Cystic Fibrosis Trust

Since 1964 | We won't stop until CF does

Season 3, episode 4: CF and exercise

Lucy (host): Hello and welcome to season three of CForYourself a podcast brought to you by UK charity Cystic Fibrosis Trust. I'm your host, Lucy Baxter, and I myself also have cystic fibrosis.

I'm one of over 11,000 people in the UK living with CF. CF is a genetic condition that causes a buildup of sticky mucus in the lungs. So that means I can experience a range of different symptoms every day, like struggling to put on weight and prone to getting lots of chest infections.

I was diagnosed with CF at two years old, but CF is just part of my life, not my whole life. And it certainly doesn't define who I am.

In each episode of CForYourself, I will 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 exercising and dealing with a new diagnosis to work and holidays.

We'll also hear from CF experts who will be sharing their knowledge and advice for everyone affected by cystic fibrosis. CForYourself is all about sharing honest insights into life with cystic fibrosis. The good, the bad and absolutely everything in between. I'll also be sharing some of my own experiences, but my views are all my own and not necessarily that of Cystic Fibrosis Trust.

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

In many of the episodes, we talk about some topics that you could find triggering 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. They can be a listening ear or just be there to talk things through. You can call on 0300 373 1000 or email helpline@cysticfibrosis.org.uk.

Lucy Baxter (host): Welcome to the fourth episode of season three of CForYourself. Our first episode of 2025. I hope you all had a wonderful festive break. Many of us might have made a New Year's resolution to take up a new exercise in 2025, or maybe have a sporty challenge in your sights ahead. So it feels like a great opportunity to focus this episode on staying active with CF.

I'm really excited to be joined by Matt, a personal trainer and running coach with CF. Matt has run marathons to raise money for the Trust over the years and has recently worked with us to develop a running guide for people with cystic fibrosis. We'll be chatting all about how exercise has helped him and his top tips for staying active.

Later on, I'll be joined by my own CF physio, Ruth, who is based at the Leeds adult CF centre. Ruth shares more about why physical activity is important for people with CF, and how it can mean different things for different people. Now, without further ado, let's welcome Matt to the podcast.

Lucy: So a huge welcome to CForYourself. How are you today?

Matt: I'm good. Thank you. How are you?

Lucy: Yeah I'm well thank you. So in this episode we really want to talk about exercise and cystic fibrosis and kind of how people can stay active and things like that. But first of all, why don't you tell me a little bit about kind of your CF journey, really, and what made you want to be a personal trainer?

Matt: Well, I was diagnosed when I was four weeks old and it was, obviously growing up, my parents, basically, they sort of got me into everything. They weren't like, didn't hold me back from doing anything. So from like a young age I was into football, running and basically everything you can do that's physical. And yeah, it just grew from there.

And then through school and everything, running and football were my main ones and I just tried to maintain that all my life. And I know that's obviously what keeps me healthy and keeps me fit.

Lucy: And you obviously found like an enjoyment in that, not just as like a hobby but wanted to make like a career out of it as well?

Matt: Yeah so running was probably my main sport, and that's been my main interest throughout life. Basically. And over the years I've dabbled in doing things like coaching and that, but it got to the point where I was like, I'm training that much, and people ask me that many questions. I was like, right, I'm going to get qualified in it now. So that was the next step for me to get qualified. And I got qualified four years ago, I think it was. So yeah, I've been doing the running coaching four years now.

Lucy: Do you feel like everyone has the potential to be a runner? And it's kind of maybe sometimes mind over matter? I mean, you're speaking to someone here who hates running. It's just a boredom thing for me and I've not got into it properly. What are your thoughts on that?

