical formalities before they're happy to go ahead. At the time though I was kind of staring vaguely around me and thinking 'fucking hell'. And I'm still partially thinking that.

It's not a 'fucking hell' that comes with any doubts, every reason I had and decision I've made about donating still stands but knowing exactly when it's happening still puts you in a spin. There's a lot of practical stuff to focus on for now, my surgery is set for the 26th of May, so about 4 weeks from now and sorting out work, sorting out the first stages of my recovery, sorting out people to help me, it all needs doing. And doing it is, I think, a good thing to focus on. Granted so far I've mostly just procrastinated and talked about all the things I need to do but the thinking and procrastinating is actually a pretty helpful way to fill the time in itself.

There are bigger thoughts hovering just out of sight too, bigger emotions that need a bit of attention as I go forward. I had a moment where one of them came into focus the other day in fact. It dawned on me that out there, somewhere, is someone who's had their own call. Someone who's had news that their surgery is going ahead too, their surgery where they'll get themselves a shiny new kidney with barely any miles on the clock. I don't know who they are, I never will in fact but that's a hell of a thing isn't it? Going beyond the practical steps you've taken and considering the life they're ultimately reaching into, well, it's humbling in a way and supremely comforting in another.

It takes the routine tests and form filling and gives it an end point, a goal you can imagine which has something a bit profound about it. I reckon in the long run I'd like to spend more time with that thought but, for now, I feel a bit reluctant to indulge it. Those practical bits are still between me and that end, that's where the focus needs to be.

The other big one to confront is the surgery itself. More than one person has asked me if I'm scared or nervous and of course I am, frankly it'd be weird as hell if I weren't. Some stranger's going to cut me open and yank out one of my internal organs, if that doesn't make you nervous then chances are you shouldn't be doing something like this in the first place. But so what really? Fear about taking a step towards something positive is one of life's plus points in a lot of ways. You feel it, take the step anyway and then there you go, you've done something good. If there were no nerves involved then it'd be a lot less meaningful. Although that said it's still one of those big thoughts I'm trying to sidestep for now, my path to the actual operation only really involves going in and getting knocked out, at least as far as I want to consider it. Which I reckon is fine.

Anyway, there you have it, that's where I am at the moment. Planning and waiting. Organising and waiting. Procrastinating and waiting.

I might invest in a deckchair for my recovery.

PART SEVEN: CLOCK WATCHING...

Well, the day's getting closer. I'm writing this on Saturday night and surgery will be first thing on Thursday morning. Or at least I have to be at the hospital first thing (7am), when they'll actually take me into surgery I'm not sure. I've been told but, like a lot of things I get told, it just drifts like tumbleweed through my mind and disappears out the other side.

Waiting is an odd experience. A couple of days before I went into quarantine/shielding I went for a quiet pint with myself to try and clear my head and think through the whole process and these final steps. Can't say I'm feeling overly confused or lost in it all, in fact day to day it just seems like a mundane process – like planning/going to work only less arduous. But there are still some thoughts pushing to be heard. Or questions looking for answers rather.

One of the main things that confuses me is the scale of it all. Personally it doesn't feel like a very big thing to be doing. As I said, it's a practical process, there's nothing in it that feels particularly profound or special. At times I can see it as something grander and that's nice, there's certainly some pride to be found in that, but those moments are fairly rare because, to be honest, I don't look for them much. Seems a bit, well, smug I suppose, or self-aggrandising. A bit of which is probably allowed, but still. Where I do see the scale is when I think of the person on the receiving end.

I went in to the hospital the other day for some final tests, to get a run down from the transplant nurse and to meet a surgeon, although not mine unfortunately. It was a fairly boring day, the surgeon I was supposed to meet, the one who'll be cutting me up, was delayed, instead I got a junior surgeon who didn't have much to say.

The guy who took my dozen or so blood samples cocked it up to the point where they had to get an older woman who knew her business to take over (always go for the older woman in a hospital, she will know the way). I also ate a crap sandwich in the canteen. One interesting thing did happen though.

