Season 2, episode 6: Navigating grief and CF carrier testing with James Dunmore

Lucy (host): Hello and welcome to season two of CForYourself, a podcast brought to you by UK charity Cystic Fibrosis Trust. I'm your host, Lucy Baxter, and I myself have cystic fibrosis. I'm one of over 10,900 people in the UK living with the cystic fibrosis.

Now, CF is a genetic disease that causes a build-up of sticky mucus in the lungs. So that means I can experience a range of different symptoms, like struggling to put on weight, feeling breathless and being tired. I was diagnosed with CF at two years old, but CF is part of my life, not my whole life. And it definitely doesn't define who I am.

In each episode of CForYourself, I'll be having a virtual chat with others in the CF community. We'll be talking openly and honestly about a whole range of topics from the latest research, employment and growing older to interior design and appearing on reality TV. We'll also hear from CF experts who will be sharing their knowledge and advice for everyone affected by CF.

CForYourself is all about sharing honest insights into life with cystic fibrosis, the good, the bad an absolutely everything in between.

I'll be sharing some of my own experiences too, but my views are all my own, and not necessarily that of the Cystic Fibrosis Trust.

If you'd like to get in touch to share your thoughts on the podcast, we'd absolutely love to hear from you. So please email us at podcast@cysticfibrosis.org.uk.

In this episode we talk about some topics that you could find triggering. So if you'd like to speak to someone, the Trust has a helpline and you can call or email to chat to one of the team. They can provide information or support with any aspect of cystic fibrosis, offer a listening ear, or just be there to talk things through.

You can call them on 0300 373 1000 or email helpline@cysticfibrosis.org.uk.

Welcome to episode six, season two of CForYourself. Today I'm going to be catching up with Cystic Fibrosis Trust Ambassador and former star of Made in Chelsea James Dunmore, who sadly lost both of his sisters, Lucinda, age 19, and Jodie, aged 22 to CF when he was a younger boy.

James has raised thousands of pounds for the Cystic Fibrosis Trust by climbing Mount Kilimanjaro, and he also supported our campaign calling for access to life saving drugs, Orkambi and Symkevi, on the NHS.

I'm looking forward to chatting with James today to hear more about his work with the Trust, his wonderful sister's, coping with grief and his experience of going through the process of carrier testing to find out if he is a carrier of a faulty CF gene.

Now people, born with CF have two copies of the faulty gene that causes CF. Carriers don't have CF, but they carry one copy of the gene. Around one in 25 People in the UK are carriers of this faulty gene, which is around 4% of the population. Relatives of someone with CF have a higher chance of being carriers.

On the podcast will also be hearing from Becky Kilgariff, joint head of Information Support and Programs at the Trust to find out more about what carrier testing screening is and how it works, what it means to be a carrier, who can have carrier testing and where you can go for testing and further information. Now, without further ado, let's welcome James to the podcast.

Hi, James. Welcome to CForYourself. How are you doing today?

James Dunmore: Hello, I am fantastic, thank you very much. How are you?

Lucy: Good, thank you. So for those that don't know you, tell me a little bit about why people know who you are.

James: Well, I mean, I was living a very what I thought normal life, I suppose, went to school, went to university.

And thought I needed to branch out, so I moved to London. And then I had a few friends who, friends who I met in London, who were on Made in Chelsea at the time. And then I ended up going for audition for that. And then the next thing I knew, I had a camera shoved in my face. All very strange.

Lucy: That kind of gave you the platform, which we'll go on to talk about a bit later of being able to kind of talk about CF and be an ambassador for the Trust in that way.

Your two sisters had cystic fibrosis. Tell me a little bit about what childhood was like growing up with CF in the family, but of course two people with CF in the same family.

James: Whenever I got asked, my answer, I always feel like my answers not very good. Life, obviously, I don't know any different. I was born into my sister's having CF. Our life was as normal as possible.

There were times when I could have probably wrapped my sisters in cotton wool and not let them do these sort of things, but they very much wanted my sisters to live life to the max and have a very normal family environment as much as possible. So as as weird as it sounds, the whole hospital trips and me going and picked up in school and then going to visit my sister in hospital, and stuff was what I was obviously I knew other people didn't do it, but that was just kind of normal for me.