Matt: It is for everybody. Yeah. I would say, but again, different forms of exercise work better for other people. Running is a very niche sport, I would say, because obviously as you said, you either enjoy it or you don't. But there are different ways to enjoy it, like going out in group sessions and bonding with friends, and I just find the benefits from it too. Not just physical, but mentally. It's brilliant for me and I think everybody should do it because the amount of clients I have that come to me and say, 'oh, that really has been great'. 'I've had a really stressful day' or 'I've had so much going on in my life' and running like helps them so much. So yeah, even if you, you do struggle with running, I would say persevere with it and build yourself up gradually and get into it because it'll make a massive difference for you.

Lucy: Yeah. And I guess we'll talk about this a bit later on. But there's different, you know, not everyone will wake up and the first run they do will be a 5K. Even like a half a mile for some, it's a really good achievement for them.

Matt: Yeah like a lot of people, like beginner runners, they usually start on like a Couch to 5K type things and that's like run, walk and then gradually build up over like a 10 week period, roughly. But that that's the best way I always recommend to get into it and just build up slowly and just get consistent. As soon as you get consistent with it, it just becomes part of your routine and then you do start to enjoy it, especially when you see yourself getting fitter. It makes a massive difference for you.

Lucy: Are you someone who kind of listens to music, a podcast or kind of just does it without anything? What's your kind of zone?

Matt: Depends. If I'm training on my own I will listen to music. And again it changes like the type of music I listen to changes depending on what type of session I'm doing. A lot of the time I do try and run in groups or with like friends because obviously it's just a lot, a lot nicer when you when you've got a bit of company. Even for me, it gets a little bit boring sometimes when I'm on my own.

Lucy: Yeah, I guess it's kind of, it's a whole body workout, isn't it? Like you can run and your abs can hurt you, like your whole body. But also for people with CF like you breathing and kind of getting that right and moving all the kind of mucus, etc.

Matt: Especially in the winter.

Lucy: Because of the cold temperatures?

Matt: Yeah. Because of the cold. Yeah. That makes a big difference.

Lucy: Makes it harder?

Matt: Yeah it does with the cold air. Obviously it hits your chest. Because when I was growing up when I used to do like cross-country in school and things, it was always the winter months and that was affecting me more like breathing wise.

Lucy: And yeah, I did cross-country when I was in year seven and I just wanted to get it over with. So I just ran as fast as I could. I was really pleased. I came like fifth, but didn't realise that because I came in the top ten I automatically got onto the cross country team. So I'm having to do all these races, so I learned the hard way with that.

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

Lucy: Would you say then, because you've been so active, has your CF been quite stable growing up or was there any kind of dip?

Matt: So yeah. Well, growing up, from the age of ten to probably 20, I probably didn't have any hospital admission. So I had no IVs or anything like that because I was like in really good fitness. But then obviously as I got older, I started picking up a few, a few more injuries which kept me out of going running or any sort of sport for a while, and then I was picking up like a few more chest complaints. So I would obviously have a few more IVs and then yeah, that was probably going through my 20s and then, yeah, that was a bit up and down at times, but the majority of the time I am fairly active and keep myself in good shape.

Lucy: It's the mindset isn't it, as well. It's something you've got to kind of force yourself to do. Sometimes you don’t feel up to it, but then you always feel better afterwards. But it's kind of, yeah, if you're in the mindset of wanting to do a workout, for instance, or go to the gym or whatever, your mindset is always better

Matt: Yeah. Like even for me. Like I've obviously always being active and into sports. But there's even times where I can't be bothered or I'll cut a session short and you know, I get demotivated a lot, but I'm fairly disciplined throughout and I'm like it with my meds and everything now. I'll never miss like any of my medications, that's just how I've been brought up and that's how I like apply myself to life. Even if I don't want to do something, I'll force myself, force myself to get it done.

Lucy: Yeah. And it was something that, I was chatting about with the physio Ruth, who we've got on the podcast as well. About how consistency doesn't necessarily have to mean every day. There's kind of peaks and troughs in people's health. And if you have to take time out, that doesn't mean you've failed or anything. That doesn't mean you're not being consistent because it's kind of the overall picture isn't it?