The transplant nurse spoke to us as a group, myself and two other donors who were getting a general run down on events to come. We chatted a little bit before hand and then we all had to introduce ourselves too. Was a first for me, talking face to face with donors. Unlike me though they were both donating to family and that's... a hell of a thing. People tend to be impressed by an Altruistic donor (someone who donates to a stranger) but their path is, I think, far harder than my own. One woman especially was donating to her 6 year old son who'd been diagnosed, from birth, with kidney issues. Granted there's far less of a choice in that than I have, in fact I doubt she saw any choice in her own sacrifice at all and the joy/comfort to come from it must be pretty profound as she'll get to watch him grow up healthier and happier than he ever could without that kidney. But consider the sheer weight of this process for both of them. The fear of the transplant being rejected, the worries about the recovery, being isolated from each other in separate parts of the hospital, the debt owed even on top of giving that kid life. That's a really big thing. And for my recipient I guess it's no less grand but maybe it is less so for me.

That's not a bad thing either, sure it's a blessing in a lot of ways. I'd despair at being so close up to an experience as big as that, I infinitely prefer being a step removed and safe(r) from the worries and stresses of it. But seeing at least a glimpse of those involved in transplants, it makes you wonder just how big a thing you're doing for that stranger out there. Ultimately it's not a question that needs answering but still, sticks in your mind.

Anyway, quarantine. It's going fine so far. I've always been very good at occupying myself and, while I go a bit funny without human contact, it's not in a way that I don't kind of enjoy. Plus work still needs doing, the flat still needs cleaning, the garden clearing – there's all sorts of stuff I can procrastinate my way out of doing so it's much the same as usual really. Albeit a little bit more solitary.

It's also a glimpse of what's to come after my recovery, although not a very clear one. I've another 2 weeks of shielding to do after the surgery and then ages signed off of work (12 weeks or so). I'll be able to do a lot less by then but I've got ideas on things I can do – write, draw, prepare for my upcoming Masters (got onto a Masters course btw!). How realistic those plans are I don't know, can only guess at how I'll feel really. As to the surgery itself? Thought of it makes me queasy to be honest. Getting sliced up, catheter up in my junk, having nurses actively focusing on when I'm going to have a shit. Doesn't bare thinking about really, which is why I mostly haven't thought about it. No point in doing so as far as I can tell, dwelling on it all doesn't make it any less necessary after all.

So, 4 more days and off we go.

PART EIGHT: MISSION ACCOMPLISHED!

It's been just about a month now since I went in for surgery and, for the most part, all is well. It has however been an exhausting process and one pretty riddled with shitty luck and some disappointments.

First things first though, my kidney donation was a success. Last I heard – and probably all I will hear – is that my kidney was deep inside some lucky soul who to their (I'm guessing) joy is now pissing liberally all over the place thanks to a small lump of my guts. So, that's a nice thing. Unfortunately it's taken a month for me to get a real chance to sit down and think about what's happened and what I've done because the intervening weeks have been some pretty brutal ones.

Post surgery my recovery was, seemingly, all good. When you wake up you're straight onto the strong stuff, a Fentanyl drip in my case with instructions to mash the button as much as you like to deal with the pain, which I did. From there it's a few days of blood tests, catheters, nurses walking you around like a geriatric toddler and various people expressing far too much interest in your urine and bowel movements. All on a ward where people are in various states of despair and where sleep, when not assisted by heavy opiates, is a luxury. All to be expected though and that early stage was exhausting, uncomfortable and just fine with me.

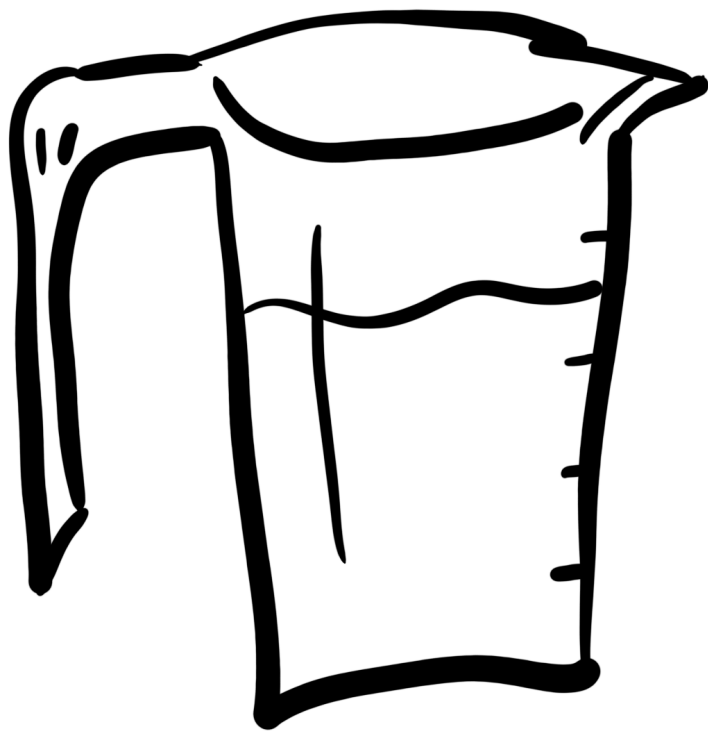
I was checked out of the ward quickly enough and went off to stay with family for a few days before heading back to my own place. All good really, my stomach was a mess, getting up was an ordeal and walking further than the kitchen wiped me out but again, that's what you're signing up for in the aftermath of a pretty major surgery. Unfortunately it was during that period that the bad news for this last month started to mount up in earnest though.

