Darren Coley - Interview.

00:55 My name is Darren Coley. I have a fistula in his left arm. Which people really find fascinating, It's a talking point. When I go to companies or schools I let them feel it, it buzzes like crazy.

03:29 My name is Darren Coley, I'm from the west of Ireland.

03:33 And we are talking to you because, you had some kidney trouble and you have had 2 transplants and you have been on dialysis for a while. How did it start? When did you first become ill? What happened? What were your symptoms?

03:52 Well, it all began for me when I was in my 2nd year in college. I was a sports and fitness studies student, so I was quite fit and active. When I younger I won titles in boxing, handball, I played Gaelic football, soccer rugby, so very active, very outgoing. One of the problems I started to get was headaches, I used to get a lot of headaches and then my vision started to go bad. And I was… I couldn't understand it, I thought maybe I need glasses.

04:20 Now in my 2nd year of college I was going out with friends, I had a girlfriend you know, so I thought that maybe I should cut back in going out so much, not that I drank a great deal but my girlfriend was getting annoyed too, like I was getting these awful headaches, severe headaches all hours of the day.

04:36 So, it got to a point where it was getting worse and worse. I had trouble reading my books and then one day playing football, I went to catch the ball and I missed it and it hit me on the head. So my sight was kind of going really bad. To me it was like these big shadows over my eyes, so to see and things I had to keep glancing sideways.

04:54 So that got very difficult and eventually I went to the college Doctor. I said my vision is going bad and I'm getting a lot of headaches and she said O.K., well then see an Optician, you are O.K. as far as I'm concerned. She assumed obviously it was coming up to Easter and I was looking for an exemption from my exams and she would have been correct, but she didn't really listen to me because I was having trouble reading the books. I was kind of you know, moving these black dots over and back so that I could read the pages but being a young guy from the west of Ireland, you know you don't go to the Doctor unless you are dying and it was starting to get like that. It was only through the football, when I missed a ball and got hit on the head and everyone laughed at me, I went.

05:34 A few days later I got to go to an Optician, I had to make an appointment and the Optician spent about 5 minutes looking at my eyes and then gave me a letter and sent me to the hospital. I said yes no problem I'll go but I have a football match today so I'll try and go someday next week. He said no, no, I insist you must go right now. So I went to the hospital, I rang my parents they were in Ireland, I was in University of Bedfordshire in England. So I said I'm going off to hospital, something to do with my eyes, no big deal, I felt great.

06:05 So, after about 10 minutes in the waiting room with 30 people, I got taken in before everyone. The alarm bell started ringing slightly then. And after a load of tests, they kept putting all these drops in my eyes. Something went down the back of my throat and I started to gag and they said listen, we will take you to a room and do a few tests. And it was there that they did my blood pressure and it should be like 120 over 70, mine was 190 over 280 and then bang, they started getting very alarmed.

06:36 They lied me down, told me I was potentially at high risk of having a stroke and that are my parents on the way. I said, well no, they are in Ireland. So they wouldn't even let me out of the bed to use the phone. There wasn't allowed a mobile phone staying in hospital so, it was 1998. So my mother had to be called and told to get to England immediately, your son is very sick, he is at danger of having a stroke. We are moving him to the Lister hospital in Stevenage, it is a specialist hospital and that's where I went from being a sports student to someone with a chronic long term illness.

07:09 Q: So the lifestyle from student to long term illness, what does that actually mean on a daily basis? How did it actually affect what we could call your…, what is your life style?

07:20 Well the changes were enormous at that stage because within 2 weeks after doing the biopsy and doing different tests, they realised that I had chronic end stage renal failure. Now I had to ask the doctor, what did that mean? Am I going to die? I actually asked him. He said not at all, no, you may need dialyses in the future. Oh that's o.k. What's dialysis? Because I just never entertained the thought that I would ever be sick in anyway and I didn't know what any of these words meant.

07:49 A few days later due to the problems weren't going away I had to start dialysis. So they had to put a line in my neck which they couldn't get so they had to go to my groin, which was remarkably uncomfortable and they started dialyses that day. So within the space of a week I went to going out with friends, having a great time, studying sports, playing sports, to having to go to a hospital every 2 days with a serious long term illness and sports career, any ideas that I ever had of having some sort of sports career, a job in sports, I just discarded immediately.

08:24 My girlfriend, I dumped her straight away and so on all accounts of my life just flipped. Everything went not the way I planned.

08:33 Q: How did this affect your self-image, your view of yourself as a person in this world.

08:39 Well my self-image at that stage suffered hugely because my whole persona all my life, now I wasn't a big strong lad, I was very slim, I was very fit but my self-image then went to someone who was sick. My attitude was I'm a sick person. I went into a dialysis unit in the Lister hospital surrounded by people in their 70's and 80's, 60's, 70's & 80's, looked around me and said well this is who I am, this is who I am. I'm a sick person, I can't do what everyone else does and I can't play sport again which was heart-breaking, absolutely heart-breaking.

09:25 Q: And so I guess at this point you are spending more time with medical staff than with your friends. How was that experience? How did they treat you?

09:41 Around that time, I obviously started dialysis which meant for me every 2 days in hospital for 3 or 4 hours. So, I got to know a lot of the nurses very well and some of the patients but the patients were not similar to me in any way as a younger person. I was 20 years old. But a lot of the nurses were in their early mid-twenties, so I formed a lot of good relationships with nurses and they saw that I was someone that was not a happy person at that time. You know my relationships with my ordinary friends might have been slipping away slightly. I couldn't go out drinking like everyone else, I couldn't do this, I couldn't play sport. So I became very attached, we both, like we all got on very well in the hospital. There were huge… they gave me a lot of confidence in that everything would be o.k. You will get a transplant down the road and everything will be back to normal, and not to worry, because they were so good and the hospital was so good, I decide not to come back to Ireland. I stayed in England and I finished off my degree in sports even though I thought that it was absolutely useless.

10:41 So, the nurses in the hospital really had a huge influence on me and the Doctors themselves. They were so confident that everything will be O.K. and not to worry and we will guide you through it and they became friends rather than the usual nurse patient that you only see for you know, once in a while, whereas I was seeing them every 2 days.

11:00 Q: And so what information where you getting form the Doctors, in terms of your current state, your prognosis, your future life, what were they telling you?

