

Cystic Fibrosis Trust

Season 2, episode 4: CF and interior design with Jack Kinsey

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.

Welcome to episode four, season two of CForYourself.

Today I'm going to be catching up with Jack Kinsey, an interior designer from Norfolk who appeared on series four of BBC Interior Design Masters, where he was awarded second place.

I'm really excited to be chatting to Jack today to hear more about his time on the show, his passion for design, his life with CF and so much more.

CForYourself is all about sharing honest insights into life with cystic fibrosis, the good, the bad and 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.

Hey Jack welcome to CForYourself. How are you doing today?

Jack Kinsey: Thanks for having me. I'm really good thank you. I'm really good. I'm excited to be on.

Lucy: So tell me a little bit more about yourself, who you are, what you do, just so the listeners can get a sense of who you are.

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Jack: I'm a really creative person. I've always sort of thought outside the box, I think, and what's expected to be normal. I've always sort of maybe gone about things a bit differently or always sort of had that creative spark.

So yeah, I always it like a bit of a creative path that led me into the sort of interior design.

Lucy: I mean, I'm so excited to chat further about interior design and kind of the creativity that that goes into that. I just think that anyone that can put colours together, patterns together, textures, it's so much more, but I think it's such a skill and different types of color and it's just so interesting.

So you mentioned it that you were you've always been creative. What kind of what led you down the path to be an interior designer?

Jack: So going back to the whole like not thinking the normal way and always thinking creatively and outside the box, when we, when me and my partner, we found an old chapel. We were like, Oh my gosh, we could like convert that, we could live in that.

Wouldn't that be really cool? It'd be really unusual. So we yeah went about buying this derelict chapel and we we kind of did the interior really well, you know, as I would say, really beautifully. And I think that's when I first clicked, I was like, oh my gosh, we like transformed this place. And, you know, we get so many compliments about it.

And so I thought, well, why not try and do it as a bit of a career path?

Lucy: Where are you now? Cause I feel like my background to this Zoom is totally inferior to wherever you are. It looks extraordinary.

Jack: Don't be silly. This is my lounge. So this is like where we kind of, like, spend most of the evenings. We've got like a cantilevered staircase in the background where it just floats. It's all like, pinned into the wall really cleverly. And that was a bit of a nightmare, but it looks really beautiful now. And yeah, we spend most of the time in here.

Lucy: It's something that takes a lot of time and I guess a lot of money to kind of have your ideas how you want them.

So what you do day to day as an interior designer, is that kind of just for houses or kind of where does your job take you?

Jack: Yeah, erm it kind of it's it's definitely been people's houses, but the more like the bit that I get like a thrill from is more like commercial spaces. So I designed a pub which is really good fun, outside of Interior Design Masters since I've designed the pub, designed the hair salon, designing a bookshop at the minute. So that's really creative. And you know, the owners are quite, you know, that quite fun. And they want all these like quite immersive imaginary ideas going on to make the bookshop feel really magical and special.

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So yeah, that's where I get like the thrill from my interior design is more of the sort of like theatrical probably commercial stuff, although it can have a lot of fun with people's houses.

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

Lucy: You also have cystic fibrosis. Talk to me a little bit about kind of growing up with CF, what your childhood was like, kind of the journey of CF, so to speak.

Jack: I was diagnosed at 16 and I was only picked up having it because my little brother was diagnosed also quite late, but because he had been picked up in him and my parents discussed it, I had had quite similar experiences that they then tested me and so I was diagnosed when I was doing my GCSE's.

So it was quite like an intense moment because it was like my whole life had been flipped on its head. And it's like trying to understand what's more important at that point for me was like school grades, GCSE's or was it like I know need to, you know, I've now got this health scare hanging over me at the time. So I was really quite panicked, obviously with like, like being told that kind of thing.