My Uncle, who'd, ironically, had surgery on the exact same day as me in a different hospital and for entirely different reasons passed away. His surgery was successful but post-op complications got him and, well, that was that. I haven't got much to say about that really, but it did make it harder for my family and my being crooked in the middle of it obviously didn't make things any better. But such is life.

The next bit of bad news came when, after being back at my own place for a few days, ambling around in the nip and being generally useless in a quiet and comfortable way I started to get hit with a lot of pain. My initial assumption was that it was routine post op issues – I'd been warned about gas and fluid build ups that could do some damage, as well as the basic pain entailed in having someone cut through your stomach and start tearing bits out. So with that in mind I left it 24 hours or so before I called into the hospital, fortunately a delay that didn't do any harm but which certainly didn't help either. At any rate the second I called into the ward I'd been on, one specialising in transplants, they told me to come in and get checked out so I did. As a quick word to the wise should you ever find yourself in a similar situation – if you've got drugs at home, take them with you. Yes, hospitals have a shitload of donkey strength pain meds on hand but until they check you in, you can't have them. And if you find yourself waiting 3 hours for a scan while you're in a lot of pain then you really are going to want something. That was a bastard of a day, although oddly enough not the worst pain I've ever been in. In fact it was maybe the one time in my life I've been thankful for Cluster Headaches because when it comes to giving you a frame of reference for suffering they're a definite 10 and even as I was completely fucked I could at least say it could be worse.

So, once the scan was done they got me straight onto the ward and hooked up to the good stuff again which was a little slice of heaven in comparison to what had come before. Next up came the initial diagnosis which was appendicitis. What's that got to do with your kidney? Nothing. Absolutely nothing.

URINE: WHAT
COLOUR IS YOURS?



It also had nothing to do with me, because that's not what the issue was although they got as far as the porter wheeling me off for surgery to have my appendix whipped out before the doctors realised that much. Apparently the scans weren't definite and, after arguing amongst themselves, they'd revised the diagnosis to one of Colitis, an inflammation of the colon and appendix. Something which taking my appendix would have done nothing to solve, although to be honest I'd have been happy enough just to have the thing out on the off chance it helped.

The next few days were hard ones. A hospital ward can be a tough place to be at the best of times, such as they are, but when you're not entirely sure what's going on and they're not entirely sure how to treat it the hours can go by very slowly. Add onto that the people around you who can't sleep because of their own crippling (and very audible) pain, the ones who have no control of their functions, the snorers, the dickheads who view headphones as optional (seriously, take them in with you if it ever comes up, people listening to shit at full volume deserve to suffer) and the fact that you'll be woken up at least 3 times a night for obs, blood samples or just because something is beeping in your vicinity and the whole experience ground me down to the bone. I was nil by mouth for most of that stay and my initial doctor was, well, someone I didn't get along with, to put it diplomatically. I think over the course of my second stay on the ward – about 5 days – I went through every surgeon, doctor and consultant in the hospital, each of them guessing at what the issue was and how best to treat it. Hence the nil by mouth bit, even once they'd put me on antibiotics they still weren't sure if they'd want to operate so they kept their options open. A cautious approach for them, a miserable one for me and certainly the toughest period I've had during all of this but there y'go.