It's only probably now when I step back and think about it, I think actually it's really not that normal, is it, to finish school and then go visit sister in hospital for two weeks or something. But at the time that's all I kind of knew.

And then obviously I was exposed to everything that cystic fibrosis kind of brings. So the physio bed, the old upside down physio bed that I'm sure you know of. And hearing my mum give my sister's physio and flutters and nebulizers in the morning and pills, all these sort of things but yeah, I think it's as I said it's, that's kind of the only life that I did know.

Lucy: A lot of the podcasts we've chatted previously are all about kind of that experience for the person with CF. But there's a lot of the for the family, such as like you go in to visit them after after school and that being your norm and you having the resilience and the strength to cope with that at such a young age that, that, you know, people in your class wouldn't know how to manage or deal with.

But there's also that kind of aspect of of family that even though the people with CF are going through it very much, the family family are going through that, too. And your your sister's sadly passed away from from the condition. How did you cope with that?

James: I was 16 years old when my first sister, Lucinda, passed away. So I'm the youngest of the three of us. She was two years older than me. My older sister was four years older than me, so I was 16 when Lucinda, what I thought was just going in for a normal hospital trip.

I think she used to she used to go in probably once every six months for a couple of weeks and have IVs and sort of intensive physio and then come out and be like, 'Oh, I feel so much better. My lungs are clear.' So I just presumed it was sort of one of those well it was one of those trips.

But she actually got influenza A so I guess the drugs weren't really making an impact or weren't really good at attacking the infection on her lungs, but it was still one of these things we didn't really think too much about it. It was still quite a normal circumstance. And then I guess I think the time I kind of knew it was I don't it's hard cause I don't know how much my parents were kind of sheltering, not telling me because obviously I was 16.

I don't know whether my parents knew it was probably worse than it was at that moment or not, but I think I was at school, it was a Saturday morning. Yes, I had Saturday school bad times. And the teacher got a call and it was only that, that was the first time I actually thought, this is bad if I'm getting called.

So she sadly passed away then. So she was 18. I was 16. Two years later, my eldest sister Jody, and they were born 18 months apart and they sadly passed away 18 months apart. She sadly passed away 18 months after. I think it was, life for her was quite tough after, she always saw it that she probably should have died first because she was older.

She kind of felt like, why? Why? She's younger and it just shouldn't be like that. And I think after Lucinda passed away, my older sister then kind of life of kind of hit her quite hard and made it quite realistic that she could die so easily and so quickly because my sister was fine sort of three weeks before and then all of a sudden wasn't there.

So I think that was a big eye opener for her, and I don't think she was ever quite the same. I think she always had a bit of fear after that.

mini interlude with slurping sounds, and a spoon stirring against a mug

Lucy: For yourself like why did you want to do so much about awareness of CF and and kind of really talk about it, you know, because some people might like, it might be too difficult or just might not want to open that box.

James: It was definitely tough. I would say the first, I don't know, five, six years I was potentially just in a healing phase. It was kind of like we'd had cystic fibrosis in our life. And and then both my sister's passed away reasonably out of the blue.

But I guess with time I kind of got my head around it a little bit more. And obviously if I could help somebody else not have their sibling pass away or if I could help somebody else have a longer life, a longer, more enjoyable life, then why would I obviously not do that?

So I probably I would have always done some form of probably raising money, etc.. But after going on Made in Chelsea, I obviously got a bit of a following on Instagram and that sort of thing. And then to me, if you have some sort of a following like that, then you might as well try and do some good with it and spread a message and get messages out to people of good as opposed to just post photos of yourself.

Lucy: And you obviously you climbed Kilimanjaro, what was that like? And that's kind of a really extreme fundraising activity rather than a cake sale.

James: Kilimanjaro was great. Anyone listening to this, if you do feel like doing something a little out there, Kilimanjaro was very enjoyable. I did it with one of my parents friends. He joined one of other family friends, so we had a little team cystic fibrosis. I don't know. I think the whole process of it very

sort of cathartic. I think it was just nice to have sort of a shared goal of trying to get to the top of this mountain with the same sort of cause.

And then obviously very overwhelming when you do get to the top and very rewarding. And just a release of, I don't know, a great feeling, that I recommend everyone should do if they are able to do so.

Lucy: What amount of training did you need?