Matt: Definitely. I do, I take breaks. So especially when I'm like marathon training and things I'll be mid marathon block and then I'll just stop and take like a week or ten days off, just let my body recover, relax my mind because obviously it does get quite intense sometimes. So I'll just have a little bit of time away from it and then get back to it eventually and pick up where I left off. Because I think you need to, because there's just no way. Like physically you can't, mentally you can't just be on it all the time. You've got to have breaks.

Lucy: Did you ever find growing up that kind of exercise was a chore? The sense that you had to do it to keep your lungs well, as opposed to kind of other peers just doing it because they enjoyed it.

Matt: Not really, but I think that, again, was due to my parents, like in the mindset they gave me. It was just the case of because I knew no different. I was thrown straight into it and that's all I knew. So I enjoyed like every, every aspect, of the sport. Yeah, I tried all the sports as well. So it was, it was never a chore. It was just nonstop for me.

Lucy: So now as a PT, you kind of focus on like running specifically, don't you? What would your tips be? Because obviously you won't work with other people with CF in person. What would your top tips be to other people with CF? You know, if they're wanting to start exercising, what would you suggest?

Matt: Don't put too much pressure on yourself is the first tip. Because again, I think everybody automatically thinks I've got to train and I've got to do this amount of exercise to keep my chest healthy. But if you've got less pressure on yourself than yeah, I think that's the best way to explain it. Less pressure. Try and get a little routine going and then gradually increase your routine.

Lucy: If you're not up to a gym workout or a run, a little walk, just some fresh air.

Matt: Yeah. Just walk. Yeah. Anything like that, like, can help everybody. Each to their own. Like there so many different sports. You can have a go at all different things. Football, tennis, walking… literally anything. Just find something that you enjoy and that you think that you'll be able to maintain. It's pointless everybody coming into one sport and being like, right, I don't enjoy it. And then they just give up. Trying a few different sports you might find something that you absolutely love and get addicted to it, which is great.

Lucy: Yeah. Growing up I think it sounds like I had similar parents to you. But my kind of exercise was tap dancing. Dancing was what I absolutely loved. And then would also do swimming and things like that. So I think it is what you enjoy and maybe if you don't class it as exercise you just enjoy it, it takes the pressure off.

Matt: That's how I feel about it when I look at it now. I do enjoy the running side of it. I don't feel like it's a job at any point, especially even now that I'm doing it as a job. It's not. I just enjoy it all.

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

Lucy: So tell me a little bit about what you do kind of in your job. Talk to me a little bit about what it involves.

Matt: So a lot of my stuff is online and I have a lot of clients all over the country now. I do have local clients as well. I'll do 1 to 1 sessions with and a whole group sessions as well locally, but the majority are probably online and that's all sorts of events marathons, half marathons, five k's. Like whatever anybody's goal is. Some people just use me to keep fit or improve their fitness slightly. It's quite varied. And I've got a good mixture of like beginners and advanced runners as well. So yeah, obviously anybody who's looking to get into running I help them as well.

Lucy: Have many people with CF come to you for help?

Matt: Yeah, I've helped a couple of them in the past year. obviously at the moment I'm helping the London Marathon team with all their tips and that through the London Marathon journey.

Lucy: So I was going to just ask you about that. So that nicely weaves into the work you're doing with the Trust. So you're developing this kind of marathon running guide for people with CF. What does that involve?

Matt: So that's just giving them like tips for hydration and stuff like that. How many times to train and there's just a lot to think about, obviously from a CF point of view as well, because obviously I have CF myself so it's got to give people an idea of what it's like running a marathon if you've got CF or CF related diabetes, because obviously I know first-hand how it is and how hard it can be. And yeah, it's just literally giving them as much support and advice throughout the marathon journey.

Lucy: And you've run marathons for the Trust in the past, what was that like, and why would you say it was important for you to kind of raise money for the Trust in and push yourself in that way?