11:12 What I heard from the Doctors initially was that, something like 2 in every 10 parts of the kidney were working. So they did try very hard initially with steroids and different drugs that I would not have known anything about. They tried very hard to try and fix that, but the huge problem for me was the blood pressure was so high that it was causing the damage, and reiterating the damage, it was constantly putting pressure on the kidneys, and my head and my eyes and everything.

11:38 So that was their main concern and I didn't know at the time but my parents were asked , you know we may have to remove his 2 native kidneys because the blood pressure is out of control and so there was all these huge operations looming just, just behind the surface. This was all kept from me because to be honest at that early days, I was sitting there going, any minute now they will realise that they have just made a mistake, they've got the wrong results because physically I felt o.k., apart from the headaches and the vision, which they were working on.

12:04 Like I just couldn't understand, I couldn't possibly be sick, this couldn't be a long term thing. But they finally after a few weeks said, you know, we can't get the kidney back you are on dialysis now. You know I was, my system was still quite good however, they couldn't understand how I was kind of so fit and I went running before I was sick. You know, I shouldn't have been able to do these things. I was eating whatever I wanted before the day I went into the hospital. I must have had a good system in place, for everything was still working quite well, but there was no chance of getting the kidneys back and the long term ideal was to get a transplant, that is the best form of treatment.

12:48 Q: And so your family was told about this before you were? How did they respond to your illness, to the situation? You said that your parents were still in Ireland and you stayed in England.

13:03 The situation when it unfolded, my mother came, flew back to England immediately to be with me even though I felt fine. My father didn't, he had the family business and he was working on that. When we were told chronic in-stage renal failure, my mother obviously broke down crying, my father couldn't deal with it really at all, you know. He was found in the car, on the side of the road you know, not in a good place. I'm an only son, I have 4 sisters and I'm an only son. My mother had to go and worry about him, get someone to collect him off the side of the road, make sure he is o.k because you know, we are a very loving family. We really all get on. So that was difficult. I have 4 sisters and they were all, everyone in Ireland thought that I was on my death bed because chronic in-stage renal failure, oh my god, that must be really serious. Is he going to make it, you know? That was the attitude, he may have a stroke.

13:58 They heard bits and pieces and I was lying in my bed going, when is this going to be over, I want to get out of here. So it was very difficult you know, it was only when I, my father came back from Ireland to see me you know and he saw me siting up in the bed and I looked perfectly normal you know, I had no tubes coming out of me or anything like that and the first thing he did was start eating the food that was on my table because he had not eaten for 2 weeks you know, so. It was a difficult transition for everybody, they saw me growing up all my life, healthy and fit and sporty and then to be in a hospital bed, it just didn't make sense to anyone.

14:34 Q: What about your sisters?

14:37 My sisters were fantastic. They are a lot younger than me, so they were pretty much looking after themselves you know, around the house in Ireland. You know they were all at school, my older sister was in college also. So they were all very worried but it was a sense of, they didn't know what was going on really, because you wouldn't be telling them any of the bad news, my youngest sisters that this kidney failure meant, because like me they wouldn't have understood it. So they all took it very well really.

15:08 Q: Now the time that you were at college and you finished your degree, so by then you were still on dialysis after graduation. Almost no student has a good time coming out into the general work space but did the dialysis and the fact of having to be in hospital so often change, affect the way you were looking at gaining employment and getting jobs?

15:36 After finishing college the chances of me getting a job that I wanted was pretty much gone. There was very little chance of that. I saw myself as a fitness instructor, a PE teacher, a teacher itself, something like that down the road that's what I was aiming for. But that final year I did in college while on dialysis, was just going through the motions, just scraping by with C's and D's you know. There was no ambition there in me whatsoever. I finished in May, I was told that I passed all my exams, whatever you know. I didn't stay around to get my degree cert, I didn't stick around. I went to Ireland straight away because I didn't go on a transfer waiting list in England because I didn't want to get the transplant while finishing out my year in college. So I came back to Ireland, went on the list and you know we went from there.

16:27 Q: So what was your response when they first said there was a chance that you are going to have to have a transplant?

16:36 I'm not sure

16:37 Q: Going back, at some point you went from it will be O.K., they have made a mistake, it is not a big deal. I'll be gone in a minute and then at some point one of the Doctors would have come up to you and said, as you said earlier, we can't get the kidney back, we are going to have to go for a transplant. What did you think? I mean this is a very invasive major piece of surgery.

17:06 After being on dialysis for several months you know I stabilised, my blood pressure was at a good place and they started talking about transplantation. Now I don't remember a great deal about that at the beginning you know, because I don't know, I think I shut down. I just didn't want to hear anymore and then they start talking about transplant, where they will be opening me up and putting in a kidney which would have belong to somebody else and I think it was too much for me at the time to understand. So whatever happened in the hospital, I wasn't a good patient but I told the Doctors whatever you have to do, just do it. Don't mind me and I'll be in pain like this you know, or it's more anxiety in my head because I hated people doing anything to me.

17:46 So the idea of a transplant and spending 2 weeks in hospital you know, they didn't really go into it in too much detail at my request. Now they did say when you get the transplant, there is no more dialysis. You just have to take tablets every day, immunosuppressant steroids, maybe blood pressure tablets, so they kind of sold it to me on the positive side effects of a transplant, as in you will get your life back. So it wasn't something I thought a lot about at the time because I was still too in shock maybe, maybe a bit depressed. I don't know for sure because you know studying sports, forget about sports you know, this is your life now and as I said, surrounded by people in a hospital who are all in their 50's, 60's, 70's so. The idea of a transplant and living a normal life just wasn't something that was sinking in with me. My normal life was dead and gone, this is where I was.

18:38 Q: And again was it something discussed with your parents before it was discussed it you?

18:43 I would think everything was discussed with my parents before me, which was perfectly understandable and not really something that I wanted to hear anyway. Like looking back now, I know when somebody starts dialysis, there is a whole education process put in place before they start. What type of dialysis are you going to do? Are you going to do CAPD. Are you going to do it at home on overnight? Home dialysis, or hospital dialysis?

19:07 I was told that maybe 1 or 2 o'clock in the day, listen your bloods are very bad, your blood pressure is out of control, we are going to put in a line, whatever that was and we are going to start dialysis tonight. That was it, O.K., you know, whatever you have to do, you know. My parents, my mother will be there, they will be talking and they say, can we speak with you for a moment outside, listen it's very serious. Whereas, I didn't know any of that, there is no point telling me anyways because my blood pressure will go even higher, so.