James: There's a place in London, you don't have to do this by any means, but there's place in London called the Altitude Center, and you can go there and you can put on a mask which simulates being at, I think, up to 5000 meters.

So you can put that mask on and it basically reduces the amount of oxygen you're breathing in. Just to try and condition your body to thinner air. So I did that for a couple of months before, twice a week. My friends who did it with me, they didn't do that and they were still fine. And then just sort of uphill walking on treadmills or on a stepper machine that sort of thing.

It's quite fun. It's nice training for something. I guess. It's like if you run a marathon marathons, like it's nice training for something months in advance when you know that you've got such a big goal at the end.

mini interlude with slurping sounds, and a spoon stirring against a mug

Lucy: Recently, you went to have your carrier testing to find out whether you carry the CF gene. For people who have CF, they're or they are a carrier and they obviously have it.

Then you've got the carriers who carry the gene and it's two carriers that have the 25% chance of having a baby with CF. What was that like and the actual physical process of getting getting that done?

James: My mum got told that I was most likely a carrier. I'm not sure how that was, why that was maybe a test when I was a child.

So I kind of had that in the back of my mind, but it wasn't at the forefront of my mind like it was one of these things kind of cross that bridge at the time. Kind of just hope that she probably isn't a carrier. But when we've been together for three, six years at the time and then obviously, oh no we've been together seven years, we just got married, and then obviously the next kind of step we're thinking of children.

So it was essential for me to have tests which I got through the NHS, obviously with my sisters having CF. So I had the test done, result came back saying that I was a carrier. So it wasn't it wasn't crazy shock to me. I mean, my mother already told me that potentially I was.

Then I guess the next step of then my wife getting tested. That kind of was a bit scary. And also you have the test done and it took sort of three weeks and months to get a result. It was a long time. We were both kind of trying to think positive, like, 'No, you won't be a carrier you won't be a carrier. Why would you? Why would you?'

But in the back of my mind, yeah, it was scary because there's so that would have opened a whole new can of worms of having a child you know what I mean, it's not just as simple as what it might have been anyway.

So she had her test and luckily enough, or fortunately she is not carrier of the genes.

Lucy: And I think the language around carrier testing and the language for people with CF, I think is quite difficult. So my husband and me, obviously I've got CF, and even though we're not at the stage of wanting children, we just, it's good to know and the waiting time was like three months, which was awful, but it was the it was the conversation of wanting to know if he was a carrier.

But kind of because we've got a life where I have CF we don't want a child with CF, and then you kind of psychologically spiral into, but would would you want me? And you know that it's a very difficult kind of conversation and and mentally, would, what would someone with CF choose to do and what I think the whole like well would you would you choose to terminate an embryo if they had CF but you wouldn't terminate it.

You know it's a really kind of icky situation and with more people now with Cf able to kind of live longer and have children and everything. It's it's kind of the wording is quite harsh. I think sometimes.

What advice would you give people then if they were waiting? You know, like we waited three months for our results. What kind of advice would you have?

James: It was a process that we tried to not really think too much about. The best case scenario was that Lucy wasn't a carrier. And then I just thought, there's so much more to think about that as you've just kind of touched on. Then you go down the whole route of if you then had a child that, well had an embryo that was tested and was positive, do you go through with that? Do you not?

And then I agree with you in the sense that obviously is very different for you because you have cystic fibrosis, but then it's exactly the same as me like, well, it's very easy for somebody to say, 'Well, no, I wouldn't want that in my life.' But then I think, well, then that wouldn't mean my sisters were here. You know what I mean?

I wouldn't have have had those sisters and I would have known those people. Until you, I guess, get the actual result. A lot of it's hypothetical, you kind of, your brain, you always, I guess it depends who you are, some people are very good. Ignorance is bliss. Try not think about it. Some people like to mentally prepare themselves for the worst. Think about every possible outcome, research everything. But you might not even be in a situation where that is actually relevant. I don't know.

I guess everyone's very different and you kind of just have to do, I guess, what works for you. As you say, it's a very long time and and and, and also it's a decision that makes, has such a big impact on your life. Just this one piece of paper coming through the post and a huge impact for the next how many months, years of your life potentially the rest of your life.