Matt: So anything charity related, I will always support the Trust. Just because of how much they've supported me, obviously, throughout my life. The marathon itself is such an unbelievable event. Although a few of them have been quite painful for me. But as a whole, yeah, it's the experience, just there's nothing like it. And obviously working with the staff just on that, it's just a nice feeling.

Lucy: What years did you do it? Which marathons have you done?

Matt: So all London. I've done the previous four. I was supposed to do it this year, but I broke my hip just before the marathon. So I ended up having to pull out this year.

Lucy: And how is your hip now? That's quite a big thing to break.

Matt: Yeah I had surgery on it. So I've had a few pins, but it's getting there, I'm back running now. Not very far. Only like small amounts of mileage at the moment.

Lucy: Do you know actually, and I'll tell you, when I got into running, I got into running when - even though I just said previously I don't like it - when it was Covid and it was the period with shielding where we could go out, but we couldn't mix. I would just go for runs around because we live in the countryside and I'd look on public footpaths and because it was so sunny and lovely and would just kind of run around the place. But the problem was I'd get to the point where I'd gone too far out and I was like, oh, having to come back now. But it can sometimes be what you need. Going back to what you said about the mental health and everything.

Lucy: Have you any plans to do any other marathons?

Matt: I've been put on a bit of a marathon ban at the moment because of the hip. So I'm not supposed to run a marathon for about 18 months. I've got a place for the London Marathon 2026. So I'll do London again then, hopefully. But I do want to go and start hopefully ticking off some of the majors ideally, but we'll see how my body holds out.

Lucy: We've spoke about Team CF and you being part of that, why would you encourage others to get involved?

Matt: I just think it's a great experience. Like every time I've done the marathon, the support from the staff has been brilliant, helping me fundraise and answering any questions you've got. They are just always there for you. So I just think it's great to be part of a team rather than going solo on a marathon and having no backup or support.

Like the things they are putting on this year, obviously with me helping them and things, I think that's brilliant. Just me helping coach all the other runners and I think probably not a lot of charities do stuff like that.

Lucy: And also, you having CF, a lot of people with CF, younger or older, who are maybe not as active, will really look up to you and be like, well, if Matt's doing it, so can I, and look up to you in that way. Is that something you're kind of you're aware of that people will probably do?

Matt: Very aware of and yeah I get it quite a lot. I get people inbox and me and things and thanking me for like doing what I do and things, because obviously they follow my Instagram page.

Lucy: What's your reaction to it? Because you're not you're not a celebrity.

Matt: I'm quite surprised a lot of the time. And yeah, like I went on holiday to Cyprus this year and I went to a restaurant with my wife and somebody came up, tapped me on the shoulder, and were like, oh, are you Matt Strange, the local runner from the Wirral, and I was like yeah, and they said oh we love everything you do. We follow your journey on Instagram. I just didn't know what to say. It's just a shock. But it does happen. In Cyprus it was like, of all places. It was quite weird.

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

Lucy: The final question we tend to ask our guests, if there was one thing you wish more people knew about CF, what would that be?

Matt: I would probably again go to the mental health side of things. Obviously I think people don't fully understand the physical side of it because obviously from the outside, they just look at you and think, oh yeah, he's running marathons. He's absolutely fine, not realising the physical side of it. But the mental side of it, I don't think people realise as well how much it affects us. Obviously things like when we get a cold, it just magnifies for us. And it's hard to deal with sometimes, a lot of the stuff that goes on for us, and I just don't think people understand that.

Lucy: That's a good a good point. And even if you're well with CF, you're constantly kind of scanning the environment you're in, or if you hear a cough, you know.

Matt: That's exactly what it's like. You hear a cough and straight away you're alert and you're thinking right, get out of there and you go home thinking, right, I'm going to get a cold. That's just your mindset. You just think you're going to get ill straight away. It just plays with your mind a lot.

Lucy: Yeah it does. So if people want to follow along with your journey, are you happy to give out your Instagram? How do people follow you?