Eventually they committed to the Colitis diagnosis which also had fuck all to do with donating a kidney, in theory at least. My assumption was that an infection got in during surgery but the odds of Colitis hitting in such close proximity to a donation are infinitesimally small apparently

so I can't testify to that and the doctors certainly weren't willing to say anything decisive. At any rate they discharged me eventually, the pain was still present but once they'd decided against surgery there wasn't much reason to keep me in and I didn't make a great secret of how much I hated being on the ward. And I should add that that's not a slight to anyone working there, the nurses and the rest were grand but a miserable place is a miserable place nonetheless. Plus there's a sort of infantilisation that takes over when you're in hospital for any length of time. You can hear it in peoples voices, the shift from regular, independent human being to a slightly cloying, pleading tone as things get harder and nursing staff especially become not just people who are doing a practical job but almost emotional carers. It's a reliance that I dislike to be honest, I find sympathy hard to deal with and pain especially is something I'm far more comfortable managing by myself rather than with an attentive audience.

Anyway, since I got out things have been getting substantially better. There was a day where I had to go back in as the pain flared back up again and they did say it was 50/50 on whether they re-admitted me but I was quick to refuse the offer and head home on the promise that I'd be liberal with the pain meds and not push myself too far. Since then though I've had more blood tests and the Colitis has cleared up, so all my physical problems now are just standard recovery stuff. Sore muscles, limited energy, no strength etc. Blissfully predictable really, not enjoyable, but entirely manageable and my narcotics regime has gone from prescribed opiates and fists full of pills to Guinness and naps.

The only other downside – and bad news comes in threes they say – is that my loss of earnings claim was largely ignored and I got a little over half of what I applied for. There are reasons for this, not good ones in my opinion, but reasons nonetheless. I can't deny that it's pissed me off a fair bit, claims should be processed before surgery or evidence should at least be rejected in advance instead of leaving people in recovery having to worry about it.

If I had the energy I'd argue the point but at this stage I genuinely can't face the prospect of back and forth discussions with some NHS finance department dickhead who's unlikely to have much, if any, sympathy for me. Besides, being broke is never a novelty and I'll get by one way or another. To anyone considering donating though I'd say be a bit more demanding about financial stuff before going under the knife, it's really not a system geared towards looking after people with limited resources. Anyway, beyond leaving a bit of a bad taste I'm not dwelling too much on that aspect. Donating was obviously never about the money and even if things are harder due to this I'm still proud of what I've done and that's what I want to focus on, nothing else.

I am proud too. Over the last month the act of donating has been obscured by a lot of other stuff and with the complications and set backs I've had my share of shitty luck but, frankly, fuck that. I'm happy with what I've done, I hope the recipient is too and that's what matters here. The rest will pass and the good part will remain. As always I wouldn't suggest anyone else donate a kidney – it's an entirely personal choice and I don't think anyone should be proactively advocating for it – but I can say that even with all the hard parts I don't regret my choice at all... So, there y'go.



PART NINE: CLOSING CHAPTERS...

It's been just over two months now since I had surgery. Perhaps a month and a half since I checked out after my second, infection related, hospital stay. In theory I've got another month off work, a month away from any commitments at all in fact. In reality though there's not much escaping life and even though I'd be happy enough to continue in my semi-holiday/retired mode the list of things to do and obligations is already getting longer and I can't avoid life any longer. A few more weeks and, some aches and tiredness aside, I'll be completely out of the donation process, the whole thing will shift from 'what's happening now' to a memory of whatever shape and weight it ends up being.

It's a weird phase in the whole process. The nervous build up is long since passed, the worst of the pain has abated, I've met pretty much everyone I know and their excitement and nerves about what I did have faded into a vague background awareness that I did it. I still get the odd stranger being surprised by my kidney donation when it comes up but that won't last much longer either really. Some people do somewhat define themselves by being an altruistic donor – and why not to be fair. It's a big thing to do and their enthusiasm for the process, their pride in having undergone it and their evangelising about the positives of it are all completely legitimate reactions to have on this side of things. It's also incredibly helpful. The same people who I got my answers from before the operation, those in the support groups especially, are still there helping through the next group of people who've chosen to donate. They're committed to it, whether through a strong sense of achievement or a personal connection to recipients and I've nothing but admiration for their attention and support of the vaguely defined community of donors.

For me though that's not really a path I'd choose, it's not how I choose to process the donation into my day to day life and self identity.

