OSCAR – HOLIDAYS

**Oscar:** The sailing race I took part in was called the ARC, which stands for the Atlantic Race for Cruisers. And it’s open to anyone who wants to race from the Canaries— the last island in the Canaries all the way through the Atlantic to the island of St Lucia in the Caribbeans. And I took part on a thirty-five foot yacht and it was a twenty day voyage.

We had quite heavy winds to start with and for seventy or eighty percent of the voyage in total. The winds are measured on a Beaufort scale which is force one up to force twelve, force twelve being more or less a hurricane, force one looking at the sea and it’s like a mirror almost. And we had force six to force seven all the way through, so quite rough. But the— you’re on the trade winds which means you— that you had the wind behind you and in the old days the— the— the tea clippers etcetera , such large sailing ships would use those winds to trade effectively around the world.

And it’s marketed as a sail in the sun, although having said that you do get squalls. Squalls will come up in the middle of the night and can be quite dangerous if you’re not ready for them. If you’re not looking at the horizon and seeing those black clouds come towards you, you can very quickly go from a— a wind which is ten knots, which might equate to something like fifteen miles an hour, to a wind which is thirty seven knots, which would be about— round about force nine, in fact. And that could be around about forty five miles an hour. And you obviously need to reef your sails. Reefing the sails is a very important part of sailing if the winds are getting up.

So we had this fantastic voyage of about twenty days across the Atlantic, and it was round about the end of November through to just before Christmas. They run it every year and I was doing it around about the time of the twenty first … uh … anniversary of this … uh … particular sail. And it’s gone from strength to strength really over the years. It’s been a way of people taking their yachts down to the Medit— … uh … sorry, from maybe the Mediterranean down to the Caribbean. Some people then put their ya—large yachts on a bigger ship and are— they’re then brought back and others leave them out there and sometimes they will charter them or maybe sell them out there. So there’s lots of reasons for people doing it and people love to have the experience of being a crew member or, indeed, captain.

And … uh … there were six people on our particular yacht, it was only thirty-five foot which is probably one— among the smaller ones. You will find people taking part in yachts that are maybe twenty-eight foot, but generally, in terms of comfort, in terms of security, you probably wanna go in something that is thirty foot plus. And there’ll certainly be yachts that are eighty foot, ninety foot in this particular … uh … race.

We were, I think, seventh in our class out of about twenty-five, so we did quite well. We had a skipper who used to be in the Navy many, many years ago and he knew what he was doing. There were some very hard bits, and as I was saying earlier, you— you get these squalls and if you’re not prepared for those they can be very tricky. But— well, you generally— well, we had three slightly older members in their sixties and then three slightly younger members, probably in our— all in our thirties I would imagine. Uh, we got on well. There was one girl and she was actually the daughter of the skipper and the rest of us were men.

Uh, the best bits were— honestly, the isolation was just fantastic. Because once you’ve left the— the start line you head on into the night and you can see the— the port lights and the starboard lights from the other ships but very slowly over the course of the hours, they become more and more faint and you realise you are out there by yourself, and there’s no one that’s gonna come— be able to come and pick you up or— or help you if you do run into trouble. Uh, or at least no one that can get to you very quickly. So you’re comfort zone is— … uh … you’re out of your comfort zone. You’ll find that the only way of reaching anyone back home is satellite telephone so if there was— if, for example … uh … you— there was a— there was a death on the ship, the satellite telephone would have been used. Um, but generally— you— you could— we could … um … log into … uh … internet facilities via that satellite phone but, you know, it was expensive, it was probably about six pounds a minute, so you— you would limit your usage of that technology.

Uh, there were lo— lots of other bits of technology that were fantastic, of course, along the way. But your— the— the GPS is— is just not as … uh … functional as it— you’d find it would be if you were nearer land because the amount of satellites that are in the sky … uh … most of which are owned— owned by America, I think one satellite’s owned by China, and you have the— the— that— that technology which we get used to on the road, we get used to around the coast, just isn’t— just isn’t there so you have to start to … um … rely on other ways of— of— other means of navigation. And fortunately we were taught how to use the sextant … uh … on board, which is a t— time old way of … uh … measuring the sun when it is at it’s zenith and … uh … then, looking at the horizon, you can start to work out where you are in terms of latitude and longitude. Having said that, you know, you still can get these files downloaded … um … by using the internet for a few minutes just to get a rough idea of your position … uh … in— in— in— in the … uh … greater scheme of things. And obviously you’re plotting it on a chart all the way along.