Matt: Yeah it's @mattstrangerunningcoaching on Instagram now. I'm happy for people to follow and if you need any help. Even like advice like, I get a lot of people with CF inboxing me and I'm happy to give just advice. I'm not the kind of guy who will charge you for it.

Lucy: You're just a good guy!

Matt: *laughs* well I didn't want to say it!

Lucy: But you are! It's been great chatting to you on the podcast today and thank you for giving your expertise and insight into exercise, and not just exercise and running, but your attitude and outlook on life. So thank you for that.

Lucy: It was really great having a catch up with Matt. Thank you so much for joining us on the podcast and speaking about your experiences of exercise. And who knows, maybe I'm even inspired to pick up my trainers and head for a run.

****Advert****

Hello, I'm Scarlett and I'm the events manager here at Cystic Fibrosis Trust. Just popping in to remind you to check out some of the exciting fundraising events we've got happening in 2025. From runs to hike, skydives to cycle rides, there's a challenge to suit everyone, and we'd love for you lovely listeners to get involved and be a part of team CF this year. Whatever you decide to do, together, we can change lives, one challenge at a time. Will you join us? Check out cysticfibrosis.org.uk/teamCF and be a part of something amazing in 2025.

Lucy: Next up, I'm delighted to chat to my CF physio Ruth. Without further ado, a huge welcome to the podcast. Ruth, how are you today?

Ruth: I'm very well, thank you. Lucy, how are you?

Lucy: Yeah I'm good, thank you. So if we kind of go back to the basics of the importance of physio and airway clearance, why people with CF need to do it and how it helps, because a lot of people listening to this podcast will have CF and maybe have done it their whole life, but not actually really understand why they're doing it. They just know they have to. And also there will be some people who are parents of people with CF as well. So kind of take us back to basics with it.

Ruth: So what we have to think about first is how CF affects the lungs. We know it's a multisystem disease, but we're specifically thinking about the lungs. We know that CF is a genetically inherited disease where you get one mutation from your mum and one mutation from your dad.

These genes code for the CFTR protein. So the cystic fibrosis transmembrane conductance regulator. But CFTR is an ion channel, so it's a chloride ion channel. So imagine if you like that that is like a tunnel. That goes from inside your cell to outside your cell to into your airway. Now, if you don't have enough of this CFTR, so enough of these tunnels or they don't work properly, what that means is that you aren't getting the right flow of fluid from inside the cell to into your airway, and that means that then you have a dehydrated airway.

Ruth: Now, for mucus to move within your airway you need little hairs called cilia. Now these do, these waft backwards and forwards. So imagine your Mexican wave, wafting sputum centrally so then it's easier to clear. Now these work in a liquid layer. And if we've just said we've got a dehydrated airway and this liquid layer isn't thick enough, they can't work properly. So this then leads to mucus pooling. And with mucus pooling there is then the chance that then you're going to get infection. So airway infection, airway inflammation. And then that ultimately leads to airway damage.

Lucy: So then the point of a physio and airway clearance being to kind of help assist the removal of the mucus. So then it's not gonna lead to the inflammation, infection and damage.

Ruth: Absolutely. So this is a real kind of vicious cycle of kind of airway infection, inflammation and ultimately damage. Exactly that, so the aim of physio is to basically to remove that pooled mucus to then reduce that or break that cycle essentially. So there are a multitude of different techniques that you can use. You've probably heard of them all. There are breathing techniques, kind of a core active cycle of breathing, autogenic drainage, or there are adjuncts that you can use. So it might be a PEP mask, or an oscillating PEP. So Flutter, Aerobika, Acapella. But the basic principle is to get air in behind the sputum and generate a sufficient expiratory flow to then, and some shearing forces, to help move mucus centrally. So then it's easier to clear and break that cycle.