But I'd say, yeah, my childhood was strange because I always knew something was wasn't right, if you know what I mean. I could always like growing up, I was always a bit out of breath or there was always like something respiratory going on. So I was always I always found like there was something up with me. So then when I did get the diagnosis, I was like, oh, this makes sense now.

But also it didn't make it any easier.

Lucy: Yeah, because when you're diagnosed with any condition and having to do so much treatment. So I was diagnosed at two. So even though that was quite late, but it was obviously not this late, but I don't remember the time before that. But you will literally remember a time before having to do your physio or nebulizers and then in your teenage years and then having to adhere and just do all that as well.

Like what was that like?

Jack: Yeah, it was really bizarre because like you say, it is like there was like a time prior to it, even even silly things like we had a hot tub at home and like we used to like jump in the hot tub and we'd always be in there, like with family and friends. And then all of a sudden it was like, you can't enjoy hot tubs you know because of the different sort of bacterias and all that kind of thing. You know, you can't go in a hot tub again. And I know it sounds really little, but something like that was like, What do you mean? You know, like, what do you mean I can't go in a hot tub? And it was just all these little things that, you know, you have to adjust to, that change forever really. It's little things like that where you're like, Oh, I used to do stuff like that. But don't get me wrong, I mean, let you just get on with it and.

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Lucy: Yeah, it sounds like you've got a really good outlook. Well, prior to being 16, kind of had you been in hospital a lot or were you kind of relatively well?

Jack: Well, yes I was, I was in hospital a lot. And so was my brother. Mum mum was always sort of up and down saying, you know, something's not right, that like she said, she'd had two births prior to me and my brother and that upbringing was relatively normal. No, no health issues. But then with me and my brother, we weren't really putting on weight and we were always having chest infection.

So mum was always, always up and down like the hospital saying, you know, the doctors saying, you know, this this isn't right, they're not well. And they just thought that we were just contracting colds really easily or we had like a bit of a knocked immune system for whatever reason, it's hard. I was never properly hospitalized, but I was always up and down the doctors with something's gone wrong or you know, this isn't quite right. So yeah, Mum went through quite a lot as well because I think she thought she was nuts at some points, thinking like, What am I doing wrong as a parent? Why aren't they as well you know as my other two children prior?

Lucy: Obviously one child with CF and then you've found out your other child's got CF and it's the whole kind of that was like, double whammy, she didn't know what CF was and having to look after one. But then also the cross-infection and everything, that like how was that?

Jack: Before we were diagnosed me and Curt used to share a bedroom. And then when we were diagnosed we were in separate rooms of the house. So yeah, we were like in separate rooms. We then had to be like, if one's ill, can't you know go into the room with the other one. So we were always quite cautious with that. I mean, now we were like in each other's company all the time, rarely ill and you know, that's lovely. But at the time it was like, What, you mean you can't like, chill with my brother? It's was a really skewed reality. It was really. Yeah. It turned my whole life on its head. Really. And my brother's. And a mum's and my dad's.

Lucy: How long ago was that when you were like diagnosed?

Jack: Oh, so like ten years ago pretty much.

Lucy: What you've done in ten years is incredible in terms of kind of your career and everything, which we're going to talk on a little bit more in a bit.

So kind of nowadays, you said that you're better kind of or more well, you see your brother, which is obviously with a cross-infection point of view, it's different to kind of two friends. It's it's completely different. And and that's a conversation the doctors and teams will have with your family to talk about the risks and everything and not advocate to meet. But as I said, it being your family, it's completely different. But how would you say it impacts CF impacts your day to day now?

Jack: I think it's like the fact that it's like a hidden thing. So you know, you're in you might go to like a party or like you know a regular setting and you appear fine and you, you know, the

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way that you come across is fine. But at the end of the day, you have got a disability and that is underlying. And people can't see that as a disability necessarily. So that's that's always a, you know, an unusual one when someone you know finds out I've got something like cystic fibrosis. So I think when I announced it on the Interior Design Masters that I've got cystic fibrosis and you know it was the NHS beach hut week, you know I sort of spoke about it, wanted to raise awareness and I think so many people were quite shocked by it because it is like an invisible illness.