19:40 Q: Where you driving yourself at this time?

19:42 No, at that stage no, I wasn't driving. So I lived in Luton, University of Bedfordshire there and I had to go to Stevenage which was maybe 30, 40 minutes away. So I had to get a bus every 2 days you know, Monday, Wednesday, Friday I think or Tuesday, Thursday, Saturday. So I had to get the bus over in the morning at 7 O'clock, to be ready to go on dialysis at 8 and then get the bus back at lunch time and eat you know, it was a life style change like no other.

20:12 Q: How is the experience different with the second set of dialysis, because by then you knew what was going on, you were, you have been through it once. After the first transplant you went back on dialysis, was, did you notice there was a change in the way you were treated in the education you were given, the facilities available, any of that sort of thing? What was the time difference from the first batch to the second?

20:42 When I had the transplant, I was lucky enough to get a transplant and then it only lasted a year and a half.

20:49 Q: So it was only about 2 years…

20:50 A maximum …

21:07 Q: So, we got as far as, you went back to Ireland because you didn't want to have transplant while you having the college degree because you wanted to finish the college degree you said, even though you were just going through the motions you still felt it important to have this document. You finished the degree and then as far as you were concerned, employment, the job you wanted was completely unavailable so you went back to Ireland or came back to Ireland because we are here now and… what happened then. Presumably you were on the list for the transplant, so what happened then?

21:43 I came back to Ireland after my third year in college, I was probably 21 years old and I was on the transplant waiting list. Now the waiting list in Ireland was quite short but you just don't know it could be 2 or 3 years, it could be a few months. It worked out, I came back in May, June time from England in 1999 and in January, in February, so it was only 6, 7 months later I got a call for the transplant and that is a surreal thing in itself you know because I wasn't prepared for it. They say have a bag packed, have this and have that. I wasn't, I didn't do that you know so.

22:20 I got the call at 7 in the morning and I got up and I was still going to the bathroom then so the first thing I wanted to do upon waking up, was to go to the bathroom and my father was up and about, so I just handed him the phone. He took the call and said they want you for a transplant. I was going oh, o.k, it was just, it wasn't, it didn't seem like real life at all. I ended up, I went to, I had a shower, got cleaned up and then we went to Dublin, got a guarded escort some of the way up, had the operation.

22:49 The first 2 weeks obviously were not much fun because you have tubes and catheters, the risk of rejection but everything was going fantastic, they were very happy. I got out of the hospital in Beaumont, in Dublin within 2 weeks. And then you know I thought, well that chapter of my life is finished, everything is going well. I represented Ireland at the transplant games in Japan, so as good as I thought I was at sports I was never going to represent Ireland, so this was a huge you know, life was becoming better, fantastic. And then after the first year you know a few results weren't going well and then in 3 months' time I went back, they were kind of a bit worse and a bit worse. They did a biopsy and they told me, you have got a BK virus, Polyoma virus.

23:32 I said oh, O.K. what do I do? We are sorry, there is nothing we can do about it, we are going to have the kidney removed, to transplant a nephrectomy. Nephrectomy that was a new word, I hadn't come across that one yet. So that was, getting kidney failure was a shock. Losing a kidney transplant at 22 or whatever, that was a low point because I knew exactly what that meant. The morning after the operation I was wheeled into the dialysis unit, all the blood pressure noises, I heard them again, surrounded by older people again and that was, I would think that was the worst time for me.

24:06 Getting kidney failure was no big deal because, I didn't know what it was. It was just life, get on with it, you know I can't do anything about it, but I went through it, experienced it, suffered it, had a transplant and everything was going to be o.k. Even then I didn't realise, transplants on average lasts 10 to 15 years, I didn't know that. But the fact that I only got 2 years, you know I hadn't even grown up, I was still only 22, 23. So that was for me definitely the worst time, having to go back on dialysis again, surrounded by all the old faces and I guess having to develop myself again into the attitude of someone who is sick and you know I'm going to be here every Monday, Wednesday, Friday.

24:47 Because I had that virus, I knew that it would take, they told me it would take a few years before I went on the list. Because I thought, right I was only 7 months waiting the last time, so 7 months from today would be, oh yeah… that's not too bad. Within a year, I would be fine again. But it was 4 years before I even went on the list, so 4 years of dialysis, then I went on the waiting list and it was another 5 years on the waiting list. So everything was different, so my whole life changed again and the long term outlook after losing the transplant was not good.

25:17 Q: You said earlier that obviously it was not good, coming out of the operation because there were tubes and things…tell me what the experience was, what your situation was when you woke up… after the first transplant. You said obviously it wasn't good because there were tubes and stuff, but I don't know what obvious is…

25:40 On having the first transplant you know, it was all very unknown, you are driven to Dublin, you are put into the hospital, they do all these tests, you wash yourself thoroughly. The anaesthetist come down and explains everything that is going to happen. They start putting a line in your hand here and another one goes in your neck. Most of them are done when you are asleep and you have to have a catheter. So when you wake up, I have a line here, a drip here, a drip here and I have of course the catheter which was to me the worst thing imaginable.

26:13 I found the first few days very difficult because you are in pain. You have a morphine drip which, my finger just went like this. It only went off every 7 or 8 minutes but I wasn't taking any chances. It was just going all the time and so it's very difficult. And I know you kind of think, oh, in 2 weeks' time I will be out of the hospital and everything will be great but at the time it's sore, you have got all these lines and drips. You can't really go to the toilet after an operation and you certainly can't sit down to go to the bathroom because your muscles in your stomach have all been cut so you can't push, so constipation is an issue for all people after transplants and a lot of other operations.

26:51 So you often have to get tablets and drugs for that, which are not always orally taken but they are put somewhere else. So, all these experiences came at me within the space of really 5 or 6 days. And I remember somebody who is on dialysis, at that time coming in to the hospital to see me and saying what is it like? It's awfully hard you know, I'm in pain, I can't wait for them to take out this and do that. And I met the same person 6 months later and they said so how are you after the transplant? Oh great, the operation was easy, it was no problem. At the time for 3 or 4 days it was painful and sore and very uncomfortable. But looking back at it now, it was fine.

27:55 Q: How much discussion did you have about the risk of rejection before the first transplant?