Lucy: So fundamentally with CF, if people don't know about it it's like oh it's the lungs and it's the mucus. And my favourite quote oh it's the massage of the chest. So for 24 years I've done this morning and night, bar a few late nights or what have you. So it is part of someone with cystic fibrosis's habit, that daily routine. Like personally myself I have the Aerobika and I also have, I think it's the PEP mask, it's not the PEP mask, it's the tube that's like the PEP mask, but it's just a mouthpiece. But I kind of jazz it up, so kind of mix it up and do different things. Just so I don't get bored. And I think that's the thing, it's kind of making physio interesting in a way, to kind of engage the person.

Ruth: Yes, physio is one of the kind of mainstay pillars of CF treatment, but yet it is still widely considered one of the most burdensome, laborious aspects of CF care. So yeah, it's a real tough one.

Lucy: My favourite phrase that one of my consultants used was that in the kind of post modulator world for the kind of 90% that can take the modulators, and there's of course lots of research going on to develop things for the 10% that can't. But in this world now, it's kind of like the old CF handbook in a way, has kind of been ripped up. And we're learning as we go with the modulators and with Kaftrio as to how it affects and how it's changed things, and it's kind of a different time. And a lot of the questions that I hear within the CF community, I'm on the modulators now, do I need to continue doing my physio as I'm not coughing anything up?

Ruth: What a contentious question! And it is, you know, it is a real hot topic. So we obviously have considered what the fundamental kind of underlying problem is with CF and kind of how that creates airway, mucus and kind of the importance of physio in that kind of scenario.

So yes, now we've started modulators and we have hopefully improved the amount of CFTR in your lungs that is working and therefore optimized airway hydration. So therefore your cilia should work more effectively. So in that case do you need to do airway clearance?

Well I think then what we also need to consider is that we have patients who we know have airway damage. So they have something called bronchiectasis. So with airway inflammation or with infection and inflammation you get damage. And this damage basically breaks down the kind of the elastic fibres within the airway. So it makes them a bit baggy and it dilates them. So it makes them wider. And that's what's known medically as bronchiectasis.

So we know that patients, or some patients pre-Kaftrio had a CT and they would have bronchiectasis. And we know now that they are on Kaftrio, and in some instances we've repeated it (the CT) and that they still have bronchiectasis. They might not have the thick mucus plugging that they once had, but they still have airway damage.

And we then look at different patient groups. So patients with non-cystic fibrosis bronchiectasis and we look at their recommendations for their care. So the BTS (British Thoracic Society) recommendations for their care. Lo and behold here we have physiotherapy airway clearance. Because if you have airway damage caused by bronchiectasis you will get mucus pooling because those cilia still don't work properly.

So you still then run the risk of the vicious cycle of airway infection, inflammation, airway damage. So physio still forms physio airway clearance, fairly interchangeable terms, still forms a really important role in that.

Lucy: Yeah. And I think that's good for people to kind of hear the science behind that as well. And a lot of research is going on for loads of treatments and loads of stuff since Kaftrio. But it's always kind of like, let's wait for the science-based stuff to come through. And then obviously people, people are obviously allowed to have chats with their individual consultants and dieticians and multidisciplinary team about what they're doing, and that's what I would always kind of encourage people to do who listen to this podcast.

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

Lucy: I also want to talk to you about exercise and kind of how that links to CF, because obviously, and I'll let you explain, but my thought is if you are getting yourself out of breath, you kind of move the mucus. And in a way that's kind of a good thing. Do you want to talk to me a little bit about that exercise?

Ruth: Exercise, pre-Kaftrio, we know that if you have improved your aerobic fitness, it slowed the rate of decline in lung function and is related to improved health related quality of life. It can help improve bone health, glycemic control. In terms of exercise as airway clearance, we know that exercise can improve the ease of sputum expectoration and sputum clearance compared to rest alone. And we know if we use exercise in combination with huffing or coughing, it can have a similar kind of effectiveness as compared with traditional airway clearance techniques.

And if we look at the UK CF Registry data from 2023, we can see that 20% of patients, adult patients, use exercise as their primary form of airway clearance. So for them that is how they clear their airways. My caveat would be if you're going to exercise and use that as your form of airway clearance, make sure you are then doing your huff and cough. And you are looking for sputum. If you have mobilized sputum, then go looking for it afterwards to make sure you are clearing it.