But yeah, I think now I just try and keep really active. I think it encourages me to, to do more exercise, it encourages me to get out and probably do more than what I would if I didn't have cystic fibrosis, if you know what I mean.

Lucy: Now, you maybe understand a little bit more compared to like when you were 16, you kind of understand, I guess, the things that you were told all of us couldn't do. You'll understand that a bit better now.

Jack: Yes, definitely. I think I think every year that you have it, you learn a little bit more about it and you've had experience with different things. You know what works for yourself. Like I know now, like if I'm feeling a bit grotty or I'm feeling a bit chesty, I know I can really kick a lot of that in the butt if I do a saline nebulizer, which is obviously salt and it kind of, you know, irritates and probably is some sort of antibiotic with it being salt and really gets my lungs into a better state just from that. So I've learned that works really well for me, for my brother. The saline, the salt thing. I think that was just too irritating for his chest.

And he I don't know if he really does it now, but for me, I know that I can kick it if I was to do that a lot of the time.

Lucy: Obviously, because it is a hidden disability, but it's also a disability, where like a condition where we we can't really understand what each other's going through because it's so different and like our family get it, but they don't feel it kind of thing.

What would you say kind of having that, having your brother to talk about these things and kind of someone, you know, a sibling who really understands it? Did that help?

Jack: I don't know. If I don't know if it helped me. It's nice knowing that you've got someone that you can like lean on your family and you go through the same thing and stuff.

But to see my brother going through it was quite tough. I'd almost prefer obviously for me to just have it rather than him to have it. But definitely at times it's nice to like be able to to ask what works for him, how he's getting on with something and you know how he deals with things. And that was really nice to have a sibling to understand on a deeper level what you're going through but at the same time, it is it's quite painful when you see someone as really close, being your brother, being really ill at times, that was quite difficult, more so than me being ill, because if you're going for yourself, you don't see you don't see a lot of it because

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you're just getting on with it. But when it's somebody else, it's like, Oh, it's so real and it's I can see everything you're going through.

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

Lucy: And talk to me a little bit about the amazing series that you were on.

So it was earlier this year, I think you appeared on season four of BBC Interior Design Masters and you came second place. First of all, like congratulations. It's such an amazing achievement. And tell me a little bit how you got onto the show, what you did and and for people who don't know what the show kind of is about.

Jack: So the show, I always say it's a bit like Bake Off, but for interior designers. So like each week is a new challenge. Got a limited time, a limited budget. So you just kind of have to get through each week and you have a new space each week that you have to come up with an amazing sort of transformation. You get given the brief and yeah, you just kind of transform these spaces each week and then one person gets eliminated, so you start off with ten and then obviously ends up with just a couple of you in the final and one winner.

So it's quite an amazing quick turnaround, crazy experience. And I'd always been a fan of it. I've always watched every season of it and like every year my boyfriend always says, you should apply something. And I'm always like no It's not the right time to do it. And it certainly wasn't the right time when I did apply because we were extending the chapel and we had like our own space to transform.

But I was like, Oh, do you know, if I don't do it, no one will do it. So I applied and wasn't really expecting to hear anything and then got a call the following day and it was just like, Are you really interested? Sounds like what you what you've done is amazing. It sounds like you really align with the program.

So I was like, god yeah, I'd love to be on it. And then a few more stages and stuff and yeah got on.

Lucy: Incredible. See this this season in CForYourself, we're chatting to so many people who have done amazing things with chatting to people from different kind of shows and people with CF who are out there living their life and also advocating about in a really, really great way.

What would you say your experience on the show was like in terms of kind of did you tell them about CF, did you disclose it? Kind of how are you in sort of mentioning that you have the condition?

Jack: So it was it was funny. I really I was like, oh, if I tell on my application, if I say I've got cystic fibrosis, I don't want them to think he's not capable of doing the show, the tasks, the competition.