I think the main thing is, is people need to know, I guess, that a lot of people, hence how cystic fibrosis and so many other illnesses are a thing, people don't get carrier tests. No one has a clue. But I guess just be proactive. I think that's the thing I can say be proactive and if that's a step you want to do in your life, then you have to really get get that step somehow. So get the test and cross that bridge. The time.

Lucy: It's tricky still, isn't it? Because obviously it's not available to everyone to have these carrier tests done. If you, unless you've got a link to CF or willing to pay for it. But I think to happen and more needs to be done about it. And also kind of the counselling/psychologist's help after you like find out if you are or not a carrier and how you process that is something that obviously is like you said, it's a piece of paper that you know, inevitably shapes kind of how your life will look.

And if you've grown up with CF and not your normal like you've said or my normal, then you don't think of it as you know, as different as someone who's never heard of it and thinks it's the worst thing. But

obviously people with CF are different and if if I had a child with CF, it might not be as well as I am sometimes.

James: That's even the case, I guess, even with sort of Kaftrio and these new drugs is is it still. I know obviously when my sisters where kids these drugs weren't around and as I said people with CF they have different levels of CF. But is it still as even if people are on drugs, do they make that much of a big difference now that you are guaranteed a longer life or is there still chance that things can go wrong or?

Lucy: Well, I think it's different depending on each person. I think people who are on Kaftrio. It's depends how they their body accepts them, and what mutation they are. And I think that for myself it's been a positive experience and definitely enabled me to live a fuller life in terms of kind of moving out from my parents, getting married, having a job.

But there's, I don't know, a lot of consultants, their kind of ripping up the old CF book and the learning alongside. There's so much research now into longevity and stuff along the way. We had a podcast episode earlier which was about like CF and the menopause as women get older and kind of that help with CF and those kind of ageing problems that happen with will happen.

But then there's so much research coming in that, you know, I think it's like a mobile phone upgrade. Something will come along and it will come along and get better. I'm hoping.

mini interlude with slurping sounds, and a spoon stirring against a mug

Lucy: I guess, looking the future for yourself. What would you say the hopes you've got for the CF community and kind of for for people growing up with CF?

James: In such a period, in a period of such short time the changes that have happened, that have come in are insane. Really. I remember as a child my parents kind of felt like, yeah, that was more tests, more sort of these things but there wasn't a huge amount around that was actually extending life or making life quality better for people with CF. And then all of a sudden Kaftrio and these sort of things come out and it felt like huge strides were made.

So I guess looking forward, if that happened in that sort of period, who knows where we could be in 20 years. I guess like I understand things like Kaftrio probably weren't just born overnight. They're probably been in the background for decades, realistically working on these things. So I guess that it's it's things like that that kind of make you think that raising awareness and raising money and funds for these things when such a big breakthrough has happened so recent, it kind of makes you believe even more that who knows where this could end up?

Could there be a full on cure or is it just could be medicines which make people, I don't know, basically live a completely normal life? Who knows what can happen. If you think as you know in somebody well, you know a lot better than I do the difference your life changed or how it's changed from just sort of this one drug, then who knows what could happen in five, ten.

Exciting, I suppose. And definitely it gives you sort of an impetus to want to raise awareness and raise money and do as much as you can.

Lucy: And obviously, other than becoming a new dad are you aiming to climb out of the mountain or what's, what's the next challenge over then sleepless nights, I guess with the little one?

James: Definitely sleepless nights, I'm a bit scared about those, I'm not going to lie.

What have I got in the pipeline? I'm doing the marathon in April for the Trust, which I'm super excited about, started doing a bit of training already for that. So that's kind of the next thing on the list. I haven't got anything, any challenge wise or anything scheduled, but I would like to do something.

There's a great time to get people together and the feeling and it's very cathartic when you're doing something with other people that have also gone through similar pain or and then you all come together for that common goal.

So hopefully, I don't know, potentially might try and organize sort of a golf day next year. But then at some point there is I don't know what it is yet, but there is something stupid, hard, crazy adventure I want to do at some point but don't know that is yet.

Lucy: Well we'll just have to watch this space then.

James: We will. The problem with nowadays though is every time you look at anyone's Instagram or something, someone's doing something that is insane. It's so now 20 years ago, if you ran a marathon, you were classes as insane. Now a marathon is like, 'Well, I know someone who does those every two weeks.' Now the now the levels are so high. It's like, 'What do I have to do, climb Everest on my hands' or I don't know.