Lucy: Yeah that's a good tip and I guess you could always do physio and then use adjunct afterwards to kind of, or do some slower breathing afterwards as well.

Ruth: Yeah. So kind of doing maybe like your AD style breathing, and kind of just assessing whether there is any, any sputum there. And I think what we found with, with Kaftrio is that, you know, having less sputum is not the same as having no sputum. So even though you may feel better because you have less sputum, it doesn't equal no sputum. So there is still the role for airway clearance.

Lucy: And for people with CF, just like anyone, it's good for you physically, it's good for you mentally. But I guess with the additional load that maybe people with CF have in terms of the tablets they have to take, staying away from kind of certain environments that might potentially have bacteria or fungus, things like that. Like being able to exercise massively helps their mental health.

Ruth: Yeah, absolutely. I mean and the effects of exercise on mental health in the general public is well known. And in, you know, the kind of endorphin release, it makes you feel good. And yeah, it's really powerful. I think, you know, there aren't any guidelines for kind of how much exercise should someone with cystic fibrosis do. So we very much apply the NHS guidelines and World Health Organization guidelines as to how active people should be, and their recommendations are you should do 150 minutes of moderate intensity exercise a week, or 75 minutes of high intensity exercise per week, which, when you say it like that, sounds like a massive amount of exercise. But we also know, there's a report from Sport England, that actually 1 in 4 adults do less than 30 minutes a week of physical activity.

Lucy: And that'll be, you know, for people like prioritizing and work and things like that.

Ruth: And yeah there are multiple barriers to that. But less than 30 minutes of physical activity a week was like wow. That's everybody. That's not just people with CF. About 31% of adults worldwide don't meet the 150 minutes of exercise per week, which is like quite mind-blowing when you think about worldwide. And I think the proportion of people is higher in the developed world than it is in the underdeveloped world. And I think that's probably, you know, we are more becoming more sedentary. You know, we get drive-throughs, we, you know, order online. We spend lots of time on the computer or driving. You know, we are definitely becoming suddenly more sedentary.

So it's really important if we think, you know, people with CF are going to be living longer. You know, in the recent registry data, the kind of median predicted survival for babies born today is 64 years old. So people are going to be living longer. So actually we really need to think about, you know, longer term health. And we know that physical inactivity puts adults at greater risk of cardiovascular disease. So high blood pressure, strokes, heart attacks, you know, risks of colon cancer, breast cancer are increased in people who are physically inactive. So, it's super important that we actually try to promote activity and any activities helps towards that.

So, 150 minutes of activity may seem insurmountable for someone who has maybe more severe disease. But actually, if you can break that up into smaller chunks, so can you break it up into 10-minute chunks? It doesn't have to be, you know, going for a run, it doesn't have to be playing football. It’s defined as getting a little bit breathless but not too breathless that you couldn't hold a conversation. So actually, is that mowing the lawn, doing some hoovering, taking, you know, you kids to school, you know, it doesn't have to be running a marathon. It doesn't have to be doing CrossFit.

You know, I think doing exercise. Well, one of the keys is to find something that you really enjoy. Exercise is a little bit like how you like your tea. Obviously it has to be a Yorkshire brew. You can't be any other teabag. But you know, some people like it really strong. You know, you can stand a spoon in it and that's kind of your, you know, really high intensity marathon runners, ultra runners. You know, I cycled 250 miles a week, type things and then other people like it so it’s only just been tickled by the teabag. And they might be the people that like, you know, Pilates or walking or gentler, lower impact forms of exercise. There's nothing to say that any is less valid than the other.

Lucy: I think that's really important as well in the fact that for someone who maybe isn't as well, their ten minute walk around their village is just as valuable and important as someone who's trying to do a triathlon or pushing themself to the max. Like, it's kind of like you need to run your own race and not compare. But I think I think that's important as well. Like you're saying, to just split it up.