28:02 After the transplant, I have no memory really of any talk of rejection at such. I was told make sure you take your tablets or different things can happen, your kidney might fail and stop working. But I was not told in detail and I think that you need to be told specifically what will happen. Now the BK virus, it could have happened to me anyway, it could happen to anyone you know. I think 60 to 70 % of the population have that virus naturally and your immune system just looks after it. But in my case due to the Immunosuppressant and that, it got in, got hold.

28:31 So there was, I thought maybe I didn't take my tablets on time every day, maybe that was the reason or I went out last night and didn't come home you know, maybe that was it but luckily it wasn't the case. I have no feeling of guilt from losing the transplant and I don't think a lack of education given to me would have had any major influence. You know my ideal situation in any of this, I don't want to be told too much. I only want to be told what I can actively you know, don't eat any bananas you know, that's the kind of directive I want because this will happen and you will get sick.

29:05 But I don't want to be told really all the deep science behind something because I'm not a Doctor. The Doctors I trust, they tell me what to do, you know normally when they tell you they give you the reason and if their reasons make sense, I know ok I'll do that, that's o.k., I'll be very good like that but then sometimes they might talk about immunisation and different other aspects of medicines that is no relevance to my day to day living, it's not going to do anything to me, to make me live a better life and to be as healthy and active as possible. So that's always my goal, is take from the Doctor what I can tangibly do today and science can be kept inside the Doctor's head.

29:50 Q: I'm sorry to keep coming back to it because you said you didn't want to be told, do you remember what you were told prior to the transplant about any risks of rejection?

29:58 Prior to the transplant I have no real recollection of any, of being told too much about it really. You know, I know in the clinic where I went in Beaumont they did do a transplant build up and you have to do a load of tests to make sure you are eligible and what type of transplant or who you are going to get it from or how it is going to work. But on the matters of rejection, I don't really recall too much of what I was told about it, you know it was a factor that happened you know. I know even when I had the transplant, the person that got the other kidney, theirs didn't work and mine did work. So like, there is always the, geez that could have been me you know and put that to the back of my head, I don't need to think about that.

30:40 So no there wasn't a great deal of talk about rejection. I certainly know a lot more about it now after years of dialysis and waiting for a transplant than I would have at the time. Because again, I was 22 years old, I just wanted to, I didn't want the serious aspects of life to over encumber me.

31:00 Q: So you had a transplant after the operation and the recovery from the actual operation, where you then good as new?

31:03 I think after the transplant everything was going fantastic you know, as I said I represented Ireland and that was one of the biggest things in my life at the time because my role models in matters of health were all in their 60's or 70's. When I looked around the room on dialysis you know, I'm looking at them saying all right, I'm like them you know. So it took going to these transplant games for me to see other role models. You know I did cycling, I said you know I used to cycle to school, I was quite fit and healthy, I'll probably win the thing you know. This was my idea going to the transplant games, I brought a bike and everything and I came third, last.

31:40 I got absolutely destroyed by everybody. And I'm looking at these other men and saying, thinking to myself, right, they look the same as me, we have similar body types but yet they are so fit, so active, so outgoing and it was only then that I realised that I had kidney failure. I didn't have heart failure, lung failure, my legs, my arms, my brain, everything else was working fine. So I wasn't sick, I had a health issue. So that change my life a huge amount, I took more of an interest in sport, in my own personal wellbeing, because I see other people doing it and if they can do it, well then so can I and they weren't in their 60's and 70's, they were young people. There was more people like me out there but their mind-set was far different to mine, so that was a fantastic thing.

32:22 So because of stuff like that, I went back to work you know. I got rid of this sick attitude, I had a transplant you know, I have to be careful always you know, that wasn't the case and that's when my degree in sports worked out well you know. I got a job at the special Olympics for a year and I have had a job in leisure centres, so I had just begun to get my life back on track. You know, I have more confidence in my body, I was working because of my degree in sports, so life was good.

32:50 Q: And what about the anti-rejection drugs, do they have any side affects?

32:55 I had no side effects whatsoever, I didn't even put on weight because of the high dosage of the steroids. So I was still very slim, very, I looked very sporty. I had a better colour in my face, I had lost that anaemic look that people on dialysis usually have, so I had no side affects as such from the drugs, no.

33:17 I felt great, I was active and outgoing.

33:28 Q: Tell me about what they said, how you felt when you realised the transplant was failing and that, more about the communication between you and the Doctors, and what you were internally feeling.

33:65 After a year and a half on dialysis…

34:01 After I had the transplant, the first year and a half everything was going fantastic. And I had been to the transplant games in August of the year, so we were around to February and the next games was coming up in Hungary, in Budapest and I thought geez, I would love to go to these, you know and I was getting my usual blood tests and communicating with the Doctors. And it was the second time he had said, your creatine levels have gone up again, they are 130 you know, and last week they were a 120. We went back 2 months later and they were 150, so he said listen we will have to do a biopsy. Well I feel fine you know, there is no physical differences, I'm looking forward to these transplant games. I'm actually doing a bit of running and training. He said I know that's great, keep it up but we need to do a biopsy anyway.

34:45 So, they did a biopsy shortly after that and about 2 weeks later I was called up and the results were back and they told me you have got this thing called a, I think it's BK Polyoma virus. And he sat me down and we had a talk about it and eventually he kind of alluded to the fact that you know there is no real cure, we have no way of treating this. Again this is 12, 13 years ago, it was 2002, maybe 2003. So there is no way of treating it and we are going to have to remove the kidney you know, so it was disbelief on my account you know. And I questioned them on everything saying, genuinely you know I feel fine, is there nothing I can take or nothing I can do? But there wasn't you know.

35:28 I have great time for this Doctor and I trust him, he is a very straight talker he didn't say maybe we will do this or, he said listen we don't have anything, this is what's happened, we are going to have to perform a transplant, a nephrectomy. So I was going to have to go in the future in to have the kidney removed, so you go through all the transplant procedure in reverse with no happy ending afterward. He did say I could go to the transplant games you know and when I came back I was going to have the kidney removed so I was happy, bittersweet I guess. So again it was a very difficult time you know and I was in the hospital a great deal then, every few weeks going up and checking the markers, the creatine, blood pressure was starting to creep up all the time, so the signs were there that something wasn't right, you know. And it took the signs like the blood pressure and seeing the results, a steady graph going up the wrong way that I realised you know, I had to do what the Doctor says.