I hadn’t done it before and so I was very excited by it. I had raced a lot down off the south coast with the skipper, and he obviously thought that I’d be okay as crew. Um, I have done little voyages around. I say little, you know, they’re— to— to the—… uh … uninitiated they might sound a bit larger, but I have crossed Biscay twice on— on yachts, and I have crossed the channel a few times on yachts, and I got to know the ropes, quite literally … uh … around Chichester harbour … uh … initially when I started sailing. So I was— I was au fait with what was going on.

I would definitely do it again. I would recommend it to anyone. It’s a fantastic experience, particularly because you are in— tho— those— … um … those— those latitudes where the weather starts to pick up and— and you actually get some sunshine which is— the sinking— sinking sun into the sea every night is just one of those wonderful visions that stays with you forever.

Uh, the preparation is huge for an— for an event like that and … uh … the thought processes that are … um … taken on by the skipper and the— and the co-skipper. You know, very serious planning all the way through, you— you— you know, the— what the— often people say ‘what’s the worst c—that can happen?’ Well, the worst that can happen is— in a situation like that is that you lose your mast, you lose any form of being able to tell the outside world that you are off course and you don’t— and you— and you lose your— your power over your engine, so you would be cast adrift in the middle of the Atlantic. That’s the worst that can happen. That’s incredibly serious, if something like that has— does happen. Um, losing your steerage on your rudder. Some people did lose steerages on the rudder and they had to ... uh … abandon ship. And there are f— there are thousands of stories to do with this, you know. You have— you have Russian ships that are aware that there might well be yachts that are worth eighty-five thousand pounds that are just being … uh … you know … um … left, because and— and— and— literally, people scavenging the sea for salvage.

And then on the other side of the coin, there’s— there were people who was— people who were in the race who were told to just hang back, stand by, because it was thought that there was, you know, immigrants from Africa into Europe … uh … who needed to be monitored by certain Navies. And so you get this, sort of— we— we weren’t one of those ships, but there’s all sorts of things that can come into play when you’re at sea and so the— that’s quite exciting.

Um, if I was ever to do it again, I would— I would probably like to do it on a different type of yacht. There’s beautiful yachts that are called Oysters that are just wonderful pieces of … um … uh … you know, the human imagination, almost. And you see them sort of coming in towards the harbour sometimes when you’re in the Caribbean, and just think ‘that would be the dream’.

Uh, working one’s way up, I’m not probably proficient enough to be a skipper at the moment. I’ve done a course as a day skipper but there’s then the coastal skipper and then there’s the yacht master, and it’s only when you’ve done a certain amount of hours, night hours included, as a yacht master you might ever think of doing— … uh … taking on the role of a skipper yourself. And if you were to do that then … um … you would have to have crew that you totally trusted, and they totally trusted you, because obviously you’re— you’re cocooned, it’s like going into space, you’re— you’re— you’re— you’re on your own little island for— for quite a while. So as I was saying, the worst that could happen is that you could be set adrift for a while, and the key thing is al— always to have more water than you think you’ll ever need, because if you run out of … uh … water then you’re going to perish.

I would recommend anyone, anyone, to take to the seas and— and— and— and try and enjoy those sort of voyages if— if they can.

­­­­RACHAEL – OPERATIONS

**Rachael:** I went to hospital to see if they could do anything and I had some medicine and eventually it went away. I got lots of … um … you know, blood tests, exam— examined and everything, and they said ‘oh … um … you’ve caught a virus’ which, you know, whatever that— you know, I must have caught it from Italy, I can only assume. Um, and I came— … um … they said ‘there’s probably a one in a two thousand chance that it could, in the future, affect one of your organs’. But I mean, you know, I was only eighteen, so I was like ‘okay, I’m fine now’. Off I went back to London.

Then when I was in London, I used to— cos I was teaching horse riding and I really wanted to go and work in Camp America, that was one of the things I really wanted to do. So I applied and I got a place in Maine, to teach riding. And it’s usual— you know, when you’re young you forget to do half your paperwork and I’d left the medical till quite late in the day. And I had noticed that when I was going to the toilet, my, like— my wee was pretty dark, but I didn’t think anything about it cos carefree and easy. And I went for a medical, and I failed the medical. And I was a bit taken aback, what’s— you know, ‘what’s going on?’ ‘Well, your kidneys are looking like they’re failing. Your kidneys are failing.’ And I was like ‘oh right. Can I still go to America? Um, cos I’m— you know, I’m going for just the summer.’ ‘I don’t think that’ll be a good idea.’ So that was the— probably a turning point in your life where you come to go and you think you’re going one way but you go another way, the way you didn’t expect to be going. So that was all put on hold.