So I was like, Oh, I know I need to disclose it. But I was like, so wary about the whole thing. So I don't want them to think I'm any different, you know? So I did obviously, on the application, I

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said that I've got cystic fibrosis and I think for the BBC they like to represent, you know, people with disabilities and various different walks of life.

So I think for them it wasn't a big issue. But I think for me in my head I was like, Oh, I really don't want to sort of think I'm not capable.

Lucy: But they can't can they, there is no way they could discriminate in that sense. And if anything, the more determined and resilient you are, the better like you'll be in the competition as well so.

Jack: Yes, exactly. So I think they you know, they were all game for having me on. And, you know, and obviously at a certain point to talk about it. And so that, you know, different things are raised and there's the awareness of people's different backgrounds. So, yeah, it was a great platform to mention, you know, I've got this thing and it hasn't stopped me.

And because, you know, I used to aspire to different people that I'd see on the telly or in a magazine, who've got the condition, I'd think, oh they are smashing it. So, you know, it was a great opportunity for me to do the same.

Lucy: Yeah, definitely be role models but a role model for lots of people with CF. To see that because I think you see a lot of people on on these kind of shows that some people will relate with and kind of connect to but then something like CF because it is, I mean, even though it's the most common rare disease, not everyone has it, do they? So it's like when someone with CF is on, it is really, really lovely to kind of root for them and see them sort of just living and achieving.

In the episode prior to this, we speak to Lyndall Grace from Married at First Sight Australia, and that was really interesting to chat to her all about how her CF was on the show and kind of what adjustments and things were in place for her. So kind of chatting to you about it. England Show not Australia is really, really interesting as well to hear about that.

Would you say that there were any adjustments that needed to be made for you then?

Jack: I think it was just it was just conversations like, you know, if you need to take a break, you need to stop if you need anything, obviously we're here, but I think I was just determined to to get on and to just, you know, kind of do as much as I can myself.

But there was certainly things in place where they were aware of of some of the things that could happen. And it didn't stop me doing anything.

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

Lucy: I think it in episode five, you redesigned a beach chalet used by NHS workers. Talk to me about what the redesign was and why this was such an important moment to you.

Jack: Yeah, so I had the, a beach chalet and the people that used it were NHS workers and it was people from all different departments of the NHS could come and use it. They just book it

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and they, they used the chalet and it's really dated. It wasn't you know, it didn't function at its best. And so like this redesign was like the best thing for them and I decided to go quite art deco with it, so quite fun. Lots of vibrant colors. I went with some quite aqua blues, I went with some sort of oranges, so it was quite like a colorful transformation and I kind of wanted this idea of unity with the NHS that they all work together. But I didn't want it to be blatantly obvious. I sort of wanted it in this artistic form.

So on the ceiling of the chalet, I did this sort of ornate molding where there's these synchronized swimmers, synchronized divers, all working in unity to make this pattern on the ceiling. And I was really happy with how it turned out because it to me and to a lot of people it translated, but it wasn't that directly obvious way of putting the message across.

It was quite artistic. So yeah, it was it was a fabulous transformation, if I do say so myself obviously.

Lucy: What's been the best or like the proudest thing you've done?

Jack: I think the proudest thing is definitely my home, because I think it's it's like it's your own space and you take certain pride in your own, your own you know environment.

And I think like the show was obviously another proud moment, but completely separate. It was like it was almost like this public proud moment. This is what I'm capable of. This is why I can do. The Beach Chalet in particular was a standout moment because it was like intertwining my creativity and my condition and sort of, you know, raising awareness of it.

Yeah, there's bit that's been lots of proud moments where if you channel, you know what deep down that you know that you're really good at what you love doing, then I don't think you can really go wrong.

Lucy: Agreed. I really, really believe that. And then when you opened up about like your CF on the on the on the show, what was the reaction like as in from people in the CF community, or I guess you're getting messages like, wow.