36:29 Q: So then you had another transplant, give me a quick rundown of how long you are on dialysis and..? Repeat please if you don't mind, how long you had to wait before you went back onto the list. Take me through to when you find out that there was a donor and that the second transplant was ready.

36:55 After losing the transplant, I had all these illusions that within a year, I'll get another transplant and then this one would work and everything would be o.k. But through communicating with the Doctor they said this Polioma virus is in your system, it's in your blood stream. Now we remove the kidney which may have been the main source of it but it's still in your blood stream and your urine, so we have to make sure that it has totally gone out of your system before you can go back on the waiting list or the exact same thing will happen again.

37:27 So I was O.K., so I was started back on dialysis, you know which wasn't easy because I thought I was gone for good. So I got use to the dialysis again you know and the first year went by and I'd go up to Dublin to give blood every 6 months or something and it kept coming back, still in your blood stream, still in your urine. And then after 2 years it was gone out of my blood stream but still in the urine, and another 2 years, so it was 4 years before they said you can go back on the waiting list. So that was 4 years gone you know, the middle of my 20's, the best years of your life, there was no travelling to America, no travelling to Australia for a year, no…, holidays were pretty much impossible.

38:07 And then I went on the waiting list, there was a sense of hope again that you know I could get a transplant but the number s of people on the waiting list had increased you know 3 fold since I'd lost the transplant. And I was spending all my time, every 2 days on dialysis and you know I had changed my mind that I was kind of very positive, that was life, that was normal you know, if ever I get a transplant it will become extraordinary but at the time that was the way it was so I have to just deal with it which I did but I never expected another 5 years after going on the list before I'd get a transplant you know. That was obviously, despair was just under the surface you know I was happy and outgoing and everything is great. Just underneath the surface was very difficult you know and I was constantly asking the Doctors you know, what is the story with the waiting list you know. You see, when you are on the list like that you see everyone else getting the transplant waiting list, all my friends from the transplant games, dialysis games were getting transplants and you are so happy for them but secretly you are thinking , when am I going to get this transplant?

39:10 I was going out with a girl for a long time at that stage over 3 years and she would have liked to have gotten married and you know, go down that road but I was refusing because I didn't want to wake up the morning after my wedding and go on dialysis you now. That's not the dream you know, oh lets go on a honeymoon, you can't go on a honeymoon anywhere exciting or abroad and if you do you have to go on dialysis every 2 days. So that's, that wasn't me. It was around that time, I was doing talks in schools, companies and all these places, talking the positive message of overcoming adversity so I thought I'd better walk my talk and practice what I preach. So eventually I did propose at a conference to my now wife and it was on I think the 9th January and coincidently exactly a month to the day I got the call for transplant. And I live the other end of the country from the hospital and on that day I was on my way to Dublin to get this engagement ring because I'd bought her a cheap one in Ebay for a tenner, so that wasn't acceptable for some reason.

40:07 So, I was halfway, I was exactly half way from the West coast of Ireland, to the East coast where the hospital is, and I got the call. So obviously that was amazing, I rang my fiancée, I said listen, want to kind of go ring shopping, she said oh great, what is it now? Where are you? You have to do this, you have to do that. And I went no, I'm going on holidays for 2 weeks to Beaumont and she went oh, good for…, what…? And it all came out and she was over the moon.

40:31 Went to Beaumont, I was very relaxed about the whole transplant operation. Got all the work up done but I was under no illusions, I still remembered all the pain that I'm going to go through for the first 5 days really, you know, 5 or 6 days after you know having a transplant. And the reality is that I'm going to go through pain and I'm going to have all the wires, the tubes, the catheters, it's not going to be much fun. But the Doctors, the Anaesthetists, they are all fantastic, they slowly talk you through it you know and I'd be listening and more conscious now you know. What can I do to help in any way and normally they say you do absolutely nothing, you just be yourself. We are going to look after everything you just concentrate on getting better.

41:17 Q: So at that point you… the transplant went well?

41:24 Q: What are you thoughts about the donors?

41:27 Obviously in Ireland where this, it's gift of life, the card, the donor card you know, people carry this gift of life card. So the person whose kidney I got was obviously carrying this donor card and their family made the decision that you know, the person is dying, there is nothing we can do, we would like to help other people. You know, we want to enhance someone else's life. It wasn't just me that got a transplant, the guy who got the other kidney right beside me, he baptised his first child a week before that he was 10 years on dialysis. You know, so we were 2, I would think very deserving people. I was 9 years after getting engaged, he was 10 or 11 years, just christened his first child. He was just so emotional, now I can really go home, I can walk, take my child for walks, we can go on holidays. It meant so much to him you know and his transplant was very difficult, afterwards he had a lot of blockages and that.

42:24 So, I was lying in the bed next to him and heard him in great distress because there was a blockage and they had to keep going up with catheters and stuff like that and I was in the bed next to him, thinking oh right, I'm next in line and if anything goes wrong they are going to be doing all these things to me. It was a very stressful place to be in a hospital beside another patient who is having a very difficult time. You know I don't, I didn't enjoy that part at all.

42:49 What is generally done in Ireland after you have had the transplant and after you see it is a success and it's going well, you write a letter to the donor family through the transplant coordinator. You send them the letter, they make sure you don't give any personal details, it's not done that way. And they forward the letter on to the donor family. Now that was an incredibly difficult letter for me to write you know. To show the gratitude that I had especially after 9 years on dialysis, especially after getting engaged you know, but refusing to get married because I wasn't going to get married on dialysis and what it meant to my whole family. What it meant to me, I could go off and have a career. It meant so many things to fit into a letter. You now so I spent a lot of time writing that letter and I put a lot into it, a lot of emotion you know. It was an emotional letter to write, very difficult and it's something I'm going to do probably every year because I think it's…, they should be reminded of what the sacrifice that they made, the difference it made to someone's life like me.

43:49 Q: How are you now?

43:50 It's been over 2 years since I had the transplant, life is great. I got married, the only hiccup I tell people is yes, I had to get married. I got married 5 months ago, in May 2013.

44:04 Q: You know we can't edit that out, don't you?