I came back from London … um … and I was … um … approa— … uh … I went down to see my local GP, who put me on to a consultant at a local— small, local hospital. And I think, in his wisdom, he thought he could stop my kidneys from failing. But what he did is that he tried something which is not something that you would practice and he put me on an extremely high dosage of steroids. It’s a dosage that I found out— a friend of mine who had cancer was on that dosage, but she was on the dosage off, on, off. And I was on continually for— for six month. I had this doctor’s home phone number which, thinking back, ‘oh that’s … um … you know, that’s a bit funny, but never mind, seems to, you know, care’. He seemed quite a nice man and everything and you think ‘oh, a doctor knows everything, follow the doctor’s instructions’. And then I started to— … um … I was lying in the bath and I thought all my skin was starting to stretch, all of this skin starting to stretch, and I was getting bigger.

And— and I did— and I really did not feel very well and as the months went on, you know, cont— went strictly backwards and forwards to hospital, you know, I’m get— ‘oh, that’s to be expected’, you know, ‘oh right, I really don’t feel very well’. You know, ‘that’s to be expected’, kept going back. And then as the months were going on I was getting bigger and bigger, and my neck was getting bigger, my face was like a balloon, you couldn’t— even when I bumped into an old school friend, she didn’t know who I was, I was so big. Uh, my legs were big and I was just this— because I was getting bigger and bigger, the skin was stretching, and I’ve got lots of stretch marks, because of just getting bigger and bigger. And then I started at times to lose consciousness, and my hair was falling out at the back. And so at this point— I’m nineteen at this point, about nineteen, twenty. Um, and losing the taste in my mouth, couldn’t taste, and I would just suck on ice. And then I was, like, in and out of— didn’t really know where I was. So my mam rang the hospital and I was rushed in, and it was like what you’d probably describe— like ER, you know, when people are rushing around. Blood transfusion. And then all of a sudden I get transferred to the proper renal unit at the Royal Victoria, Newcastle. Um, and to— to get proper— obviously, when they saw me, they just weaned me off the steroids. You had— I had to be weaned off slowly but surely to get me back.

Um, just moving forwards six years … um … that— I was watching the news and this doctor was on. He had been reported … um … he’d— he’d been suspended for— for practices. So I actually went into the Northern Regional Health Authority and gave a statement, it’s— you know, about what had happened to me. And on the— I was told by a nurse who worked there, who was then training to be a doctor - I bumped into her - he had actually killed another patient. So luckily I had been able to move on. So I was weaned off the steroids and then— and basically— you know, full of scars. And then I had to go and have some plastic surgery to— the scars— wasn’t— it wasn’t really done that well cos it’s still there, but they cut off— on my— on my lower— my upper arm, it would hang much more than what it actually does now … um … and that was all cut. It was actually hanging low and it was all cut, and that’s on both arms. I had liposuction on my knees, and all the top of my legs, the— it’s all stretch marks where it’s all gone fat. So that was just— that, probably— is probably the— one of the worst experiences, and that was before it even got to the point where the kidneys were ready to go on for dialysis. They— he had not stopped them from failing, he hadn’t done anything but make me feel extremely poorly and probably, you know, in my opinion, nearly, you know, destroyed me really.