Jack: Oh, it was amazing. So, you know, I was expecting maybe to get the odd message, but yeah, Instagram just went wild. That was like I had so many messages come through saying, Oh my God, like, we we all when we all found out that you had CF, like, my son's got it, he was like, Oh my God, he's like me.

And people's partners. I had like just loads of people reaching out, or had some people directly with CF reach now saying, Oh my gosh, I've got to. It's lovely to see that, you know, you're striving you're smashing it. I'm really well too. I'm on this medication. And so there was lots of people coming from all, all different parts of the world as well.

So it was people coming from all over saying it's amazing to see someone doing really well with the condition and it hasn't stopped you and, you know, sharing their stories.

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Lucy: I mean, there's so many treatments and lots of different things in the pipeline coming through to help sort of everyone with CF, not just the 90% that can take one certain drug or whatever.

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

Lucy: What would you say your hopes are for the future then? Like what? And this is a tough question. If you could design or redesign any building in the world, what would it be?

Jack: I'm going to think about that whilst I'm answering the first one. So where I want to be is kind of what I'm doing now. I love what I'm doing now.

I'd love to take it to the next level somehow, which is I don't really know. You know, I think at the minute I'm very Norfolk based. I love Norfolk love this part of the country, but certainly love to explore, you know, different areas of the UK and even further doing different design projects and stuff like that. But for now I'm kind of staying within the territory and I'm trying to conquer Norfolk in the interior design world, and then I want it go further. What would be the best space to interior design.

Oh my gosh. Probably something, probably something that doesn't, isn't just four walls. So like, I think with like most interior design projects, you've just got, you know, square boxes. It's, you know, everything is just angular. I think a really fun thing to do would be like a boat where there's just all these curves and all these things which, you know, you have to think outside the box maybe.

I think, yeah, a yacht would be cool, something like that. I think it's about not conforming to these square boxes that we're in and thinking about how you can use them differently or how they like can, you know, just give you a better life, basically.

Lucy: Yeah. And I guess people with CF like to, they can use their CF and use it in different ways, but also due to like what they've gone through, they can think outside the box in how to do other things in like in, you know, in everyday life. So it's, it's kind of a good mantra for life as well.

So if you, if you had like a piece of advice for a young person or maybe someone who's been diagnosed older with CF today, what what would that be?

Jack: I haven't met a thing or spoken with a single person of CF who's let it eat them up. I think there's always a fire in the belly somehow that there that there is just not the end of the world and it's not going to stop them. And so I think it's that. I think it's like have that fire in your belly and like follow follow that fire and know that you can do anything. And if you have got passion, how can you convert that into your career? How can you use it and be happy from it?

Lucy: I absolutely love that. If people wanted to get into the creative industry, kind of, how did you get into doing interior design? Because, you know, creative industries are really hard to get into.

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Jack: They are really hard. And obviously I did have the platform of of the of Interior Design Masters to further it.

But even before Interior Design Masters, I was still dealing with furniture, dealing with interiors, dealing with stuff like that. I was already in that industry. I think it was it was in lockdown. I think it was just when I had a moment to think about what do I want and I could actually step off the hamster wheel. I then thought I could I could definitely do this.

So I think it's about, like finding a moment to really just think and like to step step off the conveyor belt of life and all the rest of it. You just need to be able to like, step back and think about the next five years, ten years, and think well it's baby steps. You know, it didn't all take off overnight for me. It was literally, what's the first thing I need to do? I need to register it as a business. I need to set up a social media page. I need to set up a website. And then it it all comes. I think it all it all stems from just a simple idea, basically.

And I have got no qualifications either. So it's not like I went to art school and I went to art college well I did actually go to art college, that's a lie, but I didn't go to university and I didn't get degrees or foundations or anything like that. And I haven't worked in a practice. I'm just winging it and it's paying off.