44:07 I always say that, she is well used to it. But May 2013 I got married. You know, we had a remarkable day, we went on a lovely honeymoon, we travelled. All the things I couldn't do or refused to do while on dialysis. You know, I have nieces and nephews, we go visiting them and I just throw them around the place. I do miss playing sport, I can't play any contact sport, even while on dialysis I used to play a bit of soccer with friends. Whereas now because the kidney is here in the front, if I got a wayward belt or something and I'm not just willing to take that chance. And so I'm concentrating on swimming and I play this handball, played in a ball alley like squash, that's very intense. I love golf and hopefully I will go on to represent Ireland again at the transplant games in Athletics.

44:54 Q: One of my friends is on the English women's handball team, so I know about hand ball.

44:59 Different handball…, it's with a bug ball you play, this is like in a ball alley like squash court and it is a small hard ball and…no pads

45:25 Q: Do you feel now that your life is limited in anyway by the transplant?

45:36 Some people believe that you know your life is limited by having a transplant, by having kidney failure. I certainly don't see it that way you know, as I've said before life on dialysis after 9 years…

45:48 Q: Sorry we can't do as you have said before because we might not have that…

45:56 Q: Tell me how are you? Is your life limited in anyway now?

45:59 My life isn't limited in anyway as opposed to how it was on dialysis. So 9 years on dialysis you know, was normal, that's the way life was. Now with the transplant is kind of extraordinary because there is nothing I can't do beyond the limits of my own imagination and physically I can't do certain sports which I would have done when I was young, I can't back to the way I was. Obviously I'm 15 years older now since I got kidney failure in college and I'm a totally different person mentally and physically, but there is no real restrictions. I have to take the tablets, which I do every day. I used to have a very strict diet you know, I don't have that anymore. And the result is I have put on 2 and a half stone since I had the transplant. So within about a year I put on 2 stone. So the steroids really helped me with that but it's not the steroids, it has been a strict diet for 9 years meant now I could go through all these cookbooks that I have and cook all this pork belly with extra crackling I want. And I do that, you know, I'm still indulging in all these food cravings that I had for years, because I can.

46:58 I'm not willing to give that up yet, I'm enjoying my food. I am taking sport a bit more seriously in that I see the benefits, health wise that sport has for me. So I've really been keen on swimming, I don't want to be lazy, I don't want to get overweight because realistically I have lost 1 kidney before it's possible that I'd lose a kidney again. Well obviously I will definitely lose a kidney again but hopefully in 15 years' time or more. It's going fantastically well at the moment, all the blood results are good, so as long as that keeps happening my outlook on life will be fantastic and there is no real limitations that I can't live with.

47:36 Q: And what do you tell other people about the mind-set, the experience of having a life changing health condition.

47:44 I like to go round to schools or clubs or organisations, I often get asked to go round to do talks. I guess it has turned into a motivational talk because I like to think of myself as being positive you know, I have overcome adversity and my adversity was kidney failure. Now for someone else it could be, they could be bullied or it could be bad at school or they might have their own physical limitations. So, to me it doesn't matter what your adversity is, the tricks are still the same you know, you have to get above your shoulders.

48:16 Right, so like for me it was reading, I read a great deal of books on positive thinking and I modelled myself on people who are positive you know, in that I don't hang around people who are negative. I don't have a TV in my house, which comes as a surprise to people. That was one of the things I really wanted to get rid of because when you are on dialysis or when you are sick or when you are feeling depressed, you can sit down in front of a television and you won't get up until it's time for bed. And you lose so much of your life that way and I realised that early luckily. I developed a huge love of books and luckily my wife feels the same way, we have laptops to go online, to check and things, if there is something you want to see, you see that specifically. So that's one of the things I would say to people, but so many is who you spend time with, you know. Where your thoughts go, where your energy flows, a lot of it is *mumbo jumbo* but it works.

49:08 Q: Terrific, Anything else you want to tell us about?

49:11 If is for Doctors and work people, the fistula you might need to see that…

50:09 What were the changes in you physically? In terms of dialysis, what did you experience?

50:18 When I started dialysis, you know I did think I had this sporty healthy body and that obviously was turned on its head by starting on this thing called dialysis. The first thing they needed was an access point so they've tried to put a line in my neck and after you are awake when they doing this and it's very uncomfortable but they couldn't get into the vein here. So they had to go to my groin which was obviously for a young guy who didn't like anyone near him really, that was very, very uncomfortable and I had to every time for the first few weeks

I had dialysis, they had to do it , through my groin which was difficult because it just a sensitive area anyways. And then they out in what's called a…., another type of line in my chest here and that worked fantastically. But all these lines enter into your body and there is a point there where infection can get in, so they are not the best form of treatment.

51:10 And that is when they decided to do what's called a fistula. Now I had no idea what a fistula was, again it was another operation, so what they actually do is they join your artery and your vein in your hand and the result, 15 years later is my fistula here in my arm. So I have a huge swollen vein essentially is what it is and there is needle marks all the way along from all the needling that was done. So what happen was, that an operation here where they joined, they crossed the artery and the vein. Over a few months, the vein started to get bigger and then they can start putting in these large needles so that a lot of blood can come out through the machine, where it is filtered, cleaned, drained and back in through the other needle and that is the process of dialysis.

51:54 Now I had done in England in the Lister, 15 years ago so it is, it looks unsightly. Obviously, psychologically it wasn't a nice thing, I never wore T-shirts because people will go *'oh my god, what wrong with his arm? you know, he must be into drugs or something'*. So it took a while for me to get comfortable with that. Now I don't really mind, I show it off, I don't care and you know it's a very important part of my life, it really, it was my life saver. It kept me alive. The needles obviously were very big, it was difficult in the morning, every 2 days in the hospital where they had to put in these big needles. Even when you went on holidays, sometimes I did go on holidays, had to be done in the exact same way, same place every time so it's a different part of kidney failure, dialysis, all the tubes, the little procedures that you have done, this is the most visible one, since, well before the transplant anyways. So I have a nice big scar from where the transplant was also done, it was about 26 staples or something like that, the wound was that large so that's out of range.

52:58 Q: Ok, could you also once again show me, explain where the vein come through…, your finger and I'm going to zoom right in on the arm..

53:43 So the fistula, everyone is kind of curious that does not know about these things, is that how is that a real vein or a tube or what is it? So what actually happened was I had to have an operation here and they crossed the artery and the vein. Now the pressure from the artery, gone into the vein, the vein is meant to bring back blood to the heart nice and slowly. It made the pressure from the artery into the vein, it made it grow larger because it is not designed to take pressure it did grow larger.

