

Interview with Christopher Downs (Cystic Fibrosis – 28 years)

Interviewer: Tell me how old you are and who you live with.

Christopher: Right, I'm 28. My name's Chris Downs - I'm 28 and I live with my parents at the moment and probably for the foreseeable future, but I started living with them again three years ago, just before I got ill. I have had a period of ill health related to my CF.

Interviewer: Well let's start right at the beginning then. When were you diagnosed with CF?

Christopher: That was at six weeks, so I can't remember, I was a baby. I was diagnosed by chance more than anything. The doctor had seen it before and told my mum to get a sweat test on me and I was diagnosed but before that I was having problems digesting what I was given. I was on breast milk which has a high fat content and that was just going straight through my digestive system and that was leaving me as a baby crying all the time, gradually – well slowly dying basically. I was anaemic. I had had I think a pint of blood transfusion so things weren't looking well until they had diagnosed the CF. It was a bit of a shock to my mum finding out, well not a bit of a shock – a lot of a shock and to my mum and my dad.

Interviewer: And how did they cope when you were a baby?

Christopher: They coped as best they could but that doesn't mean that they were very comfortable about it, and I remember as a child feeling a bit kind of like I was causing trouble, like a burden in a way because they were always like worrying, you could always pick it up when I was a kid that they were worrying about this, that, or me taking my drugs, my medication and when I didn't take it they'd panic a little and I'd pick that up as well because they got cross and I could tell I wasn't the same as other kids or my sister. I have a sister, who doesn't have CF and who lives in York now, and there's problems with her as well because she thought I was getting too much attention – all this attention that I didn't want. I wouldn't say it was a bad childhood, but there was an atmosphere I think, a little bit of an atmosphere and only when I started to realise what I had to contend with and kind of take responsibility for myself that things have improved, I think. But I think it was a lot for my parents to deal with because originally they were told I would live till I was seven, then it was twelve, then it was twenty five, then it was thirty five and now people are talking about fifty, maybe sixty, so ... because the improvements of the drugs have meant that the life expectancy gets longer for most

people with CF. And CF has various degrees of severity and I have always been classed as mild to moderate but I think it may have changed since then because in the last two years I've had some quite ... a bad run of health. I think during my childhood I could do most things anybody else could do, I wasn't that physically impaired but I think maybe I was a bit too wrapped in cotton wool when I was a kid maybe, well, a lot of people were concerned with me and told me how well I was doing, impressed with how well I was and stuff so I could always feel I wasn't allowed near bonfires or in dusty places, things like that which always felt a bit ... I wish I could have done more.

Interviewer: What sort of treatment did you have to have as a child?

Christopher: I had a physiotherapist come round every week just to reassure me and show me how to do physio and show mum how to do it as well and make sure we were doing it right every week until I was sixteen I think and that was mostly percussion on the chest which was kind of hand claps on the chest. It looks on videos and stuff like it's abuse but it's actually to loosen up the phlegm on the chest and bring it up more effectively. But now I'm taught ... being taught postural drainage and active cycle breathing which means that no hand claps are needed and it just uses gravity and breathing techniques to break it up naturally without hand clapping. Some people do use hand clapping though.

Interviewer: So did your parents have to do that every day?

Christopher: My mum did, yes my mum was my primary carer I would say. She was the one that did the most worrying I think. But my dad took it badly as well. I think he struggled a little bit with her as well but he was more distant, so my dad and my sister were more on the outskirts of it and my mum was more involved. I think both my dad and my sister felt a little bit left out because my mum was kind of taking over.

Interviewer: How old were you when you could start and deal with it yourself? Or do you still have to have someone to do things?

Christopher: It must have been quite early. I think it was when I was about twelve, I remember being at school, junior school, when I was having it done.

Interviewer: Is it done every day?

Christopher: Yes, twice a day, yes. Morning and night time as well.

Interviewer: So your mother couldn't go to work?

Christopher: I suppose that's right yes. Yes she re-trained as a teacher when I was twelve, yes that must have been it. She's now a nursery school teacher, but I think it's very possible that she stayed in because of me. Very possible. I haven't been told that, but I think so.