Ruth: Yeah. And it has to be achievable otherwise you're not going to maintain it. And really, you know, we've said one of the keys is finding something you enjoy doing. And then it's kind of consistency. And building that kind of routine. That habit. Because then if you form that habit, you've got far more likely to keep doing it. And, you know, we need to do this into later life. So it's super important. And exercise may ebb and flow as you age. You know what? What you may enjoy now doesn't mean to say that's what you're going to enjoy later. And you know, you may have times where you are less fit or more fit. And that's okay. You know, it's doing what works for you at that point. But being mindful that it's really important to be to doing something.

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

Lucy: So moving on to kind of the Leeds regional CF centre that you work at. The physio team is great and does like a load of things. Do you want to touch on maybe the current stuff that you're doing with yoga and CF?

Ruth: YOGA-CF is a study that has been set up by a team at the Brompton. So professor Nick Simmonds and Doctor Gemma Stanford, who is a physio by trade. We know that there are lots of people who have CF that do yoga, and we know that in the general population that there are, reported benefits in terms of mental health, flexibility, and strength. But there's currently kind of no evidence for the benefits of yoga in the CF population. And so the idea was to basically assess what the benefits were in relation to the population. It's a randomized controlled trial where participants either randomized to 12 weeks of online yoga or are randomized to standard care. The aim is to recruit, just over 300 participants in total, and it is currently being conducted by multiple sites across the UK.

So if anyone is interested, want any more information, it is on the CF Trust Trial Tracker page. I have checked that today. You can also approach your CF team and recruitment is still open until the end of April 25. So there's still time guys.

Lucy: I’m not on this trial but recently started doing yoga from when I came back from the Bahamas where I was doing it on the beach every day, and it was like a retreat. And I was like, you know what? I'm going to keep doing this. So I do it every day before work, because I do a lot of computer work, and it makes your lungs feel great. It feels like you gives them a nice stretch. I don't know, it feels like they're just happier. So I'm like really pleased that there's research going into this.

I nearly broke my nose doing like a flying pigeon. I nearly fell over. So it's quite funny when my husband walks past and sees when I've got my foot over my shoulder and I'm stuck or, you know, it's quite funny. It'll be interesting to see kind of what comes out of that.

Ruth: Yeah, absolutely. I mean, at the moment obviously they're still actively recruiting, so there are no results yet. So it'll be really interesting in 12 months time when we can see kind of the results of that.

Lucy: So my last question is one that we always ask our guests on the podcast, which is kind of like what are your hopes for the future for people with CF, and how your role might change in the future and what it might look like?

Ruth: I think my hopes for the future of CF care, so obviously one of the big hopes would be that they find a treatment option for the 10%. So for the people that are either not eligible or can't tolerate the current modulator treatments because there is, you know, it must be really hard as someone who isn't eligible or can't tolerate them, to then see their peers doing so well. That would be a really, you know, a definite hope for the future.

In other terms, I think I'd really hope that people have a future of choices, choices that aren't dictated by CF. And I know that seems really, you know, really random thing to say because people have choices all the time and people always have had choices all the time. But I think historically those choices, you know, should I go on holiday? But what if I'm unwell? I can't get travel insurance. When do I have treatment? You know, there was always a caveat to that. And I think to be able to be spontaneous and make spontaneous choices and then not have CF bite you in the bum is a really important thing. You know, can I go to university? Well, yes, you can. Can I get a job? Yes you can. And you don't have to worry about there’s going to be real issues with sick leave. So yeah more choices.

Lucy: Yeah that's an excellent point to end on. So thank you very much for joining us on the podcast today, Ruth.

Thanks so much to Ruth and Matt and to you all for listening. For more information on what we've talked about in this episode, or to find out more about how you can be a part of team CF and take on your own sporty challenge for Cystic Fibrosis Trust in 2025, please see cysticfibrosis.org.uk/podcast.

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