So I now felt great, you know, ‘I’m in safe hands, whatever happens now, it can’t be any worse than what I’ve just been through, I’m in safe hands’. So, as I said, I was weaned off the steroids and then I had to go on dialysis. They waited till it was coming up to the Christmas … um … in— in 1989, and then they waited, and said ‘oh, you know, we’ll not put you on dial— dialysis until after the new year, we’ll give you the chance to have the Christmas’. So I had lots of drugs to keep me going, I didn’t feel too bad, you know, considering. And then in the January of 1990 I was then put on to dialysis. Um, there was— there’s two types of dialysis. One’s called CAPD and one’s a haemodialysis. Um, haemodialysis where you see people at hospital on the machine where it cleans all of their blood, and the other dialysis, CAPD, is something that you do at home. And just in— I’ll just describe it in my own terms, not in medical terms, but it’s a case of you— you’re— a— a tube was put into my side and a special fluid is drained into my stomach that does the work of the kidney, and you keep that fluid in your stomach for five to six hours and then you have to drain— drain the fluid out again and then drain some new fluid in. And so you were doing the work of the kidney. Um, you could do this at home quite nicely and it took me thirty minutes from start to finish. I always remember of an evening I used to watch *Neighbours* from start to finish and that— I knew that was my dialysis, that was done, *Neighbours*, that was done. They were in the good times when *Neighbours* was good! And— … um … and I had to do that three times a day. I still worked— I actually still worked full time. Um, I used to work about ten, fifteen minute drive away from home, so I was able to do it first thing in the morning, come back after work— you know, finish at five, straight back, you know, dialysise while *Neighbours* was on, and then wait as long as I could before I was too tired, then I would dialysise again before I went to bed.

And it— living on dialysis itself, it’s quite a— it’s quite a binding … um … it’s not so easy just to go off and stay at your friend’s for a weekend or go a weekend, because you’ve got to take all of your stu— your equipment. You know, you’ve got all of your bags full of your fluid, you have all your cleaning stuff, you have all your tubes. And it was imperative that you— you were kept ex— everything had to be kept clean. And I was lucky because when I lived at home … um … I had my own bathroom, so— and my— my mother is so house proud, you could probably eat off the toilet, just so house proud. She kept everything clean and I was lucky and I didn’t actually ever catch a— you know, an infection. She— she did look after me and I think it was easier for me to go through it— this at this point because I was so young— I was young but I was at home with my parents who could make sure, you know, everything was— I was okay. I didn’t have any other worries to think about.

So … um … I used to— … uh … there was d— I still can— there was the— things that changed, there was slight diet things, things like to cut down on was such— potatoes, cheese, coffee, dairy products. So what I used— so I— we— me and my mother got into a routine of things that I liked. So I used to have Coco Pops once a week, cos I used to get the variety packs. So Coco Pops once a week, that was my chocolate, I had a cheese sandwich once a week, and then I started— instead of having yoghurts, I used to have tinned pineapples. I remember, those were minor changes and I didn’t really— that was just when I stopped really drinking coffee and I just had a few teas. Um, so I didn’t feel— my diet wasn’t as hard to follow as some diets can be for people on dialysis. Depending how poorly you are, depending on your condition, some people have had to be so strict, but it wasn’t as strict for me and I managed, you know, having the help from my mother and family making sure— you know, we sort of discussed things I could eat and— and she would make sure I ate healthily and I ate well, really. I can’t— I didn’t lose any weight or probably put any weight on.

And exercise. They were a bit concerned cos at the time I had a pony and I wanted to still ride, I— I thought ‘there’s no way I’m stopping doing anything. Literally, I’m not— I’m nev— I’m not gonna to stop riding’. I’d been riding since I was seven. ‘Not stopping that, I’m not stopping going to work’ and I— and I think no, the dialysis is— I used to think ‘no, the dialysis will fit round me. That’s— that’s the way it’s gonna be’. And he was a bit concerned cos I had the tube put in and I had to have it all taped down to make sure it didn’t catch on anything sp— you know, get caught or anything. And I still went riding, and I still, you know, enjoyed it. And that was not gonna stop me. I still looked after her, I still went to work, I still went out with friends … um … I still had a boyfriend … um … and it didn’t really stop.

Then, as the months had gone on, you know, all this time— all this time I’m on the transplant list, so at any time I could have— you know, I was waiting for a phone call but— … um … to say, you know, there was—a— a new kidney, but you— I just sort of got on with it and in a way forgot about it, you know, thinking ‘oh, I’m just gonna get on, it’ll happen’. And I think just being that bit younger I didn’t really have the worries of anything, just thinking ‘oh, it’ll come eventually’.

Both my parents were tested to— to— to give … um … you know, to give their kidney, but they’re not the same blood group as me. In fact, nor’s my brother. And I suppose I am naturally born to them, apparently, although I’m the only one with a different blood group, I really don’t know! And my brother is younger than me so … um … there was no chance of, you know, whipping his kidney out. But my parents, they weren’t a match, so I had to wait for somebody else, you know, see what— what was gonna happen.