Lucy: But like you said, you've got the fire in your belly and kind of people with CF, never sit still. They're always busy doing stuff, loving their life. And kind of really live at like. Well I don't know if it's just me but I live at like 110 miles an hour pretty much every single day and like, burn out. But like, it's just how we do things.

Well, thank you so much Jack for coming on today. It's just been so interesting chatting to you all about like growing up with CF, late diagnosis, but also like the interior design aspect.

I think that's really fun and I think it's something I'm definitely going to follow your socials after this just to, to really like see what your style is more other than that gorgeous living room.

Jack: Oh thank you. And thanks for having me. It's like it's a great thing to talk about. And, you know, it's not very often that you would bump into somebody with cystic fibrosis and then you know talking to them can be a challenge, you got to keep a distance, all the rest of it.

So I think like talking on a podcast or you know virtually and having people reach out to you is really important. So I've loved this whole experience.

Lucy: It was lovely having to catch up with Jack. Thank you so much for joining us on the podcast and speaking so openly about your life, CF journey and interior design dreams.

Izzie (content lead): A big thank you to Lucy and Jack for sharing their expertise and stories.

Now we're going to be finding out a little bit more about the Trust's Work Forwards program, employment and getting a job with CF.

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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.

Hey, Becky. Could you tell us a little bit about the Trust's Work Forwards program?

Becky: Yeah. So Work Forwards is a new program launched in 2023 where we're providing support with work and employment to people affected by cystic fibrosis so that people with CF themselves as well as parents and carers. And the program's been made possible thanks to funding from Scope and the National Lottery Community Fund.

Izzie: And how does the program help people with CF?

Becky: Through Work Forwards, we can offer 1 to 1 support and information over the phone by email or on Teams or Zoom calls.

And that's completely personalised and tailored to the person contacting us. So we take the time to work with individuals, be led by them, and look at what their support, what the support they need and what their next steps might be. It can be anything from searching for jobs together, preparing for an interview, sometimes talking about discrimination and rights at work.

We just can't give legal advice. But we can signpost the right organisations to help. Work Forwards also includes online group sessions on a wide variety of topics from getting started in employment, to self-employment and everything in between. Those sessions provide a really safe space for people affected by CF to share their experiences and get support. And they're often delivered by people from the CF community as well.

And finally, the Work Forwards program helps us ensure we're providing lots of really helpful information, resources on CF and work. So updating some of our existing information, creating new resources where there are gaps. And we're also really busy sharing lots of case studies and stories of people with CF at work showing the wide variety of jobs and careers in the CF community.

Izzie: Who has the program helped so far?

Becky: So far we've helped a really wide range of people with all sorts of different queries and needs. So that's included people who are right at the start of their career. For some people we're hearing a real feeling that their futures are opening up for them and they've got lots of choices ahead of them. So they need support to find their way in the career they want and find the role that they want.

We've also helped people who needed support, to organise reasonable adjustments in their current job. So we're talking to them about their rights and how to request reasonable adjustments. And we've also supported people with CF who want to make changes to balance work and their health.

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So perhaps they're looking at changing career or moving to a different job that will give them more time and space they need to look after their health. So it's really varied and this is always tailored to each individual.

Izzie: Amazing. And where can people go if they would like to get career and employment support from the Trust?

Becky: Anyone who'd like support can email us. The email address goes direct to the team is workforwards@cysticfibrosis.org.uk.

Or you can just contact our helpline team that are available by phone, email and WhatsApp and they'll put you in touch with the Work Forwards team. And also keep an eye on our website and social media as that's why we're regularly promoting online sessions, providing information and sharing lots of stories of people with CF in a wide range of jobs and careers.

Izzie: Awesome. Thank you so much Becky for joining us on the podcast today.

Lucy: Thank you so much, Becky. And to Jack 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.

If you enjoyed listening to CForYourself, don't forget to subscribe rate and review so you can keep up to date with when each new episode comes out. Thank you so much and I'll see you next time.