54:10 So at that stage when it got big enough, then they could put in larger needles and the blood would come out into the machine where it's filtered and cleaned and drained and it would go back in another needle. And the benefit of this rather than having a tube in my chest was that there was no risk of infection. When the needle came out, I had to hold on for about 10 minutes and a natural scab would form, therefore it would be my own body which was covering up the wound. So there was no risk of infection really, I've been very lucky obviously, it's very big and very unsightly but it did a fantastic job and you know, I wouldn't wear T-shirts too often or short sleeve shirts because it's not a thing you like, people would be curious what that is and they won't be too afraid to ask so and a very important piece of equipment for me anyway in my life.

55:42 So essentially this is where they did the operation and then the fistula, the vein grows longer all the way up to the arm and you can see all the needle marks from where they actually did the dialysis.

56:13 Q: Go right back to the beginning, tell me about when you were in college and you first realised that you were sick the first time? And what that experience was like?

56:35 I was studying sports, fitness studies in college, so the last thing on my mind was sickness, health or anything like that. I was running, I was training, I was fit but I was getting these awful headaches and my vision started to blur, I get these shadows over my eyes which were very, very bad. I had trouble reading, I had trouble catching a football one day and I missed it and it hit me on the head and everybody laughed and it was the embarrassment that made me go to the hospital the first time.

57:33 Q: Tell me about your mothers or your family's response when they heard? You said your mother came straight over to be with you, so go from.. your mother coming over to be with you…so when they first found out.

57:55 I was sitting in the hospital at that stage, my blood pressure was, just after being realised, it was very high. I was at danger of having a stroke, the Doctor asked me, are your parents on the way? And I went no, I told them that everything was fine and they said we need your parents here, immediately you are at a serious risk of having a stroke, she actually told me that. So that was, I thought she was joking, because I didn't feel too bad, so they had to ring my mother, they had to bring a phone into the room for me. They wouldn't let me walk across and there was no mobile phones and I had to tell my mother to come back to England straight away, there is a serious problem. They don't know what it is but my blood pressure has gone very, very high we need you here immediately. So she had to rush in to, there was no rushing to the website to get an airline, you had to go into the travel agent, get the quickest flight, get Stirling and get to England immediately. So very difficult emotional time for them, because they were in the dark totally, their only son was in hospital in England and he could be dying and they had no way to could get their quickly so that was very difficult for my mother. When she arrived she was a great help to me and we pretty much went through it together. She probably suffered more than I did because I had a sense of disbelief that this is not really happening, whereas she was talking to the Doctors, knew it really was.

59:22 Q: Tell me a little bit about the operation, how you found out…

59:38 It was 7 O'clock in the morning, the phone rang and said this is he transplant coordinator, we think we have got a good kidney for you. I said hold on, I was sleepy and I was getting up to go to the bathroom, so my father was nearby and I just gave him the phone. It meant so little to me, I was in a different place. And I went to the bathroom because I was still going to the toilet then at the first time and my father took the call and you know. It's the transplant coordinator, they said to get to Dublin quick. You know, I was very relaxed, I went in and had a shower, I ironed a pair of jeans to wear up, I don't know why because I wasn't going to be wearing them for 2 weeks and we rushed to Dublin as quick as we could. We had a guarded escort which was a great experience for me because they just flew all the way through Dublin, through heavy traffic. So it was an exciting experience and because of my first transplant I had no idea what was going to happen. I had no idea the day after the transplant what it would be like, as in catheters, lines you know, drugs, tablets, you know. There is so many things that I had no idea what was coming up. I hadn't looked into the transplant too much because that was just the way I was, I left it in the hands of those who know better.

1:00:50 Q: You have just said '*I was still going to the toilet at the* time', do you know longer go to the toilet?

1:00:54 When on dialysis, after losing the second kidney there was no urine output for 9 years.

1:01:01 Q: Tell me about that…

1:01:31 Q: So, you got the call at 7 O'clock in the morning …

1:01:36 I got a call at 7 O'clock in the morning, I was, normally when I woke up you know I was going to the bathroom then. I had to go to the bathroom, the phone came, I said hello, this is transplant coordinator, I said hold on a minute and I just handed the phone to my father who was close by and I went to the toilet. And he came rushing in, it's the transplant you know, we are ready to go, they want you up there immediately. I said O.K. and I went and had a shower and I ironed a pair of jeans which was silly because, it would be 2 weeks before I get to wear them really. And I packed up my few things and we rushed to Dublin, we had a guard, an escort right through Dublin city which was an amazing thing to see. So I was all very excited about it, it was a very exciting time. Not knowing because I hadn't went through the transplant before, not knowing the pain and suffering of the first few days, of any operation but especially for a transplant. So there was a catheter, there was the lines, there was the drugs, you know, it was very difficult few days but it was all for a good end.

1:02:44 So when I went into the hospital, they checked my blood pressure, they realised that it was sky high, it was dangerously high you know. I was at danger of having a stroke that is the way they said it to me, they actually said you know you could have a stroke at any minute. Which wasn't very useful to me because it only made me probably more stressful at the time, I was only 21 years old, 20 years old. So they said is your parents on the way over? Where are they? Will they be here soon? And I said, no, because I had rang them to say that I was going to the hospital, it was no big deal, there was just something wrong with my eyes. So they had to be rang and there was no mobile phones. So a land line had to be wheeled in to me because I wasn't allowed out of bed. I rang my mother and said listen, there seems to be a problem here, my blood pressure is very high you know, I was trying to play it down but she told me afterwards, they rang her, they were talking to her and they said you know he is at serious risk of having a stroke. We are moving him by ambulance to the Lister hospital, a specialist hospital, we need you to get here immediately.

1:03:39 So in the days without, before Ryanair and online and all this kind of thing. She had to go into a travel agent to get Stirling, get the quickest flight, drive to Dublin, very stressful time for my mother. For me, I was lying in bed thinking they have made a big mistake here you know, she shouldn't bother rushing but she knew, she was talking to the Doctors, they knew that there was something very wrong. And she was listening to this all the time and I wasn't. I was probably, I wasn't believing it, I was just, disbelief, it couldn't be happening to me. I'm a sports and fitness study student, you now I can't be getting sick.

1:04:21 Q: A short version of what were the physical effects of dialysis on your system, on your life?