Just at the time when I did find out about a kidney, I was advised that I was gonna have to start doing dialysis four times a day instead of three, which I was a bit worried about cos I was thinking ‘oh, you know, only supposed to get half an hour for my lunch and— and they were so stringent, and I thought ‘oh’, and every time I went for hospital appointments he would knock the time off, I thought ‘oh’. But I thought, ‘I’m gonna have not much choice, I’m gonna have to do this four times, I’ll have to come home at lunchtime and then go back’.

But anyway, luckily for me, just before this happened I got a phonecall, one Sunday morning. I was just about— I was— I remember cos I was eating a bowl of Cheerios and I was— my friend had come to— we were gonna go out riding, and she used to keep her horse just down the way from me and … um … we’d just— she’d just come to call and I was eating my— my Cheerios ready to have my breakfast— … uh … well, having my breakfast, ready to go out riding. And I got the phonecall. And I remember cos the phone’s on the wall and then my mother, she answered the phone and just went ‘it’s for you’.

So this doctor, and I can’t remember for the life of me what he’ s called, but he was Scottish, he was very nice, he went ‘Rachael, we have a kidney just for you, you need to be in in twenty minutes.’ So I was— I was shaking a—and I thought ‘well I need to finish my Cheerios’ because I knew I wouldn’t be able to eat for ages and I— I did— I had— you know, I like my food. So I thought ‘finish your Cheerios cos you’re not gonna be able to eat for ages’. So I was sh— I remember my hand was shaking, I’m eating these Cheerios, Caroline my friend was there and everyone was in a spin and— … um … and— and then I— mother took me over to the hospital and when I went to the hospital I was the only one there, I was the only one called for this kidney. This kidney apparently was the perfect match for me. And … um … and it did actually— it has proved to be.

So, I went … um … in for the kidney on July 16th 1990 and I went to have— in for the transplant on July 17th, the next day. Um, and I— when I went for the transplant, I came round … um … and it took about ten days for the transplant to kick off, it just wasn’t starting. My body wasn’t, I don’t think, particularly rejecting it, but it wasn’t starting and it wasn’t going. So I had to go on the dialysis machine to see it and— to see— to— they could kickstart the kidney to go, and I had, I think it was probably steroid injections, something like that, some injections to— to— to really jumpstart this kidney to get it going cos it wasn’t going at first. But— and it— that was a real worry and that was quite stressful cos I thought, you know, you’ve waited— I’d waited, you know, like, nearly seven months … um … and this kidney’s just got to kick— just got to go, and I’m like ‘please, please make this kidney kickstart. And then it just did. It just kickstarted, it never looked back. And then as it kickstarted on and it started to function properly, I was just starting to feel well, well, well, well and just sort of really, you know, full of life and full of energy that I hadn’t really been before. Um, and just feel so much better.

So I was— I st— I took— I took three months off work and then I— I returned to work and then, you know, changed my career. I then joined the civil service after that and continued on. And the— one of the reasons I did actually change my job cos I knew— I— well, I was worried that in the future, if something happened to the kidney, if I worked in the public sector they would look after you more. Then we— we have a little sick room that if I had to go on dialysis they may just have a little room for me to do it in at work. Whereas where I worked now for a small sign company, it’s a factory and it was filthy dirty and it didn’t have those sort of facilities. And I knew I needed to move on just in case. Um, and I knew that probably I would get paid for some sick leave and probably paid just to be able to visit the hospital and not have my pay docked. Which, you know, I was just so lowly paid anyway, I thought ‘I’m gonna go into— I want to— I need to go to an organisation that looks after people who actually have these sort of conditions, you know, so I can work and get on with it. And that’s what I did. Um, so when I focus on something that I ha—ha— have to have, I have to— I just work for nothing else but that really. So I knew that’s what I needed to do so I did. Um, I never looked back.