Lucy: Well, James, I want to thank you so much for coming on the podcast today and chatting all about that and being so open and I'm sure kind of the advice and the tips and help that you've suggested will go a long way for some people that are struggling or just wanting to kind of hear more about about what your life was like.

James: That's okay. Thank you very much for having me. If there is anybody who does listen to this and would like to I don't know. I'm very open if you'd like to message me or something on Instagram, if you are if you have a sibling with cystic fibrosis or if you've lost somebody with cystic fibrosis and you would like I don't know, I can't give tips, I'm no pro, but I mean, I don't know if I can help you in any way, then please do message my message and I will try and get back to you and hopefully point you in the right direction to hopefully enjoy your life as best you can.

Lucy: It was a real honour having to catch up with James today. Thank you so much for joining us on the podcast and speaking so openly about your life, your sister's and your experiences with Carrier testing.

Izzie (content lead): A big thank you to Lucy and James for sharing their expertise and stories. Now we're going to be finding out a little bit more about carrier testing.

My name's Izzie and I'm content lead at the Trust and now I'm joined by Becky Kilgariff, joint head of Information Support and Programs at the Trust.

Becky, please, could you tell us a little bit about what carrier testing screening is and how it works?

Becky Kilgariff: Yeah, so carrier testing is also called family genetic testing for carrier screening. And it's essentially a tests that look for whether somebody is a carrier of the faulty gene that causes cystic fibrosis.

Izzie: What does it mean to be a carrier?

Becky: So we know that around one in 25 people in the UK are carriers of the faulty gene that causes CF. So that's about 4% of the population. And relatives of someone with CF will have a higher chance of

being carriers. Someone who is only has one copy of a faulty CF gene, which is also sometimes called a mutation or a variant is called a carrier.

A carrier doesn't have cystic fibrosis, but if their partner is also a carrier, there's a chance that that children would inherit cystic fibrosis. There's some newer research that suggests that carriers might have a very small chance of having mild symptoms of CF, but most carriers don't have any symptoms at all and carriers don't need any CF treatment.

Izzie: Okay, and who can have carrier testing?

Becky: Carrier testing's available free on the NHS to people who are related to someone who has CF or related to someone who's a known carrier. It's also available if someone's partner has CF or is related to someone with CF or is a carrier of the CF gene. So essentially, if someone has a family history of CF, either as a carrier for CF itself, or their partner does, then they're likely to be able to access carrier testing on the NHS. If people are not in that list but they still want carrier test can be quite difficult to get one on the NHS, there is some private testing available, but that does need a bit of thought as to whether it's the right thing for people and they can have a chat to their GP for some advice on that.

Alternatively, if what people are worried about is that they have symptoms of cystic fibrosis, they should go and talk to their GP because in that case they might want to refer you for a diagnostic test rather for carrier testing.

Izzie: For people who maybe want to find further information about the process, where can they go?

Becky: So anyone who wants to find out more, we do have lots of information about carrier testing or family genetic testing on our website, and there's a really detailed fact sheet that has answers to lots of common questions. If you or your partner has a family history of CF or being a carrier CF, and you want to access a test on the NHS, then you need to speak to your GP.

We do sometimes find that GP's aren't aware of who is or who isn't eligible for testing or how and where to refer people. And because that information on our website is so detailed, sometimes it can be helpful to kind of point them towards that because actually for them sometimes it answers their questions as well.

Izzie: And is there any support available for people who find out they are a carrier?

Becky: Yes, absolutely. There should be lots of support. So within the NHS carrier, testing happens through genetic centres and as well as the test itself, this provides access to genetic counselling and support. So if you have a carrier test, find out you're a carrier, you should be supported to understand what that means for you, for your family. And also you should have access to experts so that you can ask any questions about your test results.

Izzie: Amazing, thank you so much for joining us on the podcast today and talking about this.

Lucy: Thanks so much, Becky. And to James for sharing his experiences and to you all for listening. For more information on what we've talked about in this episode or to donate and help make sure everybody with CF can live without limits, please see cysticfibrosis.org.uk/podcast.

And don't forget if you've enjoyed listening to CForYourself, don't forget to subscribe, rate and review. Well, thank you so much. I've been Lucy Baxter, and I'll see you next time.