I'm proud of what I did, no doubt, but it's a tricky kind of pride for me. I know I did a thing and when people say it was a good thing I won't deny it makes me smile, it's nice to feel like you've contributed something positive to the world. But really it was nothing. Well, not nothing, but relative to what a lot of people do it was an irrelevant sacrifice. So far it's represented a tiny portion of my life, some (well, quite a lot of) pain and a lot of sitting around drugged up to the eyeballs. And that's it. The process began, there were some steps to it and now it's over. Compare that to other people, other people I know and plenty I don't whose own efforts to do good things, to look after those around them have vague beginnings and seem never to end and... I don't know, donating doesn't amount to all that much.

I don't mean for that to sound negative, although I'm aware it does a little bit. I am proud of what I did and while I don't think it was a huge act I do know it was worth something. Certainly to the recipient at least but I don't feel like it's a defining act for me. It doesn't make me good or altruistic or anything like that, although I'd like to think the way I live my life generally might. It certainly isn't something I'd choose to define myself by as some people do for perfectly fair reasons. Ultimately though I'd like the wider scope of my life not to rely on one positive act for justification but instead for that act to be representative of the rest of my self, although admittedly I'm generally far too lazy to top that one act.

At any rate, at this point my future relationship to donation seems like an interesting one, to me at least. I might not look to it as a pivotal act or anything but I'm curious as to how I'll relate to it down the road, how it'll fit into the rest of my life and my sense of self. None of which I can even find grounds to speculate on at this point to be honest. Only time will tell.

ONE YEAR ON...

I'm writing this on the 3rd of May, 2023, a few weeks shy of the one year anniversary of my donation. I've got my yearly check-up next week, my first time back at Guy's Hospital since I was given the all clear from my infection. I suppose that's what made me put this little mini-book together, now seems like as good a time as any for a bit of reflection.

I was in a car the other day with my Mum, heading up to her allotment to watch the plants grow for a while. I can't remember how but the topic of my donation came up, not as a big conversation, just in passing. I mentioned the possibility of doing it again, well, doing something similar - obviously I'm down to one kidney and that's going nowhere. I am thinking of donating a bit of my liver eventually though. She gave me a groan of disapproval, a 'here we go again' sort of thing. It was hard for her when I was in hospital, as it was for all of my family, but her brother (my uncle) died at the same time as I was recovering and, well, things like that hit hard.

My donation experience was pretty unique I suppose, most people don't have my bad luck after all, while nothing too serious happened the infection and events in my day to day life did nothing to make things go smoothly. Looking back though I find I can shrug the hard bits off. The pain and discomfort was bad but it ended, the uncertainty of awaiting diagnosis was stressful but I survived, there was nothing I couldn't endure and the memories of the bad are far outweighed by the positives of the experience.

The only negative I carry with me from it all is the stress my decision caused others. If I had any word of warning about the donation process at all it'd be to remember that - you might go into surgery alone but the world doesn't stop when you do.

That said though, would I do it again? Given the option to go back and skip it all? I would, without a second's hesitation. I don't know my recipient, I never will, but just as my world didn't stop when I went under the knife theirs didn't when they were at their own hospital appointments, or on dialysis, or having surgery or whatever else they went through. Taking on a little bit of misery to help free someone else from a lot of it is, to my mind, no bad thing.

Beyond the donation I am, at the moment, finishing up my Masters degree and planning to apply for a PhD place if I can get funding. While the work's a bit more academic than creative, which is what I'm more used to, it does allow me to create something in the form of new ideas and discussions. Beyond that I'm still writing, drawing, painting, occasionally learning to tattoo - doing all the things which I hope add something to the world which wasn't there before. But as much (or as little) success as my work ever has I doubt that any of it will ever match up to what I hope I created through my donation - a bit more time, a bit more peace and a bit more safety for someone else out there and all the people who love them.

So as I said, I'd absolutely do it again, even the bit where they yank the catheter out.

ABOUT THE AUTHOR

Dylan Orchard is a writer, artist, designer and lifelong South East Londoner. When not donating random body parts he dabbles in academia, writes various bits of fiction and poetry, draws nonsense and designs and sells clothes.

For more see DylanOrchard.com

RESOURCES

Become a Living Donor (NHS) - www.organdonation.nhs.uk/become-a-living-donor/

National Kidney Federation (UK) - www.kidney.org.uk/

Living Donor Support Group - www.facebook.com/groups/244308043137537/

Blood Donation - www.blood.co.uk/

Bone Marrow Donation - www.nhsbt.nhs.uk/british-bone-marrow-registry/

BY DYLAN ORCHARD
2023