And then the kidney, it functioned fantastic, it’s fu— it’s— it’s twenty three years old in July and up to four years ago it was functioning absolutely as normal as— as anyone with normal functioning kidneys. Um, and I got involved with— I joined the Newcastle Transplant Team, so we used to go to the British Transplant Games. Um, and I used to be on the volleyball team and play v— volleyball, and I’d never played volleyball until I was approached to play volleyball for the team. So I played volleyball for the team on numerous occasions, we’ve won loads of medals. And then I played … um … tennis, just singles tennis and … um … I have— I’ve got a gold medal for that, I’ve got a silver medal, numerous bronzes for tennis. And I was— and I was picked to represent England for the transplant games … um … but it was the point where you had to actually pay to go, you had to pay everything yourself, and I’m not very good at fundraising and I got a bit panicky. And I decided not to go, which seems crazy when I think back. And it was gonna cost a f— I dunno, it’s about a couple of thousand and I hadn’t been married very long and you— and I’d had to go, sort of, by myself. I mean, some of the other team would have been going and some people around but I didn’t— I didn’t end up going, which is probably a little bit one of the things that I— I should have done and I regret, it was a silly thing. Thinking about money was such a silly thing. I should of— and I’m not one for— I don’t like— I hate fundraising for myself. I don’t mind fundraising for anybody else, like proper charities, but not for me, and I didn’t feel it was right for— to try and raise money for me to go somewhere. And I— I couldn’t afford it at the time to pay for myself, I think that’s what put me off. But … um … the— yeah, well the fact that I was picked off the— maybe that was enough for me at that time, that was okay. But I really enjoyed go— you know, going to the British Transplant Games. They were just— you just used to meet different people who’d, you know, had … um … heart transplants, lung transplants. Got— you know, made lots and lots of good friends and it was just brilliant. Um, so I haven’t done that for a few years now, since I probably moved over to Cumbria. You know, when I was representing the team Newcastle, we’d practice over in Newcastle. Well, I moved too far away to practice so I sort of put a hold.

And then we— I— you know, I got married and then, you know, you move on with your life. And then we adopted a little boy because … um … w— w— at the time we were thinking about having a family. My husband was so worried about if I had a— if I actually had a natural born baby that it was gonna— that the function would le—well, it would lessen by about ten per cent. And he was frightened that if I lost the kidney and looking after a baby and all the complications … um … it was— it was gonna— he just— he just didn’t want— he didn’t want to do it. And I sort of— was may— was a bit put off by it, but then he said ‘have you ever thought, maybe, what about adopting?’ And at that time there was a— on the BBC that— in the morning there was a programme all about adoption and all of that’s— and about the children and the people who’ve adopted and the children who needed to be— needed— looking for homes. And I just— I said ‘oh, actually, you know, I’m— I really want to adopt. I’m not even— we’ll not try, I think we’ll just go for the adoption because I’m— we’re just gonna bring another child into this world when there’s other children that are desperate for homes. And I think we could both give a really, really good home. And then I’m not putting my health at risk so— … um … you know, having a child, you know, hopefully everything’ll be okay and I can look after them to the best of my ability, which we did, and we adopted Kane. Uh, and he was three and a half when we adopted him, he’s— he’s fourteen in September now, you know, so he’s been with us, you know, a few years.

Um, four years ago … um … uh … the kidney function started to decline. And … um … it was a bit of a worry and I had transferred from— at this point from the Newcastle specialists to a specialist who came from Preston so I’d visit in Kendal, and he started to talk about dialysis. And— and I remember him saying ‘oh … um … a transplant’s just a holiday away from dialysis’ and I was thinking ‘you know, you’re really— I’m really upset by this and I— I’m—‘ and there was something with him, I just— I didn’t really feel comfortable that he was treating me so I decided if— if my kidneys go down I want to be in the best hands I can and I transferred back to Newcastle. And they were happy to have me back, I knew them, and that’s fine.

And what had happened was the— the— the tablets that— which are called cyclosporine, that I had been taking for the last, you know, eighteen years, they dec— they— they were working against the kidney. And that’s what happened, which was the biggest shame ever really and I wish— it would— it should have been caught a bit earlier really and it probably would have been if I’d still been with Newcastle. But … um … I waited for a biopsy— cos they just— as well they wanted to— that— when— that’s how they found out it was that—the drug. Um, they were frightened in case it was the original virus that I’d caught had come back again. But it hadn’t, it was— … um … it was the drugs. So I had to go through a whole change of drugs, everything was changed. Um, that was a pretty stressful time because, you know, they’re quite strong, these drugs, and it can make you quite poorly. And then as the kidney function had declined … um … I became anaemic, and that’s just part of— because the kidney function’s so low that I’m became anaemic. So I have to inject iron— that— at that point was once a month, it’s now once every two weeks. And that just— you know, that keeps me going and … um … I don’t feel lethargic or, you know, too tired really, it just keeps me going quite nicely.