1:04:28 When I got the second kidney transplant, it was one of the biggest thing about it was, will my bladder work? Will my urethra work? Will I go to the toilet? Because the previous 9 years, I had no urine output, maybe a dribble, a few drops which meant I didn't go to the toilet in 9 years. So, all of a sudden I was supposed to be going as normal after a kidney transplant. Now that was a thing my friends found fascinating you know, I could still go to the pub and drink but I had a fuel restriction and I could drink very little, so I would have to drink shots you know and everybody would be taking their turn going to the toilet but I would never be. That was the funny side of things.

1:05:06 My father said to me once, he said you shouldn't be going out drinking , you are only peeing it down the drain, well no, you are not peeing obviously, but do you know what I mean, you know. He used to get caught up, you know, at least we have our health he would say but you don't have yours, but you know, you are O.K., so we used to have funny stories like that. But going to the toilet was a new experience for me, obviously there was a catheter at the beginning and after 4 days that came out and I had to go to the toilet every hour because my bladder is a muscle and it had shrunk down to a very small amount, so I had to go to the toilet almost every hour because I had to drink so much after the transplant.

1:05:42 Again people don't realise this was an enormous thing for me to have to stand up and urinate you know, it was just something I hadn't done for 9 years. So it was one of the interesting things, you know dialysis for me was no bathroom, no toilet, I didn't urinate. And then the transplant, after the transplant, I had to go every hour initially, then 2 hours, now it's, depending on how much I drink, it's every 3 or 4 hours. It is almost normal but not quite, but it's not a problem you know, it is a bigger problem not going.

1:06:16 Q: What about thirst, because that is often an issue…

1:06:20 Well, I can talk a little bit about that. I had… you see I used to go for sauna every day which meant, I could drink more and stuff..

1:06:36 Q: So, yes, tell me about thirst.

1:06:38 On dialysis, I had a very limited fuel allowance, so I couldn't drink whatever I wanted. I had to drink, it was 500 mls plus whatever I passed in urine, I didn't really pass anything so I was only supposed to drink half a litre a day and that's including your cereal, you know water that would be absorbed in cooking. So I, because I was a sport student and I worked a bit in leisure centres, I used to go for a sauna. So that's was one of my little tricks, I would go for sauna every day which meant I could drink an awful lot more, which made me feel normal. I would be sweating it out through a sauna. Now that is not advise I had ever got from a nurse or a doctor and kind of go, I don't know about that because there is no research to say that it is good or bad. But for me, I look to myself as the healthiest dialysis patient in Ireland, in Europe maybe.

1:07:26 When I went to the transplant games, I won the 100 meters, so I jokingly refer to myself as the fastest sick person in Europe you know, so I had a light hearted look at how it was. So that was one of my tricks, going for a sauna. I also did a good bit of sport, the more sport, I reckoned this in my head, the more sports you do the more muscle you have. I had no fat, I was very thin, it was only muscle and muscle in my opinion helped raised my metabolism through doing sport, which burnt off more fluid and more toxin, it created toxin but it also burnt off more the extra maybe potassium or phosphate, that was my thinking. And as a result every month when I gave blood, my results always came back good.

1:08:08 So exercise, the sauna for me was fantastic, it meant that I could drink a lot more. And there was days were I would be sucking ice cubes that was the trick that most people used, you know put a lollipop in an ice cube and just suck an ice cube. It quenches the thirst, there is not much satisfaction in it but you know you had to do something, you know when you couldn't drink what you wanted and you were thirsty. I'd often maybe have a can of coke, take 3 or 4 mouthfuls just to get the *' ah that was lovely'* and then forget about it. Were, since I had the transplant I never drink fizzy drinks because I can drink all the water I want. But if you have a limited allowance and you have a glass of water, there is no real satisfaction in it where coke or Lucozade or some other drink would kind of give you a sense of satisfaction that you drink something but you know, those are all little tricks.

1:09:00 I couldn't drink beer, wine or cider or these kinds of drinks because of the fluid. So a pint of Guinness like we have in Ireland would be the same as a pint of water, except if you had a few pints of Guinness, the next day on dialysis you would be seriously overloaded; 3 , 4, 5 kilos and you would be dehydrated at the same time. So, I was told a hangover on dialysis is 7 times worse than a normal hang over and I can agree with that totally. Because it is, going out drinking, I was in my 20's you have to remember and I was still a young person, I still wanted to go out and have fun with friends so I did drink you know, usually on a Friday night because I would be on a dialysis Saturday morning and it would be an instant hang over cure would be the 4 hours on dialysis, but getting to dialysis was, I felt atrocious . I might be throwing up, I would be 3.5, 4 kilos of fluid overweight and that is a lot to take off in a few hours. So they, I had to put up with some very ill health, self-inflicted, because I, when you weigh it up, I was a young person and I had a life to live too. So that was all of my balance, living as normal life as possible but at the same time adhering to the protocols of health.

1:11:30 Q: How did it affect your relationships?

1:11:31 As a young person obviously I had girlfriends, I have my moments where I'm charming I guess and they were always kind of short lived and it was mainly due to me because I was on dialysis. I couldn't see a normal future. Just like I couldn't see a normal long term job, I couldn't see a normal long term relationship you know, I found that difficult. So, we would be in a very close relationship, we would be madly in love, slowly, I would I guess self-destruct, would kick in and say they can't be interested in me you know. I'm on dialysis you know and I will have to get a transplant and this and you know this isn't going to work. Slowly, I would be the one to separate and to break away, so that happened a few times with a few different girls who I was very close to, very attached to but just couldn't see it working because of my situation, not theirs.

1:12:27 It was a very difficult thing to get across and it was difficult for me too because I would have been very happy at certain times but just you know, oh why don't we go on holiday somewhere exciting and I would be going, maybe, I couldn't really go and if I did go, I wouldn't enjoy it. A sun holiday on dialysis when you can't drink what you want as in water is not much fun. And I have been to places where I have had allergic reactions to dialysis and that has been very difficult because they just use maybe a slightly different cleaning agent in their dialysis lines and I would go into kind of anaphylactic shock, you know my throat would close up, my nose would block and they couldn't speak English, the person I was with. It was in a French hospital, this particular time. They couldn't speak English, they were running off to get a Doctor and there was I, getting worse and worse you know very frightened, it kind of put me off traveling too much. So they are some of the difficulties, with relationships and travelling I guess.