Interviewer: So how did you get on at school? Did you go to a normal school?

Christopher: Yes. I just went to the comprehensive along the road. I've been to a normal nursery, normal infants school, junior school, normal comprehensive, then I went to sixth form college, then I went to University for five years doing one degree and two masters degrees.

Interviewer: You've done well then.

Christopher: Yes, I got a bit carried away I think.

Interviewer: Did you have to have your physiotherapy every day at school as well?

Christopher: Yes, I had that in the morning before I went to school and after, after school, tea time or at night time. It was just like brushing my teeth or something, it still sort of is, but it just takes a bit longer now.

Interviewer: How long does it take?

Christopher: In those days it took like 20 minutes / half an hour, but these days it takes half an hour to an hour and I think, it depends what sort of technique. If I'm watching something good on telly, I watch telly as I do my physio, it depends how long it takes, but equally if I've got a chest infection and I'm producing a lot of phlegm I generally cough up enough to make me feel comfortable which can take up to an hour depending on how productive it is, the cough.

Interviewer: Did you have any problems socially at school?

Christopher: I was bullied in the comprehensive school when I was in my first and second years because I was given preferential treatment in P.E. (physical education) and I think that marked me out as different which ... I was also physically smaller and less developed, I was very thin when I was that age. I looked much more ill than I do now. But I was actually healthier, I don't know how that worked, but I think my metabolism was faster because I was younger. People say I have a fast metabolism. So it was quite a tough time that but I think in the

long term it helped because it made me think about things and stuff and by the second year at school they had moved me to a different class that helped a lot and things picked up from there. I have always been a bit shy, I think that's possibly because of earlier experiences, feeling different to other kids and stuff.

Interviewer: Did you have good friends?

Christopher: Some people were very good friends, very understanding and very compassionate, surprisingly compassionate, I mean for people of 12, boys of 12, but a lot of people were sort of friendly. I think it's just if you're marked out as different in any way you kind of get marginalized a bit. But some people, I have to stress, that some people have been marvellous, didn't mind that I was ill. Some people actually respect me for it, one guy wrote an essay on me, as the person they most respected, which is a bit bizarre, but ... I think he got a good grade for that. But, yes, I mean, I can't say everybody was nice to me. The people that were nice to me really stuck in my memory and really made a difference to me, kind of inspired me to get along. It's the few people who really stick their necks out for me when I need help that have inspired me to become the person I am really, do the degrees, and get through the tough times and get a decent job and a career and all that stuff. So some made me a better person, definitely.

Interviewer: Was your puberty delayed at all?

Christopher: Not noticeably. Obviously I'm the same height as everybody else and stuff, maybe, yes maybe sexual maturity, I believe that was a bit delayed. My voice broke when I was 18 or something, so, but size wise I was the same as everybody else, but yes, I think other aspects were delayed.

Interviewer: How did you manage at university?

Christopher: I started out at Coventry University doing Information Design, like designing leaflets and stuff but unfortunately I got pneumonia during that year so I had to transfer to Newcastle University to do English instead which was a move up in the University world anyway so that was a good move to make. I came back after the bout of pneumonia but my heart wasn't in it really, I got quite depressed and dispirited about it because it was my first time away from home and I felt like I had failed, and it was just through stubbornness I managed to get to Newcastle by harassing various universities close to my home with letters saying I'd got CF and this is some stuff I've done. And Newcastle University was the most attractive offer I got and it was right next to the RVI Chest Clinic, CF clinic which

was a specialist clinic for people with CF. I enjoyed it more because my parents were closer to home and I liked the course better as well to be honest with you.

Interviewer: And did having CF affect the rest of your university life?

Christopher: I worked on a student newspaper there and did quite well on that. I got promoted to music editor so I had all the free CD's – made me very popular. And yes I got a lot out of it, but if I hadn't had CF maybe I would have got a better grade, I have to say that, but I was always quite lazy naturally anyway so you can't really say that, but generally my health was good after the pneumonia and in three years I only had kind of routine IV Antibiotics was the worst I had which is a drip with antibiotics in that feeds into the blood stream and I was getting those ones every two years which is pretty good actually, I get them every three months now. But I finished that course and got my Bachelor of Arts in English Literature. From there I went to Sterling University to do publishing studies and that was much better.

Interviewer: Did it affect your social life?

Christopher: At Newcastle University a lot of people had difficulty accepting the CF thing so much so that I kind of hid the fact that I had CF even, that sounds strange now because I couldn't exactly do that now, but only people that lived with me or ... I felt were able to cope with it, because people tended to just treat me differently because I was ill and ask me daft questions and stuff. And like I said before, at school only a very few people were like ... saw it as a positive thing and I really admire them for that but ... I had problems with girlfriends and stuff if I told them, I'd get rejected, that's what it felt like at the time, it happened about three times that, I think that possibly affected my ability to have relationships in the long term. Not too badly. I think I'm okay now, but yes I had problems especially at first, and when I was at Stirling things were better because it was mostly mature students and they were more accepting. They really admired me for it rather than backed away. I didn't really realise that what I had was a positive thing in some ways, people respect the fact that I deal with this and that was the first time I realised that ... it became a positive thing in Sterling. I really liked that. When I was at Sterling I was doing Publishing Studies.

Interviewer: Has it stopped you getting the sort of job you wanted?

I wanted to go in to the publishing industry and make books basically, educational books, I wasn't sure what I was up to but I had a talent for creating print things and computers and stuff

and I wanted to do that for a living but unfortunately it would have meant having to go to London where the publishing industry is mainly based and my health wasn't up to it then and it certainly isn't up to it now. So I had to give up that idea and then as my specialism in research I chose internet electronic publishing which led to the internet which led to me applying for a scholarship to Teeside University to do a Masters in Master of Science and Multimedia Applications which is how to make websites and CD Roms .

I just got a bowel obstruction when I was there which is quite painful but I managed to keep on the course and get a really good grade, I got 67% which is top 5 I think, top 5% and that led to me being recruited by the BBC eventually, I applied for a job with the BBC and thanks to their equal opportunities policy I was able to not be judged on the CF rather than my achievements and that got me the job and that was a real, that was a big turning point as well, as I never expected to get a career deep down and yes they were wonderful to me.

The job's stressful but as regards like me having CF you know they really treated me well and unfortunately after 10 months I got a cold virus or a flu type virus which led to a collapse of my immune system which was the beginning of my bad health and I nearly got ventilators which is where they put a tube down ... kind of knock you out and put a tube down you to ease your breathing and luckily I just managed to wipe that but it was quite serious for a while. Everybody was a bit scared.

Everybody around me was panicking a bit and I slowly got back to my feet on that and the BBC supported me 100 % and eventually arranged homeworking equipment so I could work from home and after that I got another bowel obstruction possibly related to the fact that I was down so in total I was off work for nearly two years and I started working part-time again from home about three months ago.

It's been a long attempt to recovery but the signs are good and I've improved a lot thanks to DNAs which I've started two months ago which stems the mucus in the lungs and has proved quite effective with me so it gives a lot of hope for the future.

So I hope things will pick up and this has only been a minor bad spell for two years, but things will get better now and be back to being more consistent but I've learnt a lot over the last two years, I've learned to appreciate what I've got and I think I'm a lot happier than most office workers to be honest and I'm more happy than I was when I was an office worker because I didn't like the 9 to 5 lifestyle and the commuting. I can say thanks to the support I've had from the employers I think I'm going to lead a pretty good career, nothing special, nothing spectacular, but content, definitely content. That's what I'm aiming to do.

Interviewer: What about your social life now?

Christopher: I have to say I don't really fit in a social life as such. I did when I was healthier but I can't really stand smoky pubs now really and I don't really want to because I don't want to make my health any worse and I do have friends come to visit occasionally to the house and stuff but I have to say, I mean, I just don't have the energy to go out for that kind of social life. I spend some time on the internet and talk to people on the internet which is a good substitute actually. Much cheaper as well, saved a lot of money and I don't miss it to be honest. I used to drink quite a lot and having kind of like being forced not to has been a good move for me, it's made me happier in myself, richer, much richer and I can't say that disturbs me at all, I'm quite happy about that. I'm quite happy within myself.

Interviewer: Do you think about your future? Do you think about marrying?

Christopher: I did used to think that but I mean you see a lot of people especially from my point of view, men with CF that marries a girl not with CF, just obviously normal, you know kind of healthy girls who have fallen for men who have CF and I find that really touching. And I think, yes, I think in the future I wouldn't rule it out at all. You just have to kind of adapt to being someone with CF who can live a normal life, and I don't think there's any reason why someone with CF can't live a normal life, it's just they have to live it differently that's all. Compromise a little bit. But I've met some girls since I've been ill, friendships, but I mean if I ever met a girl I really liked and clicked with I would have no worries at all in trying to take it as far as I could, and if that involves marriage and children then so be it, I would be happy to try that.

Interviewer: Would you be able to have children?

Christopher: I don't know actually, it's 95% chance I can't but I don't know what it is. I guess you can find a way if you really want to but I'm not desperate for children, you know it's just like if I find myself in that position I wouldn't let CF stop me getting, you know try my best to get into that situation because I wouldn't want to deny anybody anything because of CF.

Interviewer: How do you get on with your parents now you're living with them again?

Christopher: I left home and I came back briefly after the pneumonia but since then I'd always gone back for weekends or for holidays only so it created a bit more distance between me and my parents which I kind of appreciate because CF had affected our relationship for better or worse really. But since I came

back home after university and since I got ill especially things have changed round completely. I'm very close to my parents now and I feel like I've got the ideal relationship I always wanted when I was a kid. Ironically when I got more ill, maybe because I was quite healthy I wanted to cover up the fact I was ill, but now it's more visible, more obvious I'm quite proud of being ill for coping the way that I do and taking responsibility for it myself and because me and my parents have got through some tough times over the last two years I feel closer to them now than I ever have which is nice, really nice.

Interviewer: You've said a lot about the positive aspects. What would you say is the worst thing about it?

Christopher: The worst thing is all the pain you have to go through, not just physical pain, I mean like mental pain. Like the feeling of not being able to cope is the worst feeling and once you go through it a few times you do learn to cope which is a gift in a way - but just the feeling of not being able to live a normal life whatever a normal life is. You do get depressed sometimes but the trick is to keep going and cope with it and eventually with the right frame of mind and the right determination I think you can make a good go of it but ... it's not all bad.

Interviewer: What would you say to somebody who thought they were going to have a Cystic Fibrosis child and was trying to make a decision?

Christopher: Right. That's a difficult decision to make and to be honest I would have to look at my situation if I knew I'd have a CF child after having lived through it. But I think a CF child has the potential to achieve a lot in its life despite some fairly severe odds. I think people with CF are extraordinary. I haven't met one that I've not liked, because they've had to go through such a lot and they've learned to smile through it and put a brave face on it and inspire people around them. People admired me just for being ill, I've inspired them just by living my day to day life. There are more and more people get inspired as I get older. I think the point is that people are more capable of taking it in now. I think that, yes, I'd look things up and be prepared for a few frights along the way but I think it would make the child and maybe people around him more compassionate and more, I don't know, more inspired maybe, than other people, because my sister works really hard and I think some of that's because of me. She appreciates the chances she has in life because she saw me struggle when I was younger and, yes, I think it's a difficult situation – I think deep down a parent would know if they can look after a child who will struggle a bit, I think deep down they will know and the decision's up to them. I wouldn't say definitely keep it or

definitely get rid of it because if a marriage is shaky to begin with or they've got money problems a child with CF could possibly make those problems much worse, you know families do break up, and any extra pressure. I think having a child with CF does give you extra pressure, it also gives you more rewards as well. I've learnt that over the years. But really I'm not going to condone either way. I can't say it's good, bad to abort.