When the kidney— the kidney function did start to decline, and then it just— it made a— a comeback and it started to level out. It wasn’t— not particularly a high function, but it leveled out and it’s enough for me to live on. And then— it’s going okay and then two years ago in January … um … I caught pneumonia so I had to be hospitalised, and I think the drama— the trauma of the pneumonia defected the kidney function again. I think it— it just— just so much going on, and it just— it affected it again. And it started to decline a little bit more. Um, and this is just a re— quite recent and they were talking about my options for, you know, returning to dialysis again and going for— and having a second transplant which I’ve been tested for and I am fine to have another transplant. The— the transplant kidney I have now is on my right hand side, and the new transplant kidney will— would be put, if I have it, in my left hand side. So I’ve actually been tested to be healthy enough and ready enough for another transplant. But I had another what I call little ‘mini-comebacks’, so I— the— the results slightly improved again and I’m just— it’s the— I’m just on a level and the kidney is functioning at fifteen per cent and— so it was— it was lower than that but it’s about fifteen per cent. And although it doesn’t sound a lot … um … it seems to be alright for me to be on at this moment. Um, so I’m just sort of— I’m trying to keep healthy and keep on this— keep on this fu— this function that I can actually live on. Because it’s, you know, I— I can’t— it’s very stressful to think about having to return to dialysis now that I’m— you know, I— you know, sort of living a way— I’ve got a— a child, a husband, work, and I think the reality of it’s a bit more frightening now than what it was then.

Um, my husband, he’s actually been to be tested to see if he was a match for me and he actually is a match, he’s actually got the same blood group as me. Nobody else has, but he’s got the same blood group as me! So he’s been tested for him to give— to give me one of his kidneys. Which— that’s stressful on its own to think about that, because it’s the fact that I just feel like I— I feel too guilty to be able to even take his kidney from him, just in case something happened to his kidney, the other one. And I just— I’d rather, in a way, wait and be put on the list and have someone who has passed on— passed. Um, but the— for— to— to receive a live donor is actually more successful than a dead donor. You— there’s more suc— even if you’re not a great match, i— there’s more success rate on having a live donor, which would be better.

So I’m hoping, seriously hoping, that it doesn’t actually come to this, I can just hang on and cling on just to this— this kidney I’ve got, which in a way, it’s such a shame, because it was a perfect match for me and it’s the drugs that let me down— let it down in the end. And I— I feel for it really cos it’s sad. And then just— I mean, going back really all— to— all of those years to when I received the transplant. There was a few transplants that weekend actually … um … and a few people who I was in hospital with, you know, found out who their donor was, you know, but it was what— something that you feel really weird about. So it took me about six months before I asked any questions. And I don’t know that— it was a lady, I don’t know her name, but I know that she was forty-six from Nottingham and she had passed with a brain hemorrhage. Um, cos— and I— I— after a year, I wrote to the family just to say, you know, that I’d received this kidney and I’m so thankful for that and it’s given me a life, but I’m also so sorry for your loss. Um, so they accepted that— I think they accept that letter. Then ten years after that, I thought, you know, ‘it’s been ten years, I think I’m gonna write another letter’. So I wrote another letter to the family but didn’t— there was a note in the file, they didn’t want to receive any more letters, which was fine. But I think it’s there if they ever need it. But maybe they’ve had to move on and it’s alright to know that the— that— that that person’s organs was donated and they went to a good cause, so, you know, when she passed her organs did, you know, help other people, to be honest.

I think, you know, it’s— I can understand. It’s very, very stressful when you’re— you’ve lost a loved one, you’re in the hospital and they’re, you know, they w— saying ‘well, would you like to donate any of their organs?’ Well you— I can imagine your first thought would be ‘no, no, leave them in— no, no, no’, you know, but now I think they’ve got, sort of, the— bit more training’s gone into it so coordinators— transplant coordi— coordinators can talk to families and really und— help them understand, you know. Cos— and even sometimes when it’s been the patient’s wishes, the family have said no. But I know they are trying to change the law on this, so see what happens on that. But I can completely understand where families are coming from when they’ve lost someone, it must be so hard. And then from my side of the fence, and if— if anyone has a child who needs an organ, it’s like— you don’t, you know, you don’t need it when you go and there’s so many— you know, you can give a life and you could help somebody live a full life, you— you know, it’s a difficult time when you’ve been bereaved I think. But … um … you— I think you’ll always be grateful for that person, even though you don’t know who she— who she is, but I suppose